# On the Threshold of Independence

Progress on legislative Recommendations from *Toward Independence* 

National Council on Disability (formerly the National Council on the Handicapped)

A Report to the President and to the Congress of the United State

January 1988

On the Threshold Of Independence:

Progress on Legislative Recommendations From Toward Independence

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National Council on Disability 1331 F Street, NW, Suite 1050 Washington, DC 20004-1107

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### Letter of Transmittal

(Text of identical letters sent to the President of the United States, the President of the Senate the Speaker of the House of Representatives)

January 29, 1988

The National Council on the handicapped is pleased to issue On the Threshold of

Independence, a report describing progress made toward increasing the independence and qua

life for persons with disabiliues since the Council's 1986 report, Toward Independence. On ti

Threshold of Independence was developed in response to a statutory mandate that the Counci

Not later than January 30, 1988, and annually thereafter, the National Council on the Handicapped shall issue a report to the President and Congress on the progress that ha been made in implementing the recommendations contained in the Council's January (1986, report Toward Independence. The reports issued shall present, as appropriate, available data on health, housing, employment, insurance, transportation, recreation,  $\epsilon$  education, and shall include appropriate information on the current status and trends in status of individuals with disabilities.

(Public Law 99-506, Section 502(b))

*Toward* Independence assessed the status of persons with disabilities in America and the Federal laws and programs that affect them. It presented forty-five legislative remedies to ide problems, all geared toward increasing the dignity and independence of Americans with disat Since the publication of *Toward* Independence, many doors, previously closed to persons wit disabilities, have been opened. On *the Threshold of* Independence describes accomplishment that have been achieved in response to the recommendations in *Toward* Independence, and th degree to which the recommendations have been implemented.

In some instances, the *Toward Independence* recommendations have been the driving forc behind particular legislative proposals, and the Council played a major role in the process of developing concrete statutory approaches. In other cases, the Council was but one of many v in favor of a particular proposal that led to legislative action. In either event, the Council gra acknowledges that the progress has been the result of the ideas, comments, and diligent work numerous persons with disabilities, their families, public officials, other professionals and explore consumer and service organizations, and other interested individuals from all over the country of the country of

Some progress has been made in each of the ten topics of Toward Independence. There have been major statutory many of the topic areas, bills are pending in others, and at least some positive administrative efforts or related activitic occurred in the remainder. In all, appro-3dmately eighty percent of the recommendations have been either partially or accomplished.

The Council is pleased at the many ways in which the Legislative and Executive Branches of Government have res positively to its recommendations. Yet, the significant progress that has been made does not obscure the fact that mar recommendations have not yet been addressed or addressed orily partially- many of the doors of opportunity remain fi persons with disabilities. The Council seeks to rededicate its own efforts, and to join with the President, the Congress with disabilities and their families, to achieve the objectives of Toward Independence. Only then will Americans with

escape from situations of dependence and dehumanization and cross the threshold of independence.

The Council appreciates the opportunity to continue to shape disability policy and to work toward an America in w with disabilities are afforded all the opportunities that our society has to offer.

Sincerely,

Sandra Swift Parrino Chairperson

### **Description of the National Council on the Handicapped**

The National Council on the Handicapped is an independent Federal agency comprised of 15 members appo the President and confirmed by the Senate. The Council was initially established in 1978 as an advisory boa the Department of Education (Public Law 95602). The Rehabilitation Act Amendments of 1984 (Public Lav transformed the Council into an independent agency.

The current statutory mandate of the Council assigns it the following duties:

### establishing general policies for and reviewing the operation of the National Institute on Disability and Rehabilitation Research (NIDRR);

C) providing advice to the Commissioner of the Rehabilitation Services Administration (RSA) on policies and conduct;

providing ongoing advice to the President, the Congress, the RSA Commissioner, the Assistant Secretary of the Office' of 'Special Education and Rehabilitative Services (OSERS), and the Director of NIDRR on programs authorized in the Rehabilitation Act;

13 reviewing and evaluating on a continuous basis the effectiveness of all policies, programs, and activities concerning handicapped individuals conducted or assisted by Federal departments or agencies, and all statutes pertaining to Federal programs, and assessing the extent to which they provide incentives to community-based services, promote full integration, and contribute to the independence and dignity of individuals with disabilities;

making recommendations of ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting handicapped persons;

3 reviewing and approving standards for Independent Living programs;

submitting an annual report with appropriate recommendations to the Congress and the President regarding the status of re-

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search affecting persons with disabilities and the activities of RSA and NIDRR;

- L] reviewing and approving standards for Projects with Industry programs;
- L] providing to the Congress, on a continuing basis advice, recommendations,

# and any additional information which the Council or the Congress considers appropriate; and

### El issuing an annual report to the President and the Congress on the progress that has been made in implementing the recommendations contained in the Council's January 30, 1986, report, Toward Independence.

While many government agencies deal with issues and programs affecting people with disabilities, the Natic Council is the only Federal agency charged with addressing, analyzing, and making recommendations on iss public policy which affect people with disabilities regardless of age, disability type, perceived employment 1 economic need, specific functional ability, status as a veteran, or other individual circumstance. The Counci recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by assuring an informed and coordinated approach to addressing th concerns of persons with disabilities and eliminating barriers to their active participation in community and life.

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## The National Council on the HEmdicapped

### Members

Sandra Swift Parrino, Chairperson

John S. Erthein

Theresa L. Gardner

Marian N. Koonce

Leslie Lenkowsky, Ph.D.

Nanette Fabray MacDougall

Robert Muller

Brenda Premo

\*Harry J. Sutcliffe, D. D.

Joni Eareckson Tada

Roxanne Vierra

A. Kent Waldrep, Jr.

Phyllis Zlotnick

Staff

Lex Frieden, Executive Director

Brenda Bratton, Secretary

Stacey Brov,7n, Clerk lypist

Ethel Briggs, Adult Services Specialist

Robert Burgdorf Jr., Attorney/Research Specialist

Frances Curtis, Administrative Officer

Andrea Farbman, Public Affairs Specialist

Kathleen Roy, Children's Specialist

Deborah Shuck, Staff Assistant

LaVerne Chase, Fellow D. Fay Fuller, Jr., Fellow

\*Deceased 12/87

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### Acknowledgments

The Council is indebted to Andrea Farbman for coordinating, managing, and editing this report. The contributions of staff mem

Robert Burgdorf Jr., Kathy Roy, and fellows LaVerne Chase and D. Ray Fuller, Jr. are greatly appreciated. Gratitude is also ex Moss for graphic design and production, Karen Premack for editorial guidance, and Unicor print plant for printing the report.

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### **Executive Summary**

In the 1986 Amendments to the Rehabilitation Act of 1973, Congress required the Council to:

...issue a report to the President and Congress on the progress that has been made in implementing th recommendations contained in the Council's January 30, 1986, report Toward Independence.

The reports issued shall present, as appropriate, available data on health, housing, employment, insur transportation, recreation, and education, and shall include appropriate information on the current sta trends in the status of individuals with disabilities. (Public Law 99-506, Section 502(b))

On the *Threshold of* Independence chronicles progress made on the forty-five legislative recommendation which were proposed in the Council's previous report, *Toward* Independence. Several recent studies on disa including one from the Census Bureau and two Harris polls are also discussed.

Some significant progress has occurred in the two years since *Toward* Independence was published. The has identified some twenty-one statutory provisions consistent with its recommendations in *Toward* Indepen that have been enacted into law. In addition, the Council is aware of eight bills that have been introduced in but not yet enacted, that would further proposals included in Toward Independence.

Of the forty-five legislative recommendations, eighty percent have been either parually or fully accompli Many doors to independence have been opened, others remain closed or only partially opened.

This report assesses progress made in each of the ten topic areas in Toward Independence and examines t to which each of the forty-five legislative recommendations have been implemented. The following is an ov progress that has occurred.

### **N Equal Opportunity Laws**

A major achievement in this area was the development by the Council of a comprehensive legislative propose Americans with Disabilities Act of 1988," which translates the primary equal opportunity recommendations proposed statutory language. Three other statutes- the Rehabilitation Act Amendments of 1986, the Handica Children's Protection Act of 1986, and the Protection and Advocacy for the Mentally III Individuals Act of 1 incorporated other significant,

but narrower, equal opportunity recommendations. In spite of legislative progress made, the Council remai committed to passage of its comprehensive equal opportunity proposal as an essential prerequisite to equalit independence for persons with disabilities.

### N Employment

In the area of employment of persons with disabilities accomplishments included passage of legislation inco several of the Council's major recommendations in the areas of supported employment, transition, and tax in for employers. The Council believes that these legislative changes represent unprecedented gains in terms o expanded employment opportunities for persons with disabilities. Additional congressional action is still ne implement the full range of the Council's recommendations, including the establishment of model centers on employment and return-to-work programs, and elimination of the income eligibility requirement for persons disabilities under the Job Training Partnership Act.

### N Disincentives to Work under Social Security Laws

Legislation passed in the 99th Congress furthered several of the Council's recommendations for the removal barriers under the Social Security Act that discouraged persons with disabilities from seeking gainful employ. These included the Employment Opportunities for Disabled Americans Act which made the temporary prov. Section 1619 (a) and (b) of the Social Security Act permanent and established Section 303 of the Rehabilitat Amendments of 1986 which required the National Institute on Disability and Rehabilitation Research to con study of health insurance for persons with disabilities. The Council continues to believe that the eligibility c Supplemental Security Income and Social Security Disability Insurance merit attention.

### 9 Prevention of Disabilities

The Council devoted considerable effort regarding policies and programs to prevent both primary and secon disabilities. The Office of Disease Prevention and Health Promotion, in conjunction with the Council, converse Federal ad hoc group on the prevention of disabilities which included a number of Federal agencies. The for ad hoc group was the exchange of information between Federal agencies and the development of a national prevention of disabilities, as recommended by the Council. Funds have been sought for the development national plan and a small community-based grants

program administered by the Centers for Disease Control. After these projects have been complete of Technology Assessment will be asked to conduct a study on the status of prevention of disabilitie America.

### **N** Transportation

In *Toward* Independence the Council concluded that accessible transportation is a critical componen national policy that promotes the self-reliance and self-sufficiency of people with disabilities. The a greatest progress has been that of air transportation with the passage of the Air Carrier Access Act o

Other developments included the introduction of bills to amend the Urban Mass Transit Act and to c national uniform system for handicapped parking. The Council affirms its commitment to improvin persons with disabilities.

### N Housing

The housing legislative recommendations presented direct and indirect means for increasing the hou opportunities available to persons with disabilities. Some significant legislative proposals and admin actions have furthered the Council's recommendations. At the same time, many of the Council's key recommendations have yet to receive congressional resolution and administrative implementation.

### N Community-Based Services for Independent Living

Centers providing independent living services have grov,7n substantially in number, scope, and reso Consistent with the Council's recommendation, Congress has continued to appropriate funds for indeliving. The evaluation standards for independent living services developed by the Council have been by the Rehabilitation Services Administration. Tax deductions for expenses incurred by persons wit disabilities have increased under the Tax Reform Act of 1986. Other Council recommendations region funding and institutional bias within the Health Care Financing Administration have not been imple

### N Educating Children with Disabilities

The Education of the Handicapped Act Amendments of 1986 accomplished a primary recommendat Council by creating an early intervention program to serve disabled infants from birth through age tv addition, the legislation included significant improvements in

services for three- to five-year-old children with disabilities. To further implementation of its recommenda regarding standards to clarify the concept of least restrictive environment, the Council developed a draft poli statement on this issue. One activity not mentioned in *Toward* Independence was the Council's initiation of Harris poll to examine the status of education for children with disabilities. The results of the poll will be of value to the Council, the Congress, and others in the development of educational policy to mcet the needs of with disabilities.

### N Personal Assistance: Attendant Services, Readers, and Interpreters

The Council established a task force for the development of a legislative package for a comprehensive nation personal assistance program and consulted with leaders in the field and numerous organizations around the c A legislative workplan is currently being developed which recommends amendments to legislation, and inclu

proposals to fill service gaps in developing coordination of personal assistance services.

### N Coordination

The Council participated in efforts that have fostered coordination of services for people with disabilities on Federal, State, and local levels. Examples of these efforts include participation in an ad hoe group on the pr of disabilities, observation of the regulatory negotiation process for the Air Carrier Access Act of 1986, cosp of a conference on transition with the Office of Special Education and Rehabilitative Services, and recomme in testimony for the Education of the Handicapped Act Amendments of 1986. The Council is also exploring of the Advisory Council on Intergovernmental Relations to identify data being gathered regarding coordinate at the State and local levels.

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## Foreword

In response to *Toward* Independence, President Ronald Reagan proclaimed:

I agree with the goals implicit in Toward Independence- equal opportunity and full social participation for aB America pleased to see that your report sets forth a comprehensive agenda for progress toward these goals .... [However]Tbe roa independence will not be easy.

(Reagan letter, Jan., 1986)

Toward Independence assessed the status of persons with disabilities in America and the Federal laws and pi that affect them. The report presented forty-five legislative remedies to identified problems, all geared towa increasing the dignity and independence of Americans with disabilities. Each recommendation can be viewed means of achieving a greater degree of independence; viewed together, the implementation of all forty-five recommendations can bring about an America in which disabled citizens are given the opportunity to be full participating members.

Since the publication of *Toward* Independence in 1986, many doors, previously closed to persons with disabilities, have been opened. Some doors to opportunities have been fully opened, some have been opened halfxvay, some have been only cracked slightly, and still others remain tightly shut. This report describes accomplishments that have been achieved in response to the recommendations in *Toward* Independence, and degree to which the recommendations have been implemented.

Vv'hen the accomplishments of the past two years are examined in their entirety, the overall effect can be as having placed persons with disabilities **on the threshold of independence.** For the areas in which the proposals in *Toward* Independence have been implemented and the doors to opportunity have been opened, remaining is to keep the doors open and for people with disabilities to accept the challenge of going through doorways. For those areas in which the doors to independence are ajar, the Council hopes for further efforts opening up opportunities for independence, dignity, and selfsufficiency. For areas in which no progress has made and the doors to opportunity remain shut, the Council plans to redouble its efforts, and looks to the Congress, the Admi with disabilities and their families, services providers, and others, to join with the Council to continue to push and knock until the opened.

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While President Reagan has aptly warned that -[tlhe road to full

independence will not be easy," some significant progress has occurred in the two years since *Toward* Independence was published. The Council has identified some twenty-one statutory provisions consistent w legislative recommendations in *Toward* Independence that have been enacted into law (see Table 1). In add is aware of eight bills that have been introduced in Congress, but not yet enacted, that would further proposa included in *Toward* Independence. The Council does not seek to claim for itself the credit for such laws and proposed legislation. The development of bills and the process of getting them through Congress and signed President is a highly collaborative process involving the skills and commitment of many individuals and organizaffons.

In some instances, the *Toward* Independence recommendations have been the driving force behind par-U legislative proposals, and the Council has played a major role in the process of developing concrete statutory approaches. In other cases, the Council was but one of many voices in favor of a particular proposal that lec legislative action. In either event, the Council gratefully acknowledges that the recommendations issued in ' Independence were the result of the ideas, comments, and advice of numerous persons with disabilities, their public officials, other professionals and experts, consumer and service organizations, and other interested in from all over the country.

The legislative recommendations contained in Toward Independence focused on ten major topic areas. V each of these ten areas, some progress has been made since the publication of that report. There have been r statutory advances in many of the topic areas, bills are pending in others, and at least some positive administ related activities have occurred in the remainder. Of the forty-five specific legislative recommendations in 7 Independence, 75 percent, or thirty-four of the forty-five recommendations, have been par-Ually accomplish three have been fully accomplished (see Table 2).

The Council is pleased at the many ways in which the Legislative and Executive Branches of Governmer responded positively to its recommendations. Yet, the significant progress that has been made does not obsc fact that many of the major recommendations have not yet been addressed or addressed only partially- many major doors of opportunity remain firmly shut to persons with disabilities. This report represents a recognit affirmation of the progress since Toward Independence, but it also provides an assessment of how much has

accomplished. The Council seeks to rededicate its ov,7n efforts, and to join with the President, the Congress sons with disabilities and their families, to achieve the objectives of

### Table 1

### Summary of Accomplishments on the Recommendations from Toward Independence

Topic Area	Legislative	Activity
	Statutory	Bills*
	Provisions	
Equal Opportunity Laws	6	3
Employment	4	0
Disincentives to Work	3	0
Prevention	3	1
Transportation	2	3
Housing	0	2
Independent Living	2	0
Education	1	0
Personal Assistance	0	0
Coordination	0	0
Totals	21	9

\*Includes the Council's proposed "Americans with Disabilities Act of 1988."

### Table 2

### Summary of Accomplishments on the Recommendations from Toward Independence

<b>Topic Area</b>	Level of	Achievement	
	Fu	ll Partial	No Activity
Equal Opportunity Laws (6)*		0 6	0
Employment (8)		0 4	4
Disincentives to Work (3)		1 1	1
Prevention (3)		0 2	1
Transportation (6)		1 3	2
Housing (8)		0 7	1
Independent Living (4)		0 2	2
Education (4)		1 3	0
Personal Assistance (2)		0 2	0
Coordination (1)		0 1	0
All recommendations (45)		3 31	11

\*denotes number of Toward Independence recommendations

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*Toward* Independence. Only then will persons with disabilities in the United States escape from situations o dependency and dehumanization and cross the **threshold of independence**.

# Introduction

### Background

On January 29, 1986, the National Council on the Handicapped released its comprehensive blueprint for disa policy in America. *Toward* Independence was developed in response to a 1984 congressional mandate for th to:

assess the extent to which Federal programs serving people with disabilities provide incentives or dis to the establishment of communitybased services for handicapped individuals, promote the full integ such individuals in the community, in schools, and in the workplace, and contribute to the independe dignity of such individuals. (Section 401 of the Rehabilitation Act of 1973, as amended)

In that report, the Council presented its findings, conclusions, and legislative recommendations based upon i and assessment of Federal laws and programs, as well as input from hundreds of persons with disabilities. Relevant information and data were collected by:

- El examining current legislation and programs;
- El collecting and analyzing information about exemplary programs;
- L] reviewing existing analyses of Federal programs and disability issues;
- L] consulting with experts;
- L] conducting special seminars and hearings: and
- L] conducting forums with persons with disabilities and their families throughout the United Sta

As a result, Toward Independence listed major Federal programs serving individuals with disabilities and ranked them according to expenditures, with an estimated number o with disabilities served. From its analysis, the Council drew three primary conclusions:

# 1. Approximately two-thirds of working-age persons with disabilities do not receive Social Security or other public assistance income.

2. Federal disability programs reflect an overemphasis on income support and an underemphasis on initiatives for equal opportunity, independence, prevention, and self-sufficiency.

# **3.** More emphasis should be given to Federal programs encouraging and assisting private sector efforts to promote opportunities and independence for individuals with disabilities.

The Council also analyzed Federal spending on disability. "Our nation's current annual Federal expendit disability benefits and programs exceeds \$60 billion" (p.2). Further examination of that estimate revealed the **combined spending for Fiscal Year 1986 for the education of handicapped children and vocational rehabilitation totaled less than \$3 billion, or less than five percent of the total dollars spent on disability.** This startling underemphasis of spending on programs and services oriented to the goals of independence and self-reliance caused the Council to target its legislative recommendations on 1 fiscally responsible approaches which emphasize productivity and self-determination.

The forty-five legislative recommendations in *Toward* Independence focuseel on ten major topic areas of importance to persons with disabilities. These ten topics were discussed extensively in a 600page Appendix report. In order to review the major recommendations from the topic areas, a brief synopsis follows.

### **Recommendations from Toward Independence**

Based on testimony and comments from hundreds of people with disabilities, parents, and others, the most p and recurrent problem faced by disabled persons appeared to be unfair and unnecessary discrimination.

...[VAhatever the limitations associated with parucular disabilities, people with disabilities have beer for years that their major obstacles are not inherent in their disabilities, but arise from barriers that ha imposed externally and unnecessarily. (p. 1)

### **Equal Opportunity Law**

The Council recommended the enactment of a comprehensive law requiring equal opportunity for individual disabilities, with broad coverage and setting clear, consistent, and enforceable standards prohibiting discrimit the basis of handicap.

### Employment

To increase employment among people with disabilities- a drastically unemployed and underemployed segre population- the Council recommended several legislative changes, concerning the transition from school to v supported employment, private sector initiatives, job training, job development, and placement.

### **Disincentives to Work Under Social Security Laws**

The Council outlined several ways in which provisions of existing Social Security laws- Supplemental Security (SSI), Social Security Disability Insurance (SSDI), Medicaid, and Medicare- serve to discourage and penalia with disabilities if they seek to become employed and self supporting. In response to these work disincentiv Council recommended corrective amendments to the problematic provisions.

### **Prevention of Disabilities**

To promote the prevention of disabilities and to assure that individuals having disabilities do not experience unnecessary secondary disabilities, the Council recommended that the Federal Government mount a national for the prevention of disabilities.

### Transportation

The Council recommended amendments to transportation legislation to achieve the Nation's established poli "disabled people have the same right to use public transportation as nondisabled persons." Proposals related mass transit, air transportation, intercity and interstate buses, private vehicles, and research.

### Housing

To permit people with disabilities an opportunity to obtain appropriate housing, which is an important prerea obtaining employment, living independently, and avoiding costly institutionalization, the Council made seve recommendations designed to prohibit housing discrimination and to promote increased appropriate and acca housing for persons with disabilities.

### **Community-Based Services for Independent Living**

To achieve productivity and independence, people with disabilities require a range of support services accornature and degree of their disabilities. The Council proposed a variety of measures, including amendments a support under Parts A and B of Title VII of the Rehabilitation Act, to promote the availability of community services for independent living.

### **Educating Children with Disabilities**

The Council made legislative recommendations regarding educational opportunities for children with disabil recommendations responded to: the need for special education and related services during infancy; the need children with special needs in regular

education facilities: and the need to assess progress made since the enactment of the Education for All Hanc Children Act.

### **Personal Assistance:**

### **Attendant Services, Readers, and Interpreters**

Because of the critical importance of such services in fostering independence and avoiding expensive institutionalization, the Council recommended a national commitment to developing a quality system of atte services, readers, and interpreters.

### Coordination

The Council recommended that all Federal and federally supported disability-related programs be authorized required to develop a joint plan for the systematic coordination of services and benefits.

### **Dissemination and Response**

### to Toward Independence

Reactions to *Toward* Independence were overwhelmingly positive. Some of the highest accolades were exp. a letter from President Reagan (a replica of the letter appears on page 5). In addition to sending copies to th House and to all members of the Senate and House of Representatives, the Council released Toward Indeper two Washington press conferences.

### **Media Coverage**

One of the factors that increased the visibility of *Toward* Independence was the simultaneous release of an unprecedented nationwide Harris poll that examined the perceptions of persons with disabilities (for details esee: -Recent Data and '&ends"). Toward Independence and the Harris poll were covered on the front page o Today, as well as in arucles in many local papers across the country. Television coverage included interview Chairperson Sandra Swift Parrino on "Foday in New York City" and "Live at Five" on station WPLG in Mia Florida. And radio broadcasts were generated from as far away as Seattle, Washington, St. Louis, Missouri, Florida. Based on a request from the Voice of America, the Council and Toward Independence were feature radio program broadcast in the Peoples Republic of China.

The disability community also openly embraced Toward Independence. Publications such as the *Disabil* and various newsletters ran articles emphasizing the comprehensiveness and depth of the report's recommen-

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THE WHITE HOUSE

WASHINGTON

January 29, 1986

#### Dear Mrs. Parrino:

Thank you for Toward Independence, the special report of the National Council on the HFnd-!capped.

I congratulate the members and staff of the Council on the completion of this report, and I commend the many individ the fifty states who donated their time, their talents, and their economic resources to produce this special testament to independence. Their contributions demonstrate the vitality of our democratic process and the commitment of the Ame the principles of independence and opportunity for all.

I agree with the goals implicit in Toward Independence -equal opportunity and full social participation for illAmerican pleased to see that your report sets forth a comprehensive agenda for progress toward these goals. My Administration report and cooperate with the Council, with the Congress, and with disabled Americans and their supporters to refine a these proposals.

The road toward full independence will not be easy. It will require the efforts of individuals, families, and communiti partnership between the private sector and all levels of government. You can be assured of my complete cooperation together to make the American dream a reality for all our people.

Sincerely,

The Honorable Sandra S. Parrino Chairperson National Council on the Handicapped 123 Marlborough Road Briarcliff Manor, New York 10510

#### Visibility on Capitol Hill

Opportunity for close scrutiny came when the National Council on the Handicapped appeared before the Ho Senate Committees on Appropriations to review the Council's Fiscal Year 1987 Budget request. Both Comr queried Council Chairperson Sandra Swift Parrino and Executive Director Lex Frieden about the report's rec mendations and plans for implementation.

Senator Lowell Weicker opened the Council's 1986 appropriation hearing by congratulating the Council: accomplishments and remarking about the uniqueness of the Council: "I think really, so many of these nation are a lot of show and don't do anything. I think you are terribly blessed .... You have a great outfit here." La hearing Senator Weicker added:

I want to thank you for everything that you are doing: for the report Toward Independence. I think it is a magnifice the Harris poll, with the professionalism that you are bringing with the Council to where the Council's voice is listened and for the courage in cutting across all partian and philosophical bounds in order to achieve the result of those you se what it is all about. (p. 805)

Senator Weicker asked Chairperson Parrino to summarize Toward Independence and describe how the Cour to follow up and monitor each of the forty-five recommendations. Mrs. Parrino detailed the Council's workj implementation strategies.

On the House side, Congressmen William Natcher, Silvio Conte, and Carl Pursell further explored the recommendations of *Toward* Independence. In responding to a question from Congressman Pursell, Execut Director Frieden commented on the major themes of the report:

There are two principal themes that run through this report. One of those deals with equal opportunity .... The second I theme relates to independence for people with disabilities. We believe community-based programs that facilitate indep people with disabilities are the most cost-effective means of providing disabled people the opportunity to make choices lives. (p. 443)

In addition to being a topic for discussion during the Council's appropriations hearings, a number of legislate integrated recommendations from *Toward*. Independence into their own speeches and comments on disabili legislation. For example, in his remarks on the Employment Opportunities for Disabled Americans Act, Con Steve Bartlett used *Toward* Independence to underscore the importence of employment opportunities for per disabilities.

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# Toward Independence

### **Featured at Conferences**

In the course of the two years since the publication of Toward Independence, the report has been used repeat centerpiece for conferences, meetings, and forums. Organizations such as the Paralyzed Veterans of Americ National Easter Seal Society, and the National Council for Independent Living have all employed the report from which to generate discussion about disability policy.

### Follow-up Report Mandated by Congress

Subsequent to the report, Congress reauthorized the Rehabilitation Act of 1973 in the Rehabilitation Act Arr of 1986. In the Amendments, Congress required the Council to report on progress that had been made on th recommendations in *Toward* Independence.

Section 502 of the Rehabilitation Act Amendments of 1986 states:

(b)(1) Not later than January 30, 1988, and annually thereafter, the National Council on the Handicapped shall issue a r President and Congress on the progress that has been made in implementing the recommendations contained in the Cou 30, 1986, report Toward Independence.

(2) The reports issued pursuant to paragraph (1) shall present, as appropriate, available data on health, housing, er insurance, transportation, recreation, and education, and shall include appropriate information on the current status and status of individuals with disabilities.

Thus, the intent of this followup report is to chronicle progress made on each of the forty-five legislative recommendations proposed in Toward Independence. For the purpose of this report, progress includes the c

of important meetings and conferences, the initiation of correspondence, and the development of legislation regulations. Progress was realized not solely by the Council, but also by disability organizations, service progovernment agencies, individuals, and others. The period covered by this report is February 1, 1986, throug November 18, 1987.

# **Recent Data and Trends**

Accurate statistical data in the area of disability are imperative for policy-makers and others. As reported in Independence, existing studies have been fraught with problems. Since the publication of *Toward* Independence, however, a number of significant studies have been conducted.

The Census Bureau issued an important study of functional limitations in December 1986. Entitled "Disa Functional Limitation, and Health Insurance Coverage: 1984/85," the report presents data drav,7n from the l Survey of Income and Program Participation, conducted in May through August of 1984.

In the report, researchers found that one out of five non-institunonalized residents aged 15 and over- som million persons- has difficulty performing one or more basic physical activities. The activities included seei speaking, walking, using stairs, lifting or carrying, getting around outside, getting around inside, and getting of bed. Some 13.5 million persons said that they not only had difficulty, but could not perform the activity s could not

do it without help. Among the findings of the study:

El Some 12.8 million people, or 7.1 percent of the population studied, had trouble seeing words and letters in ordinary newsprint, even with glasses or contact lenses. Approximately 1.7 million could not see words and letters at all.

El About 7.7 million people had trouble hearing a normal conversation, and 500,000 were unable to hear such a conversation.

El Some 2.5 million people had a problem having their speech understood by others.

El About 19.2 million people had difficulty walking a quarter of a mile, including 8 million who reported that they were unable to walk that far.

L] Some 18.1 millio 'n people had trouble walking up a flight of stairs without resting, and 5.2 mimon could not do so on their OVOM.

El About 18.2 milron persons had trouble lifting or carrying something as heavy as a full bag of groceries, and 17.8 million of them could not do so.

El Some 6 million individuals had trouble getting around outside the home, and 3.6 million of them could not do so on their ovin.

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13 Approximately 2.5 million people had trouble getting around inside the home, and 1.2 million were unable to do so without help.

L] Some 2.1 million people had difficulty getting into or out of bed, and 1.2 miwon of them could not do so on their own.

Of those who had trouble performing at least one function, 21.8 million were under age 65 and 15.5 milron were 65 and over. The totals for those completely unable to perform an activity or who needed help were 6 million under age 65 and 7.5 million 65 and over.

One of the data sources employed in the development of *Toward* Independence was the *Digest of* Data or *Persons with Disabilities*, prepared by Mathematica Policy Research, Inc. under contract to the Congression Research Service of the Library of Congress. The information in the *Digest* has been supplemented by two: prepared by the Human Services Research Institute and issued by the National Institute on Disability and Re Research. The *Summary of* Data on Handicapped Children and Youth (1985) compiles data from various so regarding the incidence and prevalence of disability in children.

Among the statistical highlights contained in the reporL are estimates that 4.2 percent of all children under twenty-one have a chronic activity limitation, and that about one-fourth of 1 percent of children under age statistical such as walking, going outside, dressing, eating and using the toilet. The Compilation *Statistical Sources* on Adult Disability (1 986) provides a bibliography containing profiles of major national files. It is designed to serve as a reference for researchers, administrators, and practitioners looking for statistical information on adult impairments. The Compilation describes thirty data files, some of which contain two c related surveys.

Several publications have made projections regarding the population with disabilities. These include two publications of the Menninger Foundation, *A Population Model of Working Age Disabled* Individuals (I 985 and *The Relationship Between Age* and Physical *Disability* Among *Workers: Implications for the* FUture (1986), and a book chapter by H.R. Vachon, III, entitled "Inventing a Future for Individuals with Working (1986). All three sources provide estimates of the size and characteristics of the population with through the year 2000 and beyond. Among a variety of other observations and findings, these publications v major premises of *Toward Independence* that disabilities correlate with aging, and that the proportion of the

population with disabilities will increase significantly during the next several decades.

### Harris Polls

Clearly, the two Harris poll studies initiated by the Council also made important and unique contributions to disability community. The idea for the first Harris poll evolved during the initial phases of Toward Indepen Several Council members expressed frustration at the lack of adequate data regarding the status, needs, and (Americans with disabilities. One Council member suggested a nationwide survey of persons with disabilitie

A short time later, working in conjunction with the Council, the International Center for the Disabled cor such a study from the well-known survey research firm of Louis Harris and Associates. The survey, entitled Disabled Americans into the Mainstream," was the first major national survey to study the attitudes and experpeople with disabilities. As the Harris agency correctly acknowledges:

Census Bureau and other government agencies have measured the incidence and prevalence of disabi general population, and the number of disabled people in and out of the labor force ... But no substar nationwide survey has sought to learn the impact of disability; what disabled people think about bein disabled; and what they think must be done to enable them to participate fully in the life of the nation

The Council decided that it needed to know the answers to such questions before it could address the needs ( persons and effectively set disability policy in America.

### Sample

One unique aspect of the Han-is poll was its use of a nationwide random sample. Harris researchers telepho households to obtain 1,000 respondents who met at least one of the definitional criteria (which will be discus next section). The sample represented non-institutionalized disabled persons aged sixteen and over who live households with telephones. V%Then a disabled person was unavailable for an interview, or unable to be in a proxy was chosen as the respondent. About seventeen percent of the interviews were conducted with pro2

### **Issue of Definition**

Toward Independence points out that the issue of defining disability is

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not simple. "Most eidsting studies of the disabled population employ one of two major approaches, each of its own shortcomings and limitations" (p.3). The health conditions approach stresses conditions or limitation impair health or interfere with normal functioning. This approach is best exemplified in surveys conducted Naffonal Center for Health Statistics. On the other hand, the work disability approach focuses on factors that individuals from working or limit their ability to work. Data collected by the Social Security Administration

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this type of definitional approach.

Knowing the limitations of these approaches, Harris sought to solve the problem by using a third approac purposes of the Harris survey, a person was defined as being disabled if:

<u>F'</u>He or she had a disability or health problem that prevented them from participating fully in work, school, or other activities.

El He or she said that he or she had a physical disability, a seeing, a hearing, or speech impairment, *a* emotional or mental disability, or a learning disability.

<u>F'</u> He or she considered himself or herself disabled, or said that other people would consider him or her disabled. (p. iii)

In a Council report on the Federal Government implications of the Harris survey (to be published in 1988 support was given to the application of this approach:

The Harris ... approach should be considered as a starting point or conceptual model in the developm Federal agencies of more adequate instruments and studies... In particular, the Bureau of Census shou consider the definitional approach in the Harris survey for reformulating questions on disability for the decennial Census...."

### Numbers and Types of People with Disabilities

Another issue discussed in Toward Independence was the number of people with disabilities in the U.S. Var estimates place the number between twenty million and fifty million, with thirty-five or thirty-six million be commonly used figures. Based on the Harris data, it was estimated that the incidence of disability was 15 pc that the number of Americans aged sixteen and over was between twenty-seven and twenty-eight million (p. Although the Harris survey did not use people under age sixteen in the survey, it found the overall incidence group to be 1.5 percent or about three million. This figure is drastically lower than other estimates of the nu

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of children with disabilities, and appears to reflect an undercount. According to the Harris figures, the disal population is between thirty and thirty-one million. When the number of disabled persons in institutions is c along with those in households without telephones or in households in which Telecommunication Devices fc are used exclusively, and when the undercount of children with disabilities is considered, the figure of thirty thirty-six million is roughly validated.

Another complex question to answer, and one that is somewhat dependent on which definitional approacl selected, relates to the types of disabilities. Toward Independence provided data with a variety of classificat categories from such sources as the National Center for Health Statistics, the National Institute of Mental He Office of Special Education and Rehabilitative Services.

Harris data revealed that 44 percent of respondents stated that they had a physical disability, 13 percent h

impairments (visual, hearing, speech, and/or language), 6 percent had a mental disability (mental retardation illness), -and 32 percent had other serious health impairments (heart disease, respiratory disease, etc.) Thirty percent of the Harris sample considered themselves multiply disabled, while the remainder did not. Finally, to the severity of disability, 45 percent considered themselves to be slightly or moderately disabled and 52 p considered themselves to be somewhat or very severely disabled.

#### Age

Based on Census data, *Toward* Independence confirmed what many have observed: the incidence of disabili increases dramatically with age. Harris data showed that "58 percent of people with disabilities were 55 yea older, and 71 percent were 45 or older. In contrast, only 16 percent of disabled people were between the age 34. Twelve percent were in the 35-44 age range" (p. 15).

### Income

Numerous studies have confirmed the correlation between disability and poverty. Toward Independence dree 1980 Census figures on income levels of those with work disabilities. Some 20.1 percent of the persons reprive work disability had family incomes below the poverty threshold. That figure was more than double the 1980 rate of 9.1 percent for the general population.

The Harris survey confirmed the great disparity between the incomes of those with disabilities and those general population. According to Harris, half of all disabled persons surveyed had incomes

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of \$15,000 or less. Among non-disabled Americans, just over a quarter had incomes in that bracket.

Harris highlights the alarming rate of poverty among older disabled persons. "Fully one in three (32%) c persons aged 65 and over report a household income of \$7,500 or less. Six out of ten elderly disabled perso household income of \$15,000 or less" (p.23).

Poverty also correlates with severity of disability. Using the Harris definition of disability, both those wl most severely disabled and those who stated that their activities are the most limited have the lowest family

### Education

The Harris poll examined the education levels of persons with disabilities. "Forty percent of all disabled per 16 and over did not finish high school. This proportion is nearly three times higher than in the non-disabled where only 15% of adults aged 18 and over have less than a high school education" (p. 23).

Future studies are needed to determine of the impact of the Education of All Handicapped Children Act, 94-142. As the Harris report comments: "These data provide no measure of the impact of the Education Act [sic], since only a small minority of the sample were educated since its passage" (p. 88). Thus, at the urging Council, a third Harris poll surveying parents of children with disabilities, disabled children themselves, and is being conducted and will be released in 1988 (see also "Educating Children with Disabilities").

Statistics from the first poll on college education, although not surprising, are also disconcerting. Only 2

disabled persons have had some college or at least a four-year degree, compared with 48 percent of the non-population.

### Employment

Census figures on individuals with work disabilities used in Toward Independence revealed that only 32 perworking age persons with disabilities had jobs at the time of the 1980 Census (p. 22). Data from the first Ha confirmed those figures. The chapter describing the employment status of disabled persons was enfftled "W Not Working: The Great Divide." The H"s report remarks:

Not working is perhaps the truest definition of what it means to be disabled in this country. Two-thirds of aH disabled Americans between age 16 and 64 are not worldng. Only one in four work fuu-tirne, and another 10% work

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part-time. No other demographic group under 65 of any size has such a small proportion workwg. (p.47)

Even though the number of persons with disabilities not working is so large, one optimistic finding is that of with disabilities who are not working, two-thirds say that they would like to work. As the Harris report decl finding- that most non-working persons want to work- is one of the most important and challenging findings survey. The challenge is how society can effect policies and programs which will bring these people into the mainstream" 50).

Barriers preventing the employment of persons with disabilities are significant. V%Then asked by Harri comment on barriers respondents identified being limited by their own disabilities or their need for medical and therapy. They also mentioned employers' attitudes, lack of appropriate jobs, insufficient education and lack of accessible transportation, and lack of necessary equipment or devices.

Based on data from the first Harris poll, and the conclusion that the employment picture needed more ina second Harris poll was conducted which focused on employers' perceptions of disabled employees. Althous second study is discussed more fully in the Employment topic paper, a few relevant points are summarized by supplement the overall status of employment of persons with disabilities.

Disabled employees received very high marks from employers. "Overwhelming majorities of managers a disabled employees a good or excellent rating on their overall job performance" (p. 7). The myth that the cc in hiring disabled people is high was dispelled by a 75 percent majority of managers who said that the average hiring a disabled person is about the same as the cost of employing a non-disabled person (p.9).

Managers appear to be aware of the discrimination faced by disabled employees. "A three-fourths major managers feel that disabled people often encounter discrimination from employers" (p. 12).

Although the study poi-trays disabled persons as being a strong, untapped resource, it also points out that

employment of disabled persons is not likely to increase because:

Zi Most managers think their company is already doing enough to employ disabled people and shoul make greater efforts to do so.

L] Most employers believe that the shortage of disabled job appli-

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cants with appropriate qualifications is a major barrier to their employing of more disabled people.

3 Employers give the hiring of disabled people a lower priority than the hiring of people from r groups and the elderly. And disabled people are the least likely to be viewed as an excellent source of (p. 16)

Harris concludes that efforts to increase the employment of disabled people will require an increase in the number of c applicants and employers giving the hiring of disabled persons a higher priority (p. 16).

### Social Life and Leisure

The Harris survey provided important new data regarding the limited independence of people with disabilities in regar and leisure experiences. Harris researchers included questions on social life and leisure patterns for which they had cc on the nondisabled population. They discovered a group of people who are extremely isolated and simply do not get c as many activities as non-disabled persons.

Over half of those surveyed said that their disability prevents them from getting around, attending cultural or sport socializing with friends outside their home as much as they would like. The more severely disabled the individual, th statistics increase.

Almost 80 percent of very severely disabled persons do not get around in the ways mentioned.

Harris researchers found significantly lower participation rates among disabled persons for specific activities:

L] Nearly two-thirds of all disabled Americans never went to a movie in the past year. In the ful population, only 22% said that they had not gone to a movie in the past year.

Z] Three-fourths of all disabled persons did not see live theater or a live music performance in the year. Among all adults, about 4 out of 10 had not done so.

 $\underline{F'}$  Two-thirds of all disabled persons never went to a sports event in the past year, compared to  $\pm$  adults.

3 Disabled people are three times more likely than are non-disabled people to never eat in restar Only 34 percent of disabled people eat at a restaurant once a week or more, compared to 58% majorit non-disabled people. (p.3)

Traditional leisure pursuits are not the only activities limited for

disabled persons. Those social activities associated with daily living and community life are also affected. example, 13 percent of disabled persons never go to a grocery store, compared to 2 percent of the general pu Only 36 percent of disabled persons participate actively in community, religious, volunteer or recreational g compared to 60 percent of non-disabled persons.

Because of the isolated and non-participatoiy status of persons with disabilities in leisure activities, it is c area is one that merits further investigation and policy development. The complex interactions between leist schooling, leisure and work, and leisure and health also need to be examined.

### **Emerging Political Constituency**

Disabled voters have gained increasing attention from candidates. Most recently, efforts are being made to 1 polling places accessible to persons with disabilities. Of course, these efforts have even more importance in Presidential election year.

The Harris researchers explored the degree to which persons with disabilities felt a common unity. An overwhelming majority, 75 percent, of Americans with disabilities reported that they felt some sense of com identity with other people with disabilities (p. I 10). Furthermore, the Harris report notes, "the strength of iv varies little among disabled people of all ages, those who have been disabled all or only part of their lives, an those who are moderately or severely disabled" (p. I I 0).

In analyzing this phenomenon, the Han-is report remarks:

These results show clear signs of an emerging group consciousness. Many other findings in the surv indicate that most disabled person view their disability as their own problem. But these attitudinal da that the common experience of not working and facing li.Tnitations in physical and social activities, how disabled persons relate to, and perceive, other disabled people. (p. 1 1 0)

In a Council report on the Federal policy implications of the Harris poll, further analysis is offered: "...[Piers disabilities are an emerging political constituency whose views and objectives will become an increasingly i aspect of American politics and program administration" (p.24).

### **Endorsement of Nondiscrimination Law**

A central theme of *Toward* Independence was the enactment of a comprehensive law requiring equal opport persons with disabilities. As an emerging political constituency, the views of people with

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disabilities regarding such a law are important. The Harris survey found strong support for legal protection discrimination on the basis of disability:

Vv'hen it comes to how disabled persons should be treated under the law, a near consensus emerges. Three out of ever disabled persons believe that civil rights laws that protect minorities against discrimination should also protect them. (t

it is also clear from the survey that disabled Americans strongly endorse efforts by the Federal Governme enhance the lives of persons with disabilities. "A two-thirds majority of disabled Americans think that feder passed since the late 1960's to give better opportunities to disabled Americans have helped a great deal or so 1).

Disabled Americans are not alone in their belief that they should be protected from discrimination by law manager groups in the second Harris poll on employment were asked if the civil rights laws that cover mino against discrimination should also cover disabled persons. "Majorities of top managers, EEO managers, line and small business managers think they should" (p.25). Both Harris polls have demonstrated support for equ opportunity legislation that would protect people with disabilities from discrimination.

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# Equal Opportunity Laws

A ma or obstacle to achieving the societal goals of equal opportunity and fuE participation of individuals with the problem of discrimination. Discrinidnation consists of the unnecessary and unfair deprivation of an oppor because of some characteristic of a person. It is the antithesis of equal opportunity. The severity and pervasiv discrimination against people with disabilities is well-documented. (*Appendix to Toward Independence*, p. A-

Existing nondiscrimination laws, such as Section 504 of the Rehabilitation Act of 1973, are extremely important and l engendered much progress. In an overall context, however, our Nation's laws provide inadequate protection from disc people with disabilities. Current statutes are not comparable in their scope of protection against discrimination to thos racial, ethnic, and religious minorities and women under civil rights laws.

The National Council on the Handicapped believes that equality of opportunity is a bedrock right in our society, ar discrimination against people because of their disabilities is an unacceptable denial of that right. Such discrimination affront to the dignity of the individual involved, but it undermines Federal programs that attempt to promote the indep self-sufficiency of persons with disabilities. Discrimination is a significant reason why many people with disabilities situations of dependency- dependency which costs our Nation dearly, both in lost potential productivity and in dollars support programs.

President Reagan has declared:

Our Nation's commitment to equal protection of the laws will have little meaning if we deny such protection t have not been blessed with the same physical or mental gifts we too often take for granted. I support Federal prohibiting discrffifflation against the handicapped, and remain detemiined that such laws be vigorously enfor (President Reagan, 1982)

To address the problem of discrimination against persons with disabilities, the Council has advocated comprehensi opportunity protection for persons with disabilities. In the *Toward* Independence topic paper on "Equal Opportunity I Council examined the current status of disability-related nondiscrimination laws and identified large gaps in coverage and inconsistencies in interpretation and application, and deficiencies in enforcement. To correct these problems, the recommended a series of legislative

improvements. Chief among these is the enactment of a comprehensive equal opportunity statute providing standards of nondiscrimination, with broad coverage paralleling laws prohibiting discrimination on the basis sex, religion, and national origin.

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There have been some significant, albeit limited, legislative advances achieving some of the Council's eq opportunity proposals. But the major efforts, especially regarding the enactment of a comprehensive equal c statute, have only recently begun to gain momentum.

### N Recommendations from Toward Independence

In *Toward* Independence, the Council made ten legislative recommendations regarding equal opportunity lav persons with disabilities. Five of these recommendations were directly concerned with the enactment of a comprehensive law prohibiting discrimination against persons with disabilities. The Council has tentatively draft legislative proposal "The Americans with Disabilities Act of 1988." The other five recommendations c additional legislative enactments and amendments to increase legal guarantees of equal opportunity for perso disabilities.

### **Comprehensive Equal Opportunity Statute**

### 1. Congress should enact a comprehensive law requiring equal opportunity for Individuals with disabilities, with broad coverage and setting clear, consistent, and enforceable standards prohibiting discrimination on the basis of handicap.

### N Accomplishments

The foregoing is the first legislative recommendation in *Toward Inde*pendence. Its primacy in the proposals presented to Congress and the President reflects the Council's view that protection from discrimination is a b necessity, and one that is not being adequately addressed in the e)dsting statutes and legal precedents. In for citizens with disabilities across the Nation, the Council has heard over and over that discrimination is the nu problem faced by individuals with disabilities.

"Bringing Disabled Americans into the Mainstream," a nationwide poll conducted in 1986 by Louis Harr Associates, underscores the conclusion that discrimination is a problem that people with disabiliffes frequen experience. Respondents idenfffied a variety of types of discrimination they had experienced, including wo discrimination, denials of life and health insurance, denials of educational opportuniffes, lack of access to pu buildings and public bathrooms, the absence of accessible transportation, and various forms of social rejection (others shying away or feeling them). One-fourth of those interviewed said that they personally had encountered job discrimination becaus disabilities. Forty-seven percent of those individuals who were not employed or employed less than full-tim an important reason why they were not working that employers would not recognize that they were capable full-time job. In a subsequent Harris poll of employers (1987), three-fourths of managers of businesses repc people with disabilities "often encounter job discrimination from employers."

The first Harris poll found great support among individuals with disabilities for legal protection against discrimination on the basis of disability. Its survey report declared:

V% Then it comes to how disabled persons should be treated under the law, a near consensus emerges. Three out of evidisabled persons believe that civil rights laws that protect minorities against discrimination should also protect them. C disagree. (p 1 12)

Such strong support for legal protection from discrimination corroborates the Council's priority for the enactment of a comprehe opportunity law.

While the first recommendation in *Toward Independence* is a call for Congress to enact a comprehensive statute guaranteein opportunities for persons with disabilities, the second through the fifth recommendations give more detail as to the content of su second recommendation describes the broad scope of statutory coverage that the proposed law should encompass. The third rec proposes that the law should include a definition of discrimination and standards for applying it. Recommendation deals with g accessibility, and the role of the Architectural and Transportation Barriers Compliance Board under the comprehensive statute. recommendations would be satisfied by the enactment of a single piece of legislation- the comprehensive equal opportunity law proposed by the Council.

There have been some narrow, but significant, legislative advances in the direction of the Council's equal opportunity initiati Independence, the Council noted that the Supreme Court's decision in *Atascadero State Hospital v.* Scanlon (473 U.S. 234 (198: recognized States' immunity from suits in the Federal courts to enforce nondiscrimination requirements. This situation was corr enactment of the Rehabilitation Act Amendments of 1986 (Public Law 99-

506). Section 1003 of that Act provides that States may not invoke

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immunity under the Eleventh Amendment if they are charged with discrimination on the basis of handicap i of Section 504 of the Rehabilitation Act.

The Council also recommended the correction of certain problems with the provisions regarding terms of members of the Architectural and Transportation Barriers Compliance Board under section 502 of the Rehat Act of 1973 (*Toward* Independence, p. 2 1, and Appendix, p. A-31). The wording of the statute regarding th appointment of succeeding members to the Board and the commencement of the successors' appointments haunfilled vacancies on the Board. The Council proposed that the terms of office provisions of Secffon 502 fc approach taken in most other governmental boards and stipulate that members are to serve until their success been appointed and are ready to serve. This correction was made with the enactment of Section 60 1 (a) (3) Rehabilitation Act Amendments of 1986 (Public Law 99-506), which amended Section 502 to change the la accordance with the Council's recommendation. The application of nondiscrimination requirements to airlin clarified by the Air Carrier Access Act of 1986 (Public Law 99435), which prohibits discrimination on the b

handicap by all air carriers. (The Air Carrier Access Act is discussed more extensively in this report in the se dealing with Transportation.)

The Council has also noted the restrictions upon coverage of eldsting nondiscrimination statutes protectir with disabilities resulting from the -program or activity" limitation (See, Toward Independence, Appendix, J A-9). Pursuant to decisions of the United States Supreme Court in *Grove City College v. Bell* (465 U.S. 555 (1984)) and Consolidated *Rail Corporation v.* Darrone (465 U.S. 624 (1984)), the prohibition of discriminat under such statutes as Section 504 of the Rehabilitation Act of 1973 is limited to the specific programs or ac are funded by Federal grant money. Under these decisions recipients of Federal financial assistance are perr discriminate in their other, non-federally-funded programs and activities.

A bill entitled '-Me Civil Rights Restoration Act of 1987" (S. 557) was introduced in the 100th Congress the limitations resulting from the *Grove City* and DaTTone decisions. In April of 1987, the Council was ask tesfffy before the Senate Committee on Labor and Human Resources in hearings regarding S. 557. In its tes Council reaffirmed its belief in comprehensive equal opportunity protection for people with disabilities and view that "an absolutely necessary first step is to return the scope of coverage of Section 504 and the other c laws to their status before the Supreme Court's ruling in the *Grove City* case." The proposed Restoration Act

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has been approved by the Committee on Labor and Human Resources and is currently awaiting action on th floor.

Although the statutes and pending legislation just discussed represent significant initiatives to expand or nondiscrimination protection for persons with disabilities, they address only a few relatively narrow issues. Council's primary recommendation in this areaenactment of a clear and comprehensive statute guaranteeing opportunities for people with disabilities- is now beginning to be the focus of legislative attention and suppo

Just as the recommendations in *Toward* Independence were a ciystallization of views expressed to the Co numerous individuals with disabilities at the grass roots level as well as by experts and organizational repres the Council sought additional input and feedback in regard to the actual drafting of a comprehensive equal o statute. Over the past eighteen months, the Council has engaged in numerous meetings and discussions with of Congress, congressional staff members, officers of national organizations, grassroots consumers, and othe parties to explore the content and wording of the statutory proposal. Based on the approach outlined in the  $\epsilon$ opportunity recommendations in Toward Independence, augmented by the comments and advice received, tl developed a draft of a comprehensive equal opportunity proposal entitled "The Americans with Disabilities . 1988."

The drafting of legislation is a developmental process that reflects negotiation, compromise, and continue the Council recognizes that the draft proposal presented on the succeeding pages is not the final version. The believes, however, that the draft presented herein represents a significant step toward the introduction and expassage of such a statute. The Council is confident that the "Americans with Disabilities Act" is representation need for expanded nondiscrimination protection it has heard repeatedly voiced by persons with disabilities,  $\alpha$  convinced that the enactment of such a statute is one key to increased independence and quality of life for per disabilities.

### The Americans with Disabilities Act of 1988 Section by Sect\*lon Summa''

### Section 1 - Short Title

Provides that the law may be cited as the Americans with Disabilities Act of 1988.

### Section 2- Findings and Purpose

Subsection (a) presents Congressional findings about people with disabilities, their disadvantaged status in our soc seriousness of discrimination against them, and the costliness of such discrimination to our country.

Subsection (b) provides a statement of the overall purposes of the Act centering on the establishment of a clear and National mandate for the elimination of discrimination against persons with disabilities. 4

### Section 3- Definitions

Provides definitions of key terms used in the Act, including "on the basis of handicap," "physical or mental impair "reasonable accommodation." The former are defined consistently with their definition in ensting regulations under Se the Rehabilitation Act of 1973. The definition of "reasonable accommodation" is drawn from *Accomnwdating the* Sp *Individual Abilities*, a report issued by the U. S. Commission on Civil Rights.

### Section 4- ScoT)e of Discrimination Prohibited

Tells what persons and agencies are prohibited from discriminating against persons with disabilities. Provides bro coverage in line with other types of civil rights laws. Includes, among others, the Federal Government, Federal grant Federal contractors and licensees, employers engaged in interstate commerce having fifteen or more employees, housing providers covered by Federal Fair Housing **--kit** laws, public accommodations, interstate transportation companies, and State and local governments.

### Section 5- Forms of Discriminiation Prohibited

Subsection (a) tells what actions constitute discrimination prohibited by the law. These include various types of in uninten-

tional exclusion; segregation; inferior or less effective services, benefits, or activities; architectural, transpol communication barriers; failing to make reasonable accommodations; and discriminatory qualifications and performance standards.

Subsection (b) specifies that certain actions do not constitute discrimination. These include unequal treat wholly unrelated to a person's disability, or is the result of the legitimate application of qualifications and pe standards that are necessary and related to the ability to perform or participate in the essential components or activity involved. Also explicitly defined as not discriminatory are special programs designed for persons w particular physical or mental impairments or classes of impairments.

### Section 6- Discrimination in Housing

This section provides standards regarding the application of nondiscrimination requirements in housing. standards are drawn from the current version of the disability poruons of the Federal Fair Housing Amendm the Senate Judiciary Committee. Their primary focus is upon accessibility in future design and construction

### Section 7- Limitations on the Duties o-f Accommodation and Barrier Removal

Subsection (a) provides that barrier removal or reasonable accommodations are not required to be made i would fundamentally alter or threaten the e2dstence of the program, business, activity, or facility in question

Subsection (b) permits a reasonable period of time, not to exceed two years, for making substantial modified existing buildings and facilities in order to remove barriers. This period may be extended up to five years the regulations governing particular classes of buildings and facilities.

Subsection (c) provides that regulations may permit a reasonable period of time, not to exceed ten years, substantial modifications to eidsting platforms and stations of mass transportation systems.

#### Section 8- Regulations

Subsection (a) calls for the Architectural and Transportation Barriers Compliance Board to issue minimu guidelines for accessibility of

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buildings, facilities, vehicles, and rolling stock. Other parts of the Section call for Federal agencies to issue for implementing and enforcing the requirements of the Act, including the following:

### LJ Employment

Equal Employment Opportunity Commission

### 3 Housing

Secretary of Housing & Urban Development

<u>F'</u> Transportation

Secretary of 'ftansportation

### <u>F'</u> **Public accommodations**

Secretary of Corrunerce

### LJ Federal contractors and subcontractors Secretary of Labor

Ll **State and local governments, and coordination** Attorney General (Department of Justice)

### **3 Recipients of Federal financial assistance**

The agency that provides the Federal assistance

Subsection (i) provides that regulations issued under Section 504 of the Rehabilitation Act of 1973 shall effect unless and until superseded by regulations under this Act.

Subsection 0) provides that regulations under this Act cannot provide less protection to persons with phymental impairments, perceived impairments, or records of impairment than under existing Section 504 regul

### Section 9- Enforcement

Establishes enforcement procedures for the requirements of the Act. These include administrative remed private right of action, monetary damages, injunctive relief, attomey's fees, and cutoffs of Federal funding.

Section 10- Effective Date

Provides that the Act shall take effect on the date of its enactment.

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### THE AMERICANS WITH DISABILITIES ACT OF 1988 A DRAFT BILL

To establish a clear and comprehensive prohibition of discriniinauon on the basis of handicap.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled.

#### SECTION 1.-SHORTTITLE.

This Act may be cited as the "Americans with Disabilities Act of 1988". SEC. 2. - FINDINGS AND PURPOSES.

(a) Findings. - Congress finds that -

(1) some thirty-six n-ffllion Americans have one or more physical or mental disabilities, and this number increasing as the population as a whole is growing older;

(2) historically, society has tended to isolate and segregate persons with disabilities, and, despite some in discrimination against persons with disabilities conunues to be a serious and pervasive social problem;

(3) discrimination against persons with disabilities persists in such critical areas as employment, housing accommodations, education, transportation, recreation, institutionalization, health services, voting, and access services;

(4) every day, people with disabilities encounter various forms of discrimination, including outright, inte exclusion, architectural, transportation, and communication barriers, overprotective rules and policies, refusal modifications to eidsting facilities and practices, exclusionary qualification standards and criteria, segregation tion to lesser services, programs, activities, benefits, jobs, or other opportur"ues;

(5) census data, national polls, and other studies have documented that people with disabilities, as a grouj inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educati

(6) persons with disabilities are a discrete and insular minority who have been saddled with restrictions a limitations, subjected to a history of purposeful unequal treatment, and relegated to a posiuon of political pow our society, based upon characteristics that are beyond the control of such persons and resulting from stereoty assumptions not truly indicative of the individual ability of such persons to participate

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in, and contribute to, society;

(7) the Nation's proper goals regarding persons with disabilities are to assure equality of opportunity, full participation, independent living, and,

wherever possible, economic self-sufficiency for such citizens; and

(8) the continuing e-3dstence of unfair and unnecessary barriers, discrimination, and prejudice denies pedisabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free justifiably famous, and costs the United States billions of dollars in unnecessary expenses resulting from dependent nonproductivity.

(b) PURPOSE. - It is the purpose of this Act-

(1) to provide a clear and comprehensive National mandate for the elimination of discrimination against with disabilities;

(2) to provide a prohibition of discrimination against persons with disabilities parallel in scope of covera afforded in statutes

prohibiting discrimination on the basis of race, sex, national origin, and religion;

(3) to provide clear, strong, consistent, enforceable standards addressing discrimination against persons w disabilities; and

(4) to invoke the sweep of congressional authority, including its power to enforce the fourteenth amendn regulate commerce, and to regulate interstate transportation, in order to address the major areas of discriminat day-today by people with disabilities.

#### SEC. 3. DEFINI'NONS For purposes of this Act:

(1) ON THE BASIS OF HANDICAP. - The term "on the basis of handicap" means because of a physica impairment, perceived impairment, or record of impairment.

(2) PHYISCALORMENTALIMPAIRMENT.-Theterm"physicalorme impairment" means-

(A) any physiological disorder or condiff on, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: (i) the neurological system;

- (ii) the musculoskeletal system:
- (iii) the special sense organs, and respiratory organs, including speech organs;
  - (iv) the cardiovascular system:
  - (v) the reproductive system;
  - (vi) the digestive and geriitourinaiy systems;
- (vii) the hemic and lymphatic systems;
- (viii) the skin; and
- (ix) the endocrine system; or
- (B) any mental or psychological disorder, such as mental retardation,

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organic brain syndrome, emotional or mental illness, and specific learning disabilities.

(3) PERCEIVED IMPAIRMENT.-The term "perceived impairment" means not having a physical or men

impairment as defined in paragraph (2), but being regarded as having or treated as having a physical or menta
 (4) RECORD OF IMPAIRMENT. -The te= "record of impairment' means having a history of, or having misclassified as having, a mental or physical impairment.

(5) REASONABLE ACCOMMODA'nON.- The term "reasonable accommodation" means providing or 1 devices, services, or facilities, or changing standards, criteria, practices or procedures for the the purpose of re the specific functional abilities of a particular person with a physical or mental impairment in order to provide opportunity to participate effectively in a particular program, activity, job, or other opportunity.

#### SEC. 4. SCOPE OF DISCRIMINATION PROHIBITED

- (a) INGENERAL.-Nopersonshallbesubjectedtodiscriminationonthe basis of handicap in regard to-
  - (1) actions, practices, and policies of the Federal Government, any of the agencies and departments of the

Government, or the United States Postal Service;

(2) actions, practices, and policies of a recipient of Federal financial assistance;

(3) actions, practices, and policies of a Federal contractor, subcontractor, or licensee;

(4) employer practices, employment agency practices, labor organization practices, and training programs Title VII of the Civil Rights Act of 1964;

(5) the sale or rental of housing covered by TiUe VIII of the Civil Rights Act of 1968;

(6) any public accommodation covered by Title II of the Civil Rights Act of 1964;

(7) transportation services rendered by a person, company, or agency

engaged in the principal business of interstate transportation of persons, goods. documents, or data; and,(8) actions, practices, and policies of a State, or agency or political subdivision of a State.

(b) CONSTRUCMON. -Nothing in this Act shall be construed to invalidate or limit any other Federal lav law of a State or political subdivision of a State, or jurisdiction that provides greater protection or rights for perphysical or mental impairments, perceived impairments, or records of impairment than are afforded by this Ac

#### SECTION 5. FORMS OF DESCRIMINATION PROHIBITED

(a) INGENERAL.-Subject to the standard sand procedure sestablished

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in sections 6 through 9 of this Act, the actions or omissions described in this subsection constitute discrimination on handicap:

(1) SERVICES, PROGRAMS, ACTIUITES, BENEFITS. JOBS, OR OTHER OPPORTUNINES.-

(A) IN GENERAL. -It shall be discriminatory to subject a person, directly or through contractual licensing, or other arrangements, on the basis of handicap, to any of the following:

(i) Denial of the opportunity to participate in or benefit from a service, program, activity benefit, job, or other opportunity.

(ii) Affording a person an opportunity to participate in or benefit from a service, program activity, benefit, job, or other opportunity that is not equal to that afforded others.

(iii) Providing a person with a service, program, benefit, job, or other opportunity that is 1 effective than that provided to others.

(iv) Providing a person with a service, program, activity, benefit, job, or other opportunity different or separate, unless such action is necessary to provide the person with a service, progractivity, benefit, job, or other opportunity that is as effective as that provided to others.

M Aiding or perpetuating discrimination by providing significant assistance to an agency, organization, or person that discrini.inates.

(vi) Denying a person the opportunity to participate as a

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memberof planning or advisory boards.

(vii) Otherwise limiting a person in the enjoyment of any right, privilege, advantage, or opportunity enjoyed by others.

(B) LEVELSOFACHIEVEMENT.-Forpurposesofthissection, services, programs, activities, bene or other opportunities to be equally effective, are not required to produce the identical result or level c achievement for persons with physical and mental impairments, perceived impairments, or records of and persons without such impairments, but such services, programs, activities, benefits, jobs, or other opportunities shall afford persons with such impairments an equal opportunity to obtain the same resu the same benefits, or to reach the same level of achievement, in the most integrated setting appropriatneeds of the person.

(C) OPPORTUNI-IY TO PARTICIPATE. -Notwithstanding the e2dstence of separate or differen programs or activities provided in accordance with this section, a person with a physical or mental im perceived impainment, or record of impairment shall not be denied the opportunity to participate in suor activities that are not separate or different.

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(D) ADMINISTRATW METHODS. - A person, company, or agency may not, directly or through contractual or ( ments, utilize criteria or methods of admiriistration-

(i) that have the effect of discrimination on the basis of handicap;

(ii) that have the purpose or effect of defeating or substantially impairing the accomplishment of objectives of the services, programs, activities, benefits, jobs, or other opportunities provided with res persons with physical or mental impairments, or records of impairments; or

(iii) that perpetuate the discrimination of others who are subject to conunon adn-iiriistrative contro agencies of the same State.

- (2) BARRIERS. -It shall be discriminatory-
  - (A) to establish or unpose; or
  - (B) to fail or refuse to remove;

any architectural, transportation, or communication barriers that prevent or limit the access or participation of the basis of handicap.

(3) ACCOMMODATION.- It shall be discriminatory to fail or refuse to make a reasonable accormnodation to period individual with a physical or mental impairment, perceived impairment, or record of impairment to apply, have access participate in a service, program, activity. benefit, job. or other opportunity.

(4) STANDARDS AND CRITERIA.- It shall be discriminatory to impose or apply any qualification standards, s criteria, or eligibility criteria that-

(A) screen out or disadvantage an individual because of a physical or mental impairment, perceived impa record of **im**pairment; or

(B) disproportionately screens out or disadvantages persons with particular types of physical or mental in perceived impairments. or record of impairments;

unless such criteria can be shown to be necessary and substantially related to ability to perform or participate in essent of the particular service, program, activity, benefit, job, or other opportunity.

(5) RelationshipsorAssociations.-Itshallbediscriminatoryto exclude or otherwise deny equal services, programs, *i* benefits, jobs, or other opportunities to a person because of the relationship to, or association of, that person with anot has a physical or mental impairment, perceived impairment, or record of impainment.

(b) ACTIONS NOT DISCRIMINATORY. - It shall not be considered to be discrimination on the basis of handie or otherwise deny equal services, programs, activities, benefits, jobs, or other opportunities to a person-

(1) for reasons wholly unrelated to the e-3dstence of or consequences of a physical or mental impairment impairment, or record of impai=ent;

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(2) based on a legitimate application of qualifications standards, selection criteria, performance standards eligibility criteria that are both necessary and substantially related to the ability to perform or part cipate in the components of the parucular job, program, activity, or opportunity, and such performance or participation can accomplished by a reasonable accormnodation.

SEC. 6. DISCRIMINANON IN HOUSING.

(a) INGENERAL.-Notwithstandingtherequirementsofsection5(a),it shall be an act of discrim regard to housing-

(1) to discriminate in the sale or rental, or to otherwise make unavailable or deny, a dwelling to any buye because of a physical or mental impairment, perceived impairment, or record of impairment of -

(A) such buyer or renter;

(B) a person residing in or intending to reside in such dwelling after it is so sold, rented, or made available-, or

(C) any person associated with that buyer or renter.

(2) to discriminate against any person in the te=s, condiuons, or privileges of sale or rental of a dwelling provision of services or facilities in connection with such dwelling, because of a physical or mental impai=ent impairment, or record of impai=ent of-

(A) such person;

(B) a person residing in or intending to reside in such dwelling after it is so sold, rented, or made available; or

(C) any person associated with such person.

(b) REMOVAL OF BARRIERS IN HOUSING. -For purposes of subsection (a), discrimination includes

(1) a refusal to permit, at the expense of a person with a physical or mental impairment, perceived impairecord of impai=ent, reasonable modifications of eidsting premises occupied, or to be occupied, by such person modifications may be necessary to afford such person full enjoyment of the premises;

(2) a refusal to make reasonable accommodations in rules, policies, practices, or services, when such accommodations may be necessary to afford such person equal opportunity to use and en oy a dwelling; or

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(3) a failure to design and construct qualified multifamily dwellings for first occupancy after the date that is 30 n the date of enactment of this Act, in such a manner that-

(A) the public and conu-non use portions of such dwelling are readily accessible to, and usable by with physical and mental impairments;

(B) all the doors into and within all premises within such dwellings are sufficiently wide to allow by persons in wheelchairs; and,

(C) all premises within such dwellings contain basic universal features of adaptive design.

- (c) DEFINI-NON. -As used in this section the term "qualified multifamily dwellings" means-
  - (1) buildings consisting of two or more units if such buildings have one or more elevators; and
  - (2) those units in other buildings consisting of two or more units that are on the ground floor.

#### SEC. 7. LIMITATIONS ON THE DU-fIES OF ACCOMMODA'NON AND BARRIER REMOVAL

(a) E?USTENCE THREATENING ALTERATIONS. -

(1) IN GENERAL.-The failure or refusal to remove architectural, transportation, and communication bar make reasonable accommodations required under subsection 5(a) shall not constitute an unlawful act of discrite basis of handicap if such barrier removal would fundamentally alter the essential nature, or threaten the eig program, activity, business, or facility in question.

(2) OTHERAC-nON.-Intheeventthatbarrierremovalisnotrequired because it would result in a fundamenta or threaten the existence of a program, activity, business, or facility, there shall continue to be a duty to confo requirements of this Act and to take such other actions as are necessary to make a program, activity, or service viewed in its entirety, readily accessible to and usable by persons with physical and mental impairments, percimpairments, or records of impairments.

(b) 'nME FOR ALTERA'NONS. -

(1) IN GENERAL. -If substantial modifications to existing buildings and facilities are necessary in order to remove architectural, transportation, and communication barriers, as required under subsection 5(a), such modifications shall, unless required earlier by other law or regulation, be made witl-lin a reasonable period of time, not to exceed 2 years from the date of enactment of this Act.

(2) EXCEPTION.- Regulations promulgated pursuant to section 8 of this Act may allow up to 5 years freeffective date of this Act

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where reasonably necessary for the completion of such modifications to particular classes of buildings and facilities.

#### (c) MASS TRANSPORTA'nON.-

(1) IN GENERAL. -If substantial modifications to e2dsting platforms and stations of mass transportation necessary in order to remove architectural, transportation, and communication barriers, as required under subs of this Act, regulations promulgated pursuant to section 8 of this Act may, unless required earlier by other law regulation, allow a reasonable period of time, in no event to exceed ten years from the effective date of this Act modifications to be made.

EXCEPTION.-Thissubsectionshallnotaffectthedutyofprowiders of transportation services to other requirements of this Act, including the requirement of removing other types of architectural, transportati conununication barriers, and the application of such requirements to vehicles and rolling stock.
 SEC. 8. REGLTLATIONS.

(a) ARCHITECTURAL AND TRANSPORTATION BARRIERS COMPLIANCE BOARD. -Within 61 the date of enactment of this Act, the Architectural and Transportation Barriers Compliance Board shall issue guidelines, to supplement the e-3dsting Minimum Guidelines and Requirements for Accessible Design, to est standards for the architectural, transportation, and communication accessibility of buildings, facilities, vehicle stock subject to the requirements of this Act.

(b) A-ITORNEY GENERAL.-

(1) INGENERAL.-Withinlyearofthedateofenactmentofthis Act, the Attomey General shall proregulations for the implementation and enforcement of the requirements of this Act as it applies to States and political subdivisions of States.

(2) MINIMLTMGUIDELINES.-TheAttorneyGeneraloftheUnited States shall coordinate the ti development of regulations required under this section and shall issue, within 6 months of the date of enactmeniiriimum guidelines for the development of such regulations.

- (c) EQUAL EMPLOYMENT OPPORTLTNI-IY COMMISSION. -
  - (1) EMPLOYER PRACnCES.-
  - (A) IN GENERAL.-Witl-lin I year of the effective date of this Act, the Equal Employment Oppor

Commission shall promulgate regulations for the implementation and enforcement of the requirement Act as it applies to employer practices.

(B) PROHIBITIONS.-Theregulationspromulgated undersub-

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paragraph (A) shall prohibit discrimination in regard to job application procedures, the hiring and discharge of emplo compensation, job training, and other te=s, conditions. and privileges of employment.

(2) REQUIREMENTS. -The regulations promulgated under subparagraph (A) shall include, for all covered empl fifteen or more employees, a requirement of outreach and recruitment efforts to increase the workforce representation with physical or mental impairments, or records of impairments, and shall establish a process and timelines for the de implementation, and periodic revision of such outreach and recruitment efforts.

(3) PREEMPLOYMENT INQUIRIES.-

(A) IN GENERAL.- The regulations promulgated under paragraph (1)(A) shall include a requirement tha may not conduct a preemployment medical examination or may not make preemployment inquiry of an applic whether the person has a physical or mental impairment, perceived impairment, or record of impairment, or as or severity of such impairment.

(B) PERMMED INQUIRIES.-AN EMPLOYER-

may make a preemployment inquiry into the ability of an applicant to satisfy legitimate qualifications stand selection criteria, performance standards, or eligibility criteria as permitted under section 5(b)(2);

(ii) may condition an offer of employment on the results of a medical examination conducted prior to the duty of the applicant, if-

(I) aR entering employees are subjected to such an examination regardless of physical or mental impairment, perceived impairment, or record of impairment: and

(II) the results of such an exantination are used only in accordance with the requirements of this s

(iii) taking remedial action to correct the effects of past discrimination or engaged in outreach and recruitn to increase the participation of persons with physical or mental impairments may invite applicants for employ indicate whether and to what extent they have a physical or mental impai=ent, if-

(I) the employer states clearly on any written questionnaire used for employment purposes, or ma orally if no written questionnaire is used, that the info=ation requested is intended for use solely in co with its remedial action or outreach and recruitment activities: and

(II) the employer states clearly that the information is being requested on a voluntary basis, that s information

will be kept confidential as provided in subparagraph (C), that refusal to provide such information will not subject the employee to any adverse treatment, and that such info=ation will be used only in accordance with the requirements of

(C) CONFIDENTIALITY. - InformaUon, as to the medical condition or history of the applicant, in accordance with this paragraph shall be collected and maintained on separate forms that shall be ac same confidentiality as medical records, except that-

(i) supervisors and managers may be informed of restrictions on the work or duties of p with physical or mental impairments and of necessary accommodations for such persons;

(ii) first aid and safety personnel may be informed, where appropriate, if such a condition require emergency treatment: and

(iii) government officials investigating compliance with this Act shall be provided relevar information on request.

(d) SECRETARY OF HOUSING AND URBAN DEVELOPMENT. -Within I year of the effective date the Secretary of Housing and Urban Development shall promulgate regulations for the implementation and en the requirements of tins Act as it applies to sellers, landlords, and other providers of housing.

(e) SECRETARY OF TRANSPORTATION. -

(1) IN GENERAL. -Within 1 year of the effective date of this Act, the Secretary of Ransportation shall pregulations for the implementation and enforcement of the requirements of this Act as it applies to State and by systems and to those engaged in the business of interstate transportation.

(2) STANDARDS.-The regulations promulgated under paragraph
 (1) shall include standards regarding the accessibility of vehicles and rolling stock consistent with the req of paragraph (3).

(3) REQUIREMENTS.-WithrespecttoStateandlocaltransitsystems, rail and light rail services, and bus co the standards issued under paragraph (2) shall-

(A) ensure that all vehicles or rolling stock that are purchased, leased, renovated, or otherwise pla service after the date of enactment of this Act shall be accessible to and usable by persons with physic impairments, including wheelchair users:

(B) permit a reasonable period of time, not to exceed 7 years, for such transportation operators to acquire, or modify sufficient vehicles and rolling stock so that the peak fleet has at least 50 percent of and rolling stock that are accessible to and usable by persons with physical or mental impairments, in

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#### wheelchair users; and

(C) ensure that the use of paratransit and other specialized transportation services for persons with physical impairments shall be used as a supplement to other forms of transportation, but shall not affect the requirement transportation systems and services available to members of the public shall be accessible to and usable by pe

physical or mental impairments, including wheelchair users.

SECRETARY OF COMMERCE. -Within 1 year of the effective date of this Act, the Secretary of Comme promulgate regulations for the implementation and enforcement of the requirements of this Act as it applies to public accommodation.

(g) SECRETARY OF LABOR. -Within I year of the effective date of this Act, the U.S. Secretary of Lab promulgate regulations for the implementation and enforcement of the requirements of this Act as it applies to Federal contracts and subcontracts.

(h) FEDERAL AGENCIES.- In addition to the regulations required pursuant to paragraphs (a) through (g executive agencies shall issue, within 1 year of the date of enactment of this Act, such additional regulations a necessary to implement and enforce the requirements of this Act as such requirements apply to programs and which such agencies provide Federal financial assistance.

(i) REHABILITATION ACT OF 1973.- Regulations of Federal agencies issued under section 504 of the Rehabilitation Act of 1973 shall remain in effect unless and until they are superseded by regulations promulga Act.

0) LEVF-LOFPROTECTION.-InnoeventshallregulaUonspromulgated under this Act provide less prote against discrimination to persons with a physical or mental impainuent, perceived impairment, or record of in under ensting regulations for the implementation of section 504 of the Rehabilitation Act of 1973.

#### SEC. 9. ENFORCEMENT

(a) ADMINISTRATIVE ACTIONS.-

(1) IN GENERAL-Any person who believes that he or she or any specific class of individuals is being o be subjected to discrimination on the basis of handicap in violation of the Act, shall have the right, by himself by a representative, to pursue such administrative enforcement procedures and remedies as are available in conthe regulations issued pursuant to Secuon 8 of this Act.

(2) REMEDY. -Agencies enforcing such regulations shall have the authority to order all appropriate rem including compliance orders, cutoff of Federal funds, rescission of Federal licenses, monetary

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damages, and back pay.

(b) CIUL ACTIONS. -

(1) RIGHT TO FILE. - Any person who believes that he or she or any specific class of individuals is bei to be subjected to discrimination on the basis of handicap in violation of this Act, shall have a right, by himse or by a representative, to file a civil action for injunctive relief, monetary damages, or both in a district court of States.

(2) ADMINISTRATIVE ENFORCEMENT. -The exhaustion of administrative enforcement procedures a remedies as contemplated in section 9(a) shall not be a prerequisite to the filing of a civil action under this sub-

except in regard to employer practices, employment agency practices, labor organization practices, and trainin covered by paragraph 4(a)(1) of this Act, for wl-iich such exhaustion shall be required urfless-

(A) administrative enforcement procedures and remedies as contemplated in section 9(a) are not : or

(B) such enforcement procedures are not concluded within 180 days after the filing of a complain discrimination prohibited under this Act.

(c) ADDITIONAL EVIDENCE. - In any action brought under this section, the court shall receive the rec administrative proceedings, shall hear additional evidence at the request of a party, and, basing its decision on preponderance of the evidence, shae grant such relief as the court deems appropriate.

(d) JURISDIC-flON. -The district courts of the United States shall have jurisdiction of actions brought u Act without regard to the amount in controversy.

(e) IMMLJNITY.-AStateshallnotbeimmuneundertheEleventh Amendment of the Constitution of the Uni from suit in Federal Court for a violation of this Act. In a suit against a State for a violation of the requiremen remedies (including remedies both at law and in equity) are available for such a violation to the same extent a remedies are available for such a violation in a suit against any public or private entity other than a State.

ATFORNEY'SFEES.-Inanyactionoradmirdstrativeproceeding commenced pursuant to this section, the cou in its discretion, may allow the prevailing party, other than the United States, a reasonable attorney's fee in ad and the United States shall be liable for costs the same as a private person.

(g) BURDEN OF PROOF. -In any administrative proceeding or civil action brought under this Act, the l proving the legitimacy of any qualifications standard, selection criteria, or eligibility criteria at issue in a case proving the defense that a particular reasonable acconuno-

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dation or removal of an architectural, transportation, or communication barrier would fundamentally alter or threaten of the program, activity, business, or facility in question, shall be on the person, agency, or entity alleged to have cont discrimination, and shall not be on the complainant. SEC. 10. EFFECTIVE DATE.

This Act shall become effective on the date of enactment.

## **Consumer Leverage of U.S. Government**

2. The law should direct the Federal Government to use its leverage as a consumer of goods and services to set standards and timelines for requiring that businesses and companies from which it purchases or rents goods, services, or facilities shall make such goods, services, and facilities accessible, available to, and usable by people with disabilities on a nondiscriminatory basis.

## N Accomplishments

The first five recommendations in *Toward* Independence concerned the enactment of the Americans with Di Act and described the elements that such a law should contain. The remaining five legislative recommendat regard to equal opportunity laws involve specific concerns that can be addressed by separate pieces of legislative amendments.

The first of these, set out above, involves a legal mandate to require U.S. Government agencies to use the 'consumer clout" as purchasers and lessors of numerous types of services, merchandise, and facilities in orde persuade businesses they deal with to make their products and services accessible to persons with disabilities proposed by the Council in *Toward Independence*, this initiative pertains to a wide array of goods and servic obtained by the Government from private companies, including conference and meeting room rentals, airling tickets, rental cars, hotel rooms, and office equipment.

Congress has not yet enacted legislative directives requiring the Federal Government to limit its purchase rentals to equal access companies on an across-the-board basis.

To date, the Federal Government's purchasing power has been invoked to apply pressure for accessibility but increasingly important area- electronic equipment. In February of 1986, as Congress was considering th amendments to the Rehabilitation Act of 1973 that would culminate in the Rehabilitation Act Amendments (Public Law 99-506), the Council recommended the addition of a new section to the Act to require that all o automation equipment obtained by the Federal Government be accessible to and usable by persons with disa response to this proposal, Congress included Section 603 in the Rehabilitation Act Amendments of 1986. The provision adds a new Section 508, entitled "Electronic Equipment Accessibility," to the Rehabilitation Act or requires the Naffonal Institute on Disability and Rehabilitation Research and the General Services Administic consultation with the electronics industry to establish "guidelines for electronic equipment accessibility designed for the section of the section is provided to a section with the electronics industry to establish "guidelines for electronic equipment accessibility designed for the section for the section for the section for electronic equipment accessibility designed for the section for the section for the section for electronic equipment accessibility designed for the section for t

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insure that handicapped individuals may use electronic office equipment with or without special peripherals September 30, 1988, such guidelines are to be adopted by the Administrator of General Services, and compl Government agencies in their purchases or leases of electronic office equipment. Section 508 represents a n quite significant implementation of the Council's recommendation that Government procurements of service and facilities make accessibility to persons with disabilities a condition precedent.

## El Discrimination in Medical Services

## 3. The law should apply to discrimination in medical services.

## **N** Accomplishments

This recommendation was primarily in response to the decision of the United States Court of Appeals for the Circuit in United *States v. University Hosp., State U. of New York* (729 F.2d 144 (2d Cir. 1984)), in which the court ruled that Section 504 of the Rehabilitaffon Act of 1973 does not apply to medical treatment. Sub the publication of *Toward Independence*, the United States Supreme Court had occasion to review the ration the *University Hospital* decision in a separate case, *Bowen v.* American *Hospital Association* (1 06 S. Ct. 2 1 01 (1986)). The regulations regarding treatment of handicapped infants, at issue in both cases, were ultimate dov,7n by the Supreme Court, but not because Section 504 does not apply to medical services. On the contr Court expressly ruled that "handicapped infants are entitled to 'meaningful access' to medical services provic pitals, and that a hospital rule or State policy denying or limiting such access would be subject to challenge to Secffon 504" (106 S. Ct. at p. 2111 (1986)). The Section 504 regulations regarding medical treatment of ha provide adequate documentation of the problem being addressed and of the necessity for the procedures initi

Currently, instances of alleged denials of medical treatment to infants with disabilities are much more lik dealt with under the Child Abuse Amendments of 1984 (Public Law 98-457) than under Section 504. These Amendments and the regulations issued to implement them (45 C.F.R. 1340.15) provide standards regarding dering of medical treatment to handicapped infants and establishing when the failure to provide treatment co child abuse or neglect.

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Because of the subsequent developments in legislation, regulations, and case law, the objectives underly Council's recommendation in regard to coverage of medical services have largely been achieved.

# El Bin of Rights for Persons with Disabilities

# 4. An enforceable Bill of Rights for Persons with Disabilities should be enacted.

## N Accomplishments

The Council's proposal of a Bill of Rights for persons with disabilities has been the subject of some legislativ advancement, but the initiatives have not been as broad nor as forceful as the Council recommended. The C proposed that a Bill of Rights be created for persons with all types of disabilities. The Council suggested tha listed be patterned after the existing Developmental Disabilities Bill of Rights and that proposed by the Task Legal and Ethical Issues of the President's Commission on Mental Health. A key feature of the Council's recommendation was that such a Bill of Rights "should explicitly be made enforceable administratively and Federal courts" (Toward Independence, Appendix, p. A-57).

No Bill of Rights for the overall class of persons with disabilities as a whole has yet been enacted. A sign

development was the passage of the Protection and Advocacy for Mentally III Individuals Act of 1986 (Publ 99-319), which contains a "Restatement of Bill of Rights for Mental Health Patients." Reaffirming statement contained in Title V of the Mental Health Systems Act, these provisions direct each State to review its menta laws and revise them if necessary. In doing so, the States are to "take into account the recommendations of the President's Commission on Mental Health" and a lengthy list of rights regarding conditions of treatment and sites to confinement.

The list of rights contained in this Act is very useful and consistent with the Council's concept of a Bill o primary shortcoming, however, is that the list of rights appears to be unenforceable. The list is simply one t are to "take into account" as they review and revise their laws. A subsequent provision provides that the Act be construed as establishing any new rights for mentally ill individuals" (Section 301). The lack of enforcea (which is also a problem with the Developmental Disabilities Bill of Rights) makes this list of rights somewl a true Bill of Rights.

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# **Private Right of Action Under Section 503**

# 5. Equal opportunity obligations upon Federal contractors and subcontractors should be made enforceable by a private right of action.

# Accomplishments

Secffon 503 of the Rehabilitation Act of 1973 places affin-native action and nondiscrimination requirements Federal contractors having contracts in excess of \$2,500. The enforcement of such requirements is assigned Department of Labor. The weight of judicial precedent is that an aggrieved individual subjected to discrimin violation of Section 503 does not have a right to file a lawsuit to challenge such illegal discrimination. In *T* Independence, the Council echoed views expressed for many years by persons with disabilities and legal cor when it proposed that Section 503 be made enforceable by a private right of action. To date, Congress has r followed up on this proposal. A private right of action for individuals complaining of discrimination on the handicap would be provided under the Council's proposed comprehensive equal opportunity law.

# El Advocacy System and Legal Fees

6. To assure the recognition and implementation of the rights estabUshed in this equal opportunity law, Congress should authorize an expanded Protection and Advocacy System in each State to protect and advocate for the rights of individuals with all types of, disabilities, regardless of the age of onset; Congress should authorize the awarding of reasonable attomeys fees and litigation expenses to prevailing complainants.

# N Accomplishments

Significant legislative progress has occurred in regard to the Council's recommendations of an expanded Pro

Advocacy System and for the awarding of attorneys fees to successful litigants in lawsuits by individuals wi disabilities and their families. The Protection and Advocacy for Mentally III Individuals Act of 1986 (Publi-99-319) provides authority and funding for expanding the responsibilities of the existing developmental disa Protection and Advocacy Systems in each State to encompass protection and advocacy of the rights of menta individuals. In addition, Section 1 12(a) of the Rehabilitation Act of 1973 (as amended by Public Law 98-2: establishes a program of grants to the States for the establishment and operation of "client assistance program vocational rehabilitation clients. Section 112(b) makes funding of State vocational rehabilitation programs c

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ungent upon the eidstence of a client assistance program that "has the authority to pursue legal, administrati other appropriate remedies to ensure the proteeffon of rights of handicapped individuals who are receiving to services, or rehabilitation under this chapter."

The addition of the protection and advocacy systems for mentally ill individuals and the vocational rehab client assistance programs to the previously ensting protection and advocacy systems for persons with develo disabilities represents a very significant expansion of advocacy services for individuals with disabilities. Su expansion has not yet equaled the scope of the Council's recommendation of advocacy services for persons v types of disabilities, but it certainly reflects vigorous congressional action in that direction.

Attorneys fees and litigation expenses for people with disabilities and their families who successfully pro have been denied their rights would be a specific feature of the Council's proposed comprehensive equal opp law for persons with disabilities. To date there has been one major legislative advance regarding these issue enactment of the Handicapped Children's Protection Act of 1986 (Public Law 99-372). This law provides th "may award reasonable attomeys' fees as part of the costs to the parents or guardian of a handicapped child c who is the prevailing party" in a lawsuit brought under the provisions of the Education of the Handicapped *A* enactment of this provision constitutes a critical milestone for children with disabilities and their parents in p them realistic access to the expensive legal representation someffmes necessary for contesffng inappropriate educational placements and programs.

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# Employment

Employment has consistently headed the list of major concerns of persons with disabilities in this country. *I* for most other Americans, a major prerequisite to economic self-sufficiency and quality of life is a job. Emj offers the possibility of dramatically improving an individual's lifestyle, while at the same time resulting in t financial savings for the Government. Perhaps most important is the ability of gainful employment to facilit integration of persons with disabilities into all facets of community life. In fact, employment for persons wi disabilities is critical in determining independence. Recognizing the seriousness of barriers to employment opportunities for persons with disabilities, employment was selected as one of the ten areas in the Council's *Toward* Independence.

In order to explore and fully understand the problems of employment for persons with disabilities, the Cc conducted a series of forums throughout the United States to gather data from consumers, parents, service pi experts, and others. In addition to public forums, the Council initiated two Harris polls.

The first Harris poll examined overall attitudes and life experiences of persons with disabilities, including employment. Findings from the first Harris poll indicated that:

Not working is perhaps the truest definition of what it means to be disabled. Two-thirds of all disabl Americans between the ages of 16 and 64 are not working. Only one in four work full-time, and anc work part-time .... Furthermore, unemployment among persons with disabilities as a group is a bigge than among any other demographic group of working-age Americans. (p. 47)

Another significant finding from the first Harris poll was that 66 percent of working-age persons with dis who are not working, want to have a job. This overwhelming absence from the labor force of people with a desire to work is a tragic failure of the American dream.

Data from the first Harris poll coupled with the importance of employment in the lives of persons with di generated a second Harris poll devoted solely to employment, "Employing Disabled Americans."

Based on interviews with over 900 companies, the purposes of the second survey were to determine what across the country were doing to employ persons with disabilities and to return persons with disabilities to w experiences employers had had with persons with disabilities, what barriers prevented employers from

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hiring persons with disabilities; and what steps the public and private sectors could take to increase the emp persons with disabilities.

A great majority of employers rated the performance of disabled workers as "good to excellent." Another finding dispelled a common myth about the cost of hiring a disabled person: 75 percent of managers said that employing persons with disabilities is no greater than the cost of hiring non-disabled workers. Most employ appeared to be willing to consider the employment of more disabled people if they are qualified.

Unfortunately, data from the survey indicated that without some new stimulus, the employment of disable unlikely to increase significantly. Most managers thought that their company was already doing enough to  $\epsilon$  disabled people and should not make greater efforts to do so. Employers gave the hiring of disabled people priority than the hiring of people from minority groups and elderly persons. Furthermore, disabled people a likely to be viewed as an excellent source of employees.

Finally, several steps that leaders in government, business, and voluntary organizations could take to incr employment of persons with disabilities were suggested: increase job training programs; make available wid information on qualified applicants; create programs to make employers aware of agencies which have disat applicants; and encourage disabled people to apply for positions.

Data from both Harris polls regarding overcoming barriers to employment for persons with disabilities st reinforce the eight recommendations made by the Council in *Toward* Independence. These recommendation addressed a variety of issues, including transition from school to work, supported employment, private secto **j**ob training, and **j**ob development and placement.

During the 99th Congress, legislation was passed that included several of the Council's major recommend the areas of supported employment, transition, and tax incentives for employers. The Council believes that t legislative changes represent unprecedented gains in terms of expanded employment opportunities for person disabilities. Additional congressional action is still needed to implement the full range of the Council's recommendations, including the establishment of model centers on employment and return-to-work program elimination of income eligibility requirement for persons with disabilities under the Job Training Partnership

In addition to legislative activity, the Council has played a major role with the promulgation of regulaffor to the Rehabilitation Act Amendments of 1986 by holding numerous meetings and

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teleconferences of consumers and service providers to solicit input and feedback.

A detailed summary of progress toward the eight recommendations follows.

# **N Recommendations from Toward Independence**

# **El** Transition

1. Congress should direct the Department of Education to designate the State educational agency as the lead agency to start, develop, and carry out the transition planning process.

2. Congress should direct the Department of Education to strengthen regulations requiring the involvement of education coordinators and vocational rehabilitation counselors in the transition process.

# N Accomplishments

Transition is an outcome-oriented process encompassing a broad range of experiences and services resulting competitive employment. In *Toward* Independence, the Council used the transitional model developed by th of Special Education and Rehabilitative Services (OSERS) which represents a bridge between the security o the risks and opportunities of adulthood. It is based on sound preparation in high school, adequate support n upon leaving school, and secure opportunities and services, as needed, in adulthood (Will, 1984). The Coun that a coordinated, well-planned collaborative transition process will lead to successful employment for stud disabilities.

Although the precise Council recommendations regarding transition were not enacted by the 99th Congreintent of the recommendations was included in the Education of the Handicapped Act 1986 Amendments (P 99-457).

Title III- Discretionary Programs, Section 626, which provides for transitional services to handicapped y amended in two ways. First, it clarifies the policy that transitional programs can serve not only children and currently in school, but also youth who have recently left school. Second, the legislation extends transitiona include "services provided to a handicapped child throughout his or her years in school, not simply during th or three years before he or she graduates out of the special education system." Both of these provisions clear the Council's conviction that transitional services need to be improved and expanded to increase

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employment opportunities for youth with disabilities.

In addition to these legislative changes, the Council cosponsored, with the Office of Special Education ar Rehabilitative Services and the President's Committee on Employment of the Handicapped, a parent-employ conference on best practices in transitional programming. The conference brought together parents, employ people with disabilities, service providers, educators, and representatives of Federal, State and local governn discuss employment opportunities and to develop strategies and guidelines that parents can use when assistir daughters or sons with special needs in seeking employment. Conference proceedings, published in Noveml outlined strategies and guidelines developed by participants for use by parents and employers in promoting j development, placement, and retention.

## El Supported Work

# 3. Congress should amend the Rehabilitation Act to add a Title expressly authorizing programs of supported work for persons with severe disabilities who can be competitively employed with the assistance of such a program.

# N Accomplishments

Defined simply, supported work refers to paid employment for some individuals with severe disabilities who ongoing support and assistance in a work setting. Recognizing the increased importance of the role of support in the lives of severely disabled individuals, Congress incorporated the Council's recommendation regarding work into the 1986 Rehabilitation Act Amendments (Public Law 99-506). Furthermore, a new State Grant I was added, Part C of Title VI, entitled "Supported Employment Services for Individuals with Severe Handic section establishes supported employment as a State formula-grant program, supplementing the Title I alloca

Another key provision in the Rehabilitation Amendments is the definition of "supported employment" wl compatible with the definition used in *Toward* Independence.

'Supported employment' means competitive work in integrated settings-

(A) for individuals with severe handicaps for whom competitive employment has not traditionally occurred, or

(B) for individuals for whom competitive employment has been interrupted or interriffittent as a r severe disability, and, who because of their handicaps, need ongoing support services to perform suc

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In addition to persons with developmental disabilities and mental retardation, the definition includes transit services for persons with chronic mental illness and persons with physical disabilities.

Other key changes related to supported employment include the addition of supported employment under an eligible funded service and the addition of supported employment as an authorized vocational rehabilitati and outcome under Title I.

Establishment of supported work programs will substantially reduce the number of severely disabled pers residing in residential facilities and allow these individuals to become employed in competitive work setting community. Supported employment programs also will provide persons with severe disabilities an opportur become independent, taxpaying citizens.

The regulations governing supported employment under the Rehabilitation Act Amendments of 1986 hav finalized and approved. At the beginning of Fiscal Year 1988 rehabilitation agencies in each State received provide supported employment services and programs.

Federal Support for Private Sector Initiatives

# 4. Congress should extend and expand the Targeted Jobs Tax Credit Program (Deficit Reduction Act of 1984, Public Law 98-364).

## **N** Accomplishments

The Targeted Jobs Tax Credit (TJTC) Program offers employers a credit against their tax liability for hiring from nine target groups who traditionally have had difficulty in obtaining and holding jobs. The Targeted Jo Credit Program has created work opportunities for persons with disabilities and is continuing to create a favo climate throughout the business community for hiring persons with disabilities.

The success of incentives for employers was corroborated in the second Harris poll: 68 percent of the ma interviewed indicated that a government policy subsidizing the salaries of handicapped employees for a trial would be an effective incentive for employers to increase the hiring of persons with disabilities.

Although the TJTC program was to expire on December 31, 1985, the Tax Reform Act of 1986, Public I

reauthorized the pro-

gram for a three-year period, through December 31, 1988. The same nine target groups were authorized, or was persons with disabilities who are referred to employers from a State vocational rehabilitation office or V Administration program.

Major changes in the TJTC program under the new legislation relate to the amount of credit and retention

a. Amount of Credit- The credit for first year's wages is limited to 40 percent of up to \$6,000 eamed, with a maximum credit credit for second year wages is eliminated. Wages paid during the retention period (see b) apply if the minimum retention requirer economically disadvantaged summer youths remains at 85 percent of up to \$3000 for a maximum credit of \$2,500 for each individu

b. RetentionPeriod-Aminimumemploymentperiodof9Odaysorl2Ohoursofpaid employment (14 days or 20 hours in the case c disadvantaged summer youth employees) is required before the employer can claim the tax credit.

The TJTC program gives employers a financial incentive while providing disabled job seekers an opportunit demonstrate their capabilities. According to a study based on FY 1985 TJTC usage, the Committee on Emp Opportunities found a nationwide savings in public assistance payments of \$418,000,000. Tax credits such geted Jobs Tax Credit Program are cost-beneficial by contributing directly to a reduction in government pay people with disabilities, including those on Social Security (SSDI and SSI), Aid to Families with Dependent (AFDC), and the cost of institutionalization. The amount of money paid in taxes by disabled employees assis program may offset the tax credits allowed to employers. In addition to the economic benefits which will ac Nation as a result of the Targeted Jobs Tax Credit Program, it also promotes selfrespect and independence fc with disabilities

Although the TJTC program was extended for three years and made retroactive to January 1, 1986, this p not expanded in as broad a way as the Council recommended. Therefore, the Council will continue to moni legislation and determine the best way to effect the necessary changes.

# 5. Congress should make Section 190 of the Internal Revenue Code permanent and expand it to a maximum amount of \$75,000 per year.

#### N Accomplishments

Section 190 of the Internal Revenue Code allows an employer a tax

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deduction for expenses incurred in connection with the elimination of architectural and transportation barrie persons with disabilities and elderly persons at the place of business.

The Tax Reform Act of 1986 (Public Law 99-514) made Section 190 a permanent provision, as recomme

the Council. Section 190 was made retroactive to January 1, 1986. The amount that an employer can deduc taxable year remains \$35,000. Qualified expenses include only those specifically attributable to the removal barriers.

Once again, data from the Harris poll on employers confirmed the wisdom of this legislative change. Ap 74 percent of the managers surveyed agreed that a policy by the Government to provide additional tax deduc share in the cost of expensive accommodations would increase the employment of persons with disabilities.

# 6. Congress should develop innovative and effective incentives to promote the establishment of return-to-work programs.

#### N Accomplishments

Most managers surveyed by the Harris agency were supportive of and committed to the rehabilitation of emj who become disabled. Approximately three-quarters of each of the three types of managers surveyed respor employers have a responsibility to rehabilitate disabled employees. The large majority felt that the rehabilitation disabled employees is cost-effecffve.

The provision of incentives to businesses that provide retum-towork programs would increase the returna significant number of persons who become disabled. However, the Council's recommendation on retum-to programs was not included in legislation enacted by the 99th Congress. The Council will continue to attend important recommendation.

Although these porgrams are relatively new, the Council believes that retum-to-work programs that invol employees in the early stages of rehabilitation will enable a substantial number of employees to maintain an employment. Incentives to companies will encourage more employers to develop retum-to-work programs, reducing the number of persons with disabilities not working. This will eventually reduce the amount of mc on income support programs.

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#### **Job Development and Placement**

# 7. Congress should support the development of area model centers on employment for persons with disabilities.

#### Accomplishments

Many persons with disabilities experience difficulty in finding suitable employment. Job development and  $\mu$  are fundamental rehabilitation services to assist persons who are vocationally handicapped by a disability to employment consistent with their vocational assets and limitations. Job development is the process of development

appropriate job site; placement is actually obtaining the job.

As stated previously, the findings from the first Harris poll indicated that two-thirds of persons with disal this country who are of working age are not working. Even more important is the fact that two-thirds of tho individuals not working want to work. Although no action has been taken on this recommendation, the Cou continues to believe that area model centers on employment could assist in reducing the number of unemplowith disabilities.

### El Job Training

# 8. Congress should amend the Job Training Partnership Act (JTPA) to eliminate the income eligibility requirement for persons with disabilities and to increase the representation of persons with disabilities on Private Industry Councils.

### N Accomplishments

The Job Training Partnership Act (,JTPA) authorized job preparation and job training for people who are ecdisadvantaged and for people who face serious barriers to employment. The JTPA also symbolizes cooperate between the public and private sectors to achieve the shared goal of providing employment opportunities for persons. The 1986 Amendments to the JTPA were primarily technical in nature because of the many substate changes to the Act in 1982, and the Council's recommendation was not incorporated.

Some changes, however, did relate to disabled persons. A new section entitled "Projects for Special Population 456, was added. This section mandates the Secretary of Labor to expend a portion of the discretional for research, demonstration, and pilot projects to assist groups of individuals who are not otherwise targeted Federal, State, or service delivery area set-asides. Special consideration is to be given to displaced workers with disabilities. In addition, several sections of the Act emphasize the provision of

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services to disabled veterans.

The Council believes that these provisions will improve and increase the services provided to persons wit disabilities under the Job Training Partnership Act. However, the Council reaffirms its belief that for persor disabilities to be adequately served by the JTPA, the income eligibility criteria must be eliminated. The Cou continue to encourage Congress to amend this legislation to reflect that position.

# Disincentives to Work Under Social Security Laws

An overwhelming consensus e2dsts as to the importance of work in our society; that consensus applies to disabled and persons alike. The previous section on employment dealt in general with the world of work, including the transition f work, supported work, private sector initiatives, and job development, placement and training. Toward Independence section that took a closer look at Social Security legislation and its impact on securing a job. This section details prog elimination of disincentives in the Social Security system.

In Toward Independence, the Council explored the extent to which income and medical benefit programs authorize Social Security Act encouraged persons with disabilities to become self-sufficient and gainfully employed. Economic provided by those programs, e.g., Social Security Supplemental Income (SSI) and Social Security Disability Insurance intended to partially compensate for the earning loss which typically accompanies disability.

In addition to income supplements, persons with disabilities and/ or their families may be eligible for assistance will care (Medicaid and Medicate), housing, education, training, and employment. The tenet that underlies this form of G assistance is that alleviating financial stress through the provision of disability benefits will allow persons with disabilit recovery, rehabilitation and the eventual return to work.

However, some of the Federal programs under the Social Security Act not only fail to promote employment and in citizens with disabilities, but actually penalize and discourage people with disabilities if they seek employment. Even programs provide many people with severe disabilities the basic life necessities, the experiences of consumers and ser demonstrate that some programs actually encourage dependence and discourage gainful employment.

In order to eliminate or reduce the disincentives to work under the Social Security Act, the Council recommended legislative changes. The first change relates to the existing process for deterining eligibility for Social Security bene Council believes that the eligibility determination process should be revised to include a functional assessment of the disabling condition. Other changes include developing work incentives for recipients of Supple-

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mental Security Income and conducting a study on cost-effective methods of providing health insurance to 1 with disabilities.

Legislation passed in the 99th Congress contains several of the Council's recommendations for the remov barriers that discourage persons with disabilities from seeking gainful employment under the Social Security Council believes that this legislation will have a positive impact on the number of persons receiving SSI and to work. The Council continues to believe that Congress should revise the eligibility criteria for SSI and SS

# **N Recommendations from Toward Independence**

# **1** Congress should amend the Social Security Act to make ergibility for SSI and SSDI programs dependent upon the presence of a severe medical disability and a

# functional assessment to determine vocational potential whenever deemed appropriate.

# N Accomplishments

By definition, eligibility for SSI disability benefits or SSDI benefits is based on the assumption that disablec beneficiaries are unable to work. In principle, a person who is able to work should not be entitled to disabili However, disabilities obviously cannot be categorized simply as those that prevent one from working and th not.

Currently, individuals with certain medical diagnoses are automatically considered eligible for SSI and S disability income benefits unless they have a substantial work history after the onset of disability. Because t work is dependent upon a large number of factors and varies tremendously from one individual to another, t eligibility process should be judged by a thorough functional vocational assessment.

Although agreement exists that the eligibility process needs to be improved, Congress has not yet acted o recommendation made by the Council. Because of the Council's commitment to this issue, it will continue t the Social Security Administration and Congress to encourage the revision of the eligibility criteria for SSI a The Council believes that this revision will change the focus of disability determinations from a purely medi to one that recognizes the full range of factors affecting the ability to work.

# 2. Congress should amend the Social Security Act to assure that SSI and SSDI recipients who become gainfully employed are permitted to retain benefits and have access to medical insur-

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# ance in circumstances where the loss of such benefits would substantially negate the income they might earn.

# **N** Accomplishments

The health insurance problems of disabled persons are widespread. Some disabled workers are forced into i support programs primarily because they cannot obtain private medical insurance coverage. Persons with di who are self-employed often have great difficulty because they rarely have access to group insurance progra Furthermore, many small businesses that offer the low paying jobs held by many people with disabilities hav medical coverage at all.

Congress attempted to alleviate problems in this area by the passage of the Employment Opportunities Fc Americans Act (Public Law 99-643), which makes the temporary (demonstration) provisions of Section 161 (b) permanent. Passing this legislation implemented the aforementfoned Council recommendation.

Under this important program, eligibility for Supplemental Security Income cash assistance and Medicai extended for persons with disabilities who go to work and have earnings above the Substantial Gainful Activ indicator, currently \$300 per month. Previous barriers which consisted of the termination of the SSI cash as after the trial work period and the loss of eligibility for Medicaid have been eliminated in this new legislatio

Re-entitlement problems for persons who have fluctuating earnings and other changes have also been adc Re-entry is improved and waiting time and reexaminaton requirements are eliminated. The Act also provide persons who are reinstitutionalized for treatment, thus bridging another gap in the SSI program for persons v disabilities. As a direct result of this legislation, more persons with disabilities, especially those with more s disabilities, will have the opportunity to become employed, some for the first ffme.

In addition to the Employment Opportunities for Disabled Americans Act, Congress established an Advis Council on Disability within the Social Security Administration to study and make recommendations on the and vocational aspects of the Social Security disability programs [Consolidated Omnibus Budget Reconcilia 1985 (Public Law 99-272, Secffon 12102), enacted April 7, 19861. In addition to studying the areas manda Congress, the Advisory Council will address work incentives and disincentives in disability programs. A rej findings of the Advisory Council is scheduled for December 31, 1987. The National Council on the Handica forward to the report's recommendations regarding the removal of disincentives to employment for persons v disabilities.

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3. Congress should direct the Health Care Financing Administration to study and recommend cost-effective methods for providing health insurance coverage to persons with preexisting conditions who cannot obtain adequate health insurance coverage from private insurers at affordable rates. The study should be conducted in consultation with the National Council on the Handicapped, and findings and recommendations should be reported in hearings before Congress within two years of the date of the enactment of this provision.

#### Accomplishments

As was stated previously, the problems that disabled persons have with health insurance are monumental. A health insurance is certainly one key toward independent functioning. The Council believes that further inversion into this area is essential.

A study of the type recommended by the Council on health insurance was incorporated by Congress in th Rehabilitation Act Amendments (Public Law 99-506, Section 303). Congress requested the Director of the Institute on Disability and Rehabilitation Research to conduct a study on health insurance practices and polic affecting persons with disabilities. A report on this study is to be presented to the appropriate congressional by February 1, 1990.

# Prevention of Disabilities

A Federal initiative to prevent primary and secondary disabilities could substantially reduce the costs of disa health care for Americans, reduce Federal spending for disability in the near future, and decrease the incider disability for future generations. Research indicates that preventive measures would reduce the number of n additions to the disabled population. For example:

3 One dollar spent on the Childhood Immunization Program saves \$ 1 0 in later medica. (Monitoring *the Health of* America's Children, 1984).

Seventy percent seat belt use would save an estimated 9,000 lives and prevent 34,000 severe i or disabilities per year (National Highway Traffic Safety Administration, 1984).

Because it is clear that our Nation has the knowledge, technology, and resources to mount an effective an national program for the prevention of primary and secondary disabilities, the Council has devoted concerter this area, and considerable progress has been achieved in the past two years.

The Council's recommendations regarding prevention have three components: 1) a national plan on the p disabilities; 2) a small community-based grants program; and 3) further research on incidence and prevalenc primary and secondary disabilities. The first component consists of the Federal Government's development national plan for the prevention of disabilities. Such a plan would focus on the major causes of primary and disabilities and how they can be prevented. Recognizing the fiscal constraints being placed on the Federal C today, the Council believes that the implementation of this recommendation must not create any new Govern agency or department, but rather be built into an already existing Federal agency.

The Office of Disease Prevention and Health Promotion has issued a report, Promoting Health/Preventing which outlines national objectives to be reached by 1990. The Council is impressed with the report, but is certain the objectives outlined focus on the prevention of mortality and not disability. If this Office were to rec additional monies and staff, it could, with Council involvement and oversight, develop a plan focusing on the prevention of disabilities. The development of such a plan would help prevent disabilities and would also ga important, sorely needed statistical information.

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The second component of the Council's prevention plan is a small community-based grants program, wh be administered by the Centers for Disease Control. Such a program would allow local communities to appl grants to eliminate or ameliorate one or several disabling condiffons. For example, a small community in N State recently developed a plan to reduce the number of persons killed or injured in traffic accidents by educ significant number of high school youth, as well as others in the community. Data indicate that this program significantly reduced the number of traffic fatalities and injuries. By allowing local communities to set their ties, this program is likely to receive broader community involvement and support.

The third component reflects an overall need within the disability community for valid and reliable statis Accordingly, the Council has recommended that such data be gathered by the Office of Technology Assessn

# 2 Recommendations from Toward Independence

# 1. Congress should enact a law related to prevention entitled "The Prevention of Disabilities Act."

# N Accomplishments

When Toward Independence was published, the Council believed that a separate piece of legislation was nee prevention of disabilities. Since that time, however, the Council has learned that eidsting legislation could a the same objectives, i.e., the development of a national plan on the prevention of disabilities and a communi grants program to demonstrate effective prevention strategies. The Public Health Service Act contains sever which authorize the type of preventfon activities which the Council believes must be funded.

First, Title XVII, Health Informaffon and Health Promotion, authorizes the activities of the Office of Dis Prevention and Health Promotion. Senate Report 99-408, which accompanies the Labor, Health and Human and Education Appropriaffons bill for Fiscal Year 1987 (Public Law 99-591), contains language which direc Office of Disease Prevention and Health Promotion to begin to consider the development of a National Plan Prevention of Disabilities. Recently, the Office of Disease Prevention and Health Promotion has convened a meetings of several Federal agencies involved in the prevention of disabilities. Although these meetings hav productive, the Council believes that additional staff and funding for the Office of Disease Prevention and H Promotion are necessary for the

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goals of the Council's prevention initiative to reach fruition. Furthermore, the Council sees its role as maint oversight responsibility for the development of such a national plan in order to assure that the plan addresses issues confronting the disability community.

Title III of the Public Health Act, General Powers and Duties of the Public Health Service, contains a nussiall grants programs which may lend themselves to the implementation of the Council's recommendation f community-based grants to prevent disabilities. Specifically, Section 317, Project Grants for Preventive Health Services, could be directed toward the prevention of disabilities.

In addition, Title XVII of the Act, entitled Health Information and Health Promotion, also contains a veh small community-based grants program, Section 1703, entitled Community Programs. This section authoriz activities which could promote the prevention of disabiliffes within local communities. The Centers for Disadministers both of these community-based programs.

# 2. Congress should provide appropriate levels of funding for special program

# priorities related to disabinty prevention.

Accomplishments

The Council has officially adopted two recommendations for appropriate funding levels for disability prever activities. First, adequate funds should be appropriated to the Department of Health and Human Services to Office of Disease Prevention and Health Promotion to develop a National Plan on the Prevention of Disabili Second, the Centers for Disease Control should be appropriated sufficient funds over the next five years to f community-based programs which would promote the prevention of both primary and secondary disabilites.

The Council firmly believes that the implementation of these recommendations could make a tremendous only by preventing needless disabilities from occurring, but also by assuring that persons with eidsting disab able to live more independent and productive lives. Over the past two years, the Council has worked conscissecure appropriations related to prevention.

# 3. Congress should direct its Office of Technology Assessment to conduct a study of the status of primary and secondary prevention of disability in the United States, and to submit a report of its findings two years after the issuance of the National Plan on the Prevention of Disabilities.

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## N Accomplishments

Before such a study of the status of primary and secondary prevention of disabilities by the Office of Techno Assessment can be of value, it is imperative that the Council's first two recommendations on prevention be f operational. The Council continues to urge the Federal Government to initiate a national program for preven coordinating Federal prevention-related programs, and believes that when these programs become functiona study regarding the prevention of disabilities will be of great assistance.

# Transportation

In *Toward* Independence the Council concluded that accessible transportation is a critical component of a national policy that promotes the self-reliance and self-sufficiency of people with disabilities: "People who cannot get to work or to the voting place cannot exercise their rights and obligations as citizens" (p. 33). According to Government data (DoT, 1978), the number of transportation-handicapped people is 7.4 million in urban areas; of that group 1.4 million are unable to use transit at all. Transportation is not a problem in a vacuum- the magnitude of the problem is increased exponentially by complex interactions between transportation and employment, housing, independent living, education, and leisure activities.

The 1986 Harris poll, -Bringing Disabled Americans into the Mainstream," underscores the fact that transportation is a major problem for persons with disabilities. A clear majority of disabled persons state that their disability prevents them from getting around, socializing, or going to cultural events as much as they would like. Forty-nine percent of the respondents believe that their mobility is limited because they "are not able to use public transportation or because [they] can't get special transportation or someone to give [them] a ride when [they] need one" (p. 65).

'ftansportation barriers not only limit social and community life; they also severely restrict employment options, and may explain a porUon of the 66 percent of disabled persons who are without jobs. According to the Harris survey, approidmately three out of ten people say that a lack of accessible or affordable transportation is an important reason why they are not working.

In the Council's 1986 report, recommendations were provided in the following areas: urban mass transit, air transportation, intercity and interstate buses, private transportation, and research. Without a doubt, the area in which the greatest progress has been achieved is that of air transportation, with the passage of the Air Carrier Access Act of 1986.

#### Recommendations from Toward Independence

#### El Urban Mass Transit

1. Congress should amend Section 16 of the Urban Mass Transit Act to require full accessibility to mass transportation to be achieved over a realistic period of time; such amendments should: a. Prohibit discrimination on the basis of disability by recipients of Federal funds under this Act.

b. Require recipients to provide a level of service to disabled and elderly persons that is equivalent with that available to nondisabled persons in terms of-. 1) service range, 2) transfer frequency, 3) fare, 4) travel purpose.
5) trip decision/travel time, 6) capacity, and 7) availability.

c. Require that all new facilities and vehicles constructed or purchased with funds under this Act be accessible.

d. Require recipients of funds under this Act to develop specific transition plans for achieving, within a reasonable period of time, full access and comparable service levels. These plans should be developed with the substantial and meaningful involvement of disabled and elderly consumers.

e. Create a private right of action for persons who believe they have been discriminated against by recipients of funds under this Act.

Accomplishments

In today's highly mobile society, transportation barriers conffnue to exclude many disabled persons from most forms of public transportation. Such discriminaton prevents many people from realizing their full potential for independence and productivity. Although the Urban Mass Transit Act of 1964, as amended, espouses a national policy establishing a right to equal use of public transportation for disabled and elderly persons, the legislation lacks the underlying foundation necessary to render it enforceable. It contains no clear mandate.

Section 16 of the law requires that -special efforts shall be made in the planning and design of mass transportation facilities and services so that the availability to elderly and handicapped persons of mass transportation which they can effectively utilize will be assured..... This language weakens the policy of equal use by not setting a physical standard for compliance. Judicial interpretations have found that this section creates no requirement for a fully accessible system. The legislative history of the Act, on the other hand, tends to support the idea that the intent of Section 16 is to create full accessibility.

The Council proposed amendments to Section 16 that would alleviate its weaknesses in terms of disabled persons and attempt to fulfill its philosophical promise of a fully accessible system of transportation. Unfortunately no action has been taken on the proposed remedies. Instead, Congress has taken the role of policeman by proposing legislation to reverse regulatory setbacks imposed by the Department of Transportation.

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The regulatory setbacks Congress is attempting to reverse relate to the Department of Transpor-taffon's promulgation of its final rule on May 23, 1986, for urban mass transportation pursuant to Section 504 of the Rehabilitation Act of 1973, and Section 317(c) of the Surface lYansportation Assistance Act of 1982. In a letter to the former Secretary ofRansportation Elizabeth H. Dole, the Consortium for Citizens with Disabilities remarked: "...Mhis rule fails to implement the principles of Section 504 and jeopardizes the availability of desperately needed transportation for people with disabilities."

The two most glaring problems of that final rule are: 1) a regulatorily imposed limit of 3 percent on the amount of funds required by a recipient of Federal financial assistance in order to fulfill its obligations to providing services to persons with disabilities-, and 2) the unprecedented exclusion of one category of disabled persons, i.e. mentally disabled persons, from coverage under the definition of disability under tl,-e regulations (unprecedented in terms of Section 504 regulations). The regulations cover only persons who are physically unable to use the services. In his January 29, 1987, statement for the Record, Senator Cranston concluded:

[I]t has now been nearly **17** years since Congress proclaimed in section 16(a) of the Urban Mass'ftansportation Act of 1964 that it is'national policy that elderly and handicapped person have the same right as others persons to utilize mass transportation fadities and services' [Ilt is stin too often the case that disabled persons lack the access to

transportation services that they need.... It is time we gave greater meaning to the Congress' 1970 declaration of handicapped rights, and we can do so in this legislation. (p. S 1412)

Identical bills are now pending in both the Senate and the House (S. 1077, H.R. 2887). These proposals, if enacted, will reverse the regulations with regard to the exclusion of mentally disabled individuals and the 3 percent cap. Also included is a provision which was one of the Council's five recommendations made to amend Section 16, the creation of a private right of action for persons who believe they have been aggrieved under the Act.

If Congress passes the proposed legislation, the two regulatory setbacks will be negated and a private right of action will be established for the first time. However, the Council strongly reaffirms its commitment to the other four recommended amendments, especially the requirement that all new facilities and vehicles constructed or purchased be accessible.

A related issue to amending UMTA is monitoring the enforcement of the UMTA Section 504 regulations that require the submission of transition plans describing how local transit authorities intend to achieve compliance. The Paralyzed Veterans of America, the Council,

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and the National Easter Seal Society are currently analyzing transition plans that have been submitted to assess the status and level of compliance as reported.

2. Congress should amend the Architectural Barriers Act of 1968 to establish the Department of Transportation as a standardsetting agency for the development of access standards for buildings, facilities, and public conveyances, including rolnng stock and aircraft, which are designed, altered, constructed, or purchased with Federal funds to insure that they are readily accessible and usable by disabled and elderly persons.

The Architectural Barriers Act of 1968 establishes four Federal agencies as standard setting- the General Services Administration, the Department of Defense, the Department of Housing and Urban Development, and the U.S. Postal Service. Although the Department of Transportation sets transportation standards govening such matters as configurations of vehicles, communication access, and appropriate signage and safety, DoT is not allowed to establish standards for accessible transportation. The Council continues to believe that this situation should be remedied.

#### 13 Air Transportation

3. Congress should amend the Federal Aviation Act to:

a. Prohibit discrimination on the basis of disability by all airlines using federally assisted airports.

b. State that all airlines using federally assisted airports are subject to the provisions of Section 504 of the Rehabintation Act of 1973 and regulations promulgated thereunder.

#### N Accomplishments

At the ffme of the publication of *Toward* Independence, only a few small air carriers that were federally subsidized were required to be accessible. However, since that time, Congress has responded to this inequity by enacting legislation to prohibit discrimination in air travel. The Air Carrier Access Act of 1986, Public Law 99-435, echoed the nondiscrimination language of Section 504 of the Rehabilitation Act by prohibiting air carriers from discriminaffng against qualified handicapped individuals in the provision of air transportation.

This law, in effect, reversed the Supreme Court decision in the case of the *Department of* 7Yanspoitation *v. Paralyzed* Veterans ofamerica. Specifically, the Act amends Section 404 of the Federal Aviation Act to prohibit discrimination on the basis of handicap by all air carriers.

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Symbolically, the law has been a clear message from Congress that discrimination against persons with disabilities will not be condoned.

In a statement made to the House of Representatives, Congressman Norman Mineta, chairman of the Aviation Subcommittee, remarked:

The bill now before us ... will make it clear that airlines may not discriminate against handicapped persons .... I strongly believe that handicapped passengers are entitled to take full advantage of the mobility afforded by air transportation and that handicapped passengers are entitled to be treated with dignity when they travel. (p. H 7193)

The law also directed the Department of Transportation to promulgate regulations to implement its provisions by January 31, 1987. Recognizing the potential adversarial positions which the regulations might evoke, and in an attempt to get those parties together to negotiate compromises, the Department of Transportation utilized a process referred to as "regulatory negotiation." This process, which had been employed by the Department on three previous occasions, was originally developed by the Administrative Conference (47 FR 30706).

On June 10, 1987, a team led by two facilitators from the Federal Mediation and Conciliation Service convened to establish parameters for the negotiation process. The team was composed of 15 individuals representing the disability community, the air travel industry, the Federal Government, and observers.

Disability interests were represented by the American Council of the Blind, Paralyzed Veterans of America, National Federation of the Blind, National Association of Protection and Advocacy Systems, National Association of the Deaf/National Center for Law and the Deaf, National Council for Independent Living and the Society for the Advancement of Travel for the Handicapped. The Federal Government was represented by the Department of Transportation and the Architectural and Transportation Barriers Compliance Board. The National Council on the Handicapped, although not asked to be part of the official team, was encouraged to participate and voice its views on issues of concern.

For purposes of discussion, potential problem areas were divided into seven groups: 1) on-board accessibility, equipment, stowage of aids, layovers, and enplaning and deplaning; 2) information briefing and personnel training; 3) seating, dog guides, emergency evacuations, and no segregation: 4) refusal of service, contagious diseases, advance notice, mandatory special assistance, and limitations on the number of handicapped persons on one flight: 5) reimbursement and special charges: 6) contractors and security; and 7) unequal treatment of people with disabilities not requiring accommodations compared with treatment of non-handicapped persons.

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The team decided on an ambitious schedule which included approidmately twenty-five meeting dates from June through early November. It was agreed that small work groups would also be formed for indepth exploration of specific topics. In addition, the committee scheduled two days of open public hearings for September so that any individuals or groups that felt their needs were not being heard would have an opportunity to testify and submit materials for the record.

At this juncture, the committee has completed the majority of its meetings and will issue its final consensus document on November 6, 1987. Subsequently, the Department of Transportation will issue proposed regulations in the Federal Register.

#### 13 Intercity and Interstate Buses

#### 4. Congress should extend coverage of handicap

nondiscrimination requirements to interstate commerce, thus prohibiting such discrimination by interstate bus companies.

#### N Accomplishments

Bus transportation is often the sole form of public transportation connecting people in rural areas with major cities and towns. Because a significant number of disabled people reside in rural areas and rely on bus transportation, the Council recommended prohibiting discrimination by interstate bus companies.

'I'he Council is aware of no activity with regard to extending nondiscrimination coverage to bus companies. However, there do appear to be increasingly more examples of bus companies retrofitting and purchasing vehicles which are accessible.

#### 13 Private Transportation

5. Congress should establish a low-interest loan program based on income to assist disabled persons and families with disabled children or elderly persons to purchase vehicles or to make necessary access modifications.

#### N Accomplishments

Private transportation provides the only means by which many disabled persons and elderly persons can parucipate fully in community life, including employment, recreaffon, education, etc. Since the cost of purchasing and modifying vehicles is prohibitive for many disabled persons and their families, such a low-interest loan program is needed. To date, no such program has been developed.

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Much effort has gone into the development of legislation that would create a national uniform system for handicapped parking so that persons with disabilities who require special parking arrangements can travel freely between States. To date, the Senate has approved such a system in S. 853, legislation authorizing the National Highway Traffic Safety Administration. The House legislation, H.R. 1442, is still pending.

#### <u>F'</u> Research

6. Congress should direct the Department of Transportation to commission a study, based upon its existing authorities and targeting currently available funds, to assess the impact of increased access to transportation on employment, education, and quality of life for disabled and elderly persons.

#### N Accomplishments

Very few reliable studies have been conducted on the impact of accessible transportation. Most eidsting studies have methodological weaknesses. Therefore, the Council believes that Congress should direct the Department of Transportation to commission such a study.

The study proposed by the Council for the Department of Transportation has not been requested by Congress. However, Congress has requested that the Architectural and 'ftansportation Barriers Compliance Board present a report on its activities, including transportation barriers, by February 1988. It is anticipated that since the ATBCB conducts research, a segment of that report will be devoted to the status of available data and research needs in the area of transpor-tation barriers.

# Housing

In *Toward* Independence, the Council described housing as "a major prerequisite to social integration and living independently for persons with disabilities," and noted:

The lack of appropriate housing opportunities for individuals with disabilities frequently results in the unnecessary and expensive institutionalization of such persons. Available data suggest that the costs of providing appropriate housing options for people with disabilities are well worth the investment because of the significant savings that may be engendered by enabling disabled people to live in the community, get jobs, and pay taxes. Various reports of Federal agencies, disabled persons, and the few formal studies of the subject have documented a serious shortage of housing options for people with disabilities. (p. 37)

The legislative recommendations of the Council in regard to housing presented direct and indirect means for increasing the housing opportunities available to persons with disabilities. If implemented, these would greatly enhance the quality of life of Americans with disabilities, with a secondary effect of reducing dependency-related costs. Some significant legislative proposals and administrative actions have furthered the proposals made by the Council in the area of housing. At the same time, many of the Council's key housing recommendations have yet to receive the congressional attention and implementation they merit.

# N Recommendations from Toward Independence

# 1. Congress should prohibit housing discrimination against persons with disabilities on as broad a basis as race, color, rengion, sex, and national origin discrimination are prohibited under Title VIII of the Civil Rights Act of 1968.

# Accomplishments

Responding to the anomalous situation in which one of the Nation's largest minorities- persons with disabilities- is omitted from the coverage of Federal Fair Housing laws, the Council proposed the expansion of housing nondiscrimination requirements to protect individuals with disabilities. Several bills currently before the Congress would provide to persons with disabilities protection from housing discrimination comparable to that available to other minorities. The proposed Fair Housing Amendments Act of 1987 (S.558 and H.R. 1 158) would amend Title VIII of the Civil Rights Act of 1968 to add "handicap' to the list of

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prohibited types of discrimination. Currently, Title VIII prohibits discrimination in housing on the basis of race, color, religion, sex, and national origin. As an alternative to amending Title VIII, the Council's comprehensive equal opportunity proposal- "The Americans with Disabilities Act"would create a separate prohibiffon of discrimination on the basis of handicap in housing. The housing subject to the comprehensive nondiscrimination requirement under this proposal would be identical to the housing covered by Title VIII.

2. Congress should require that all housing units constructed or substantially altered with Federal financial assistance, Federal loans, federally subsidized or insured loans, or by agencies of the Federal Government, should be required to meet accessibility standards.

# N Accomplishments

Based upon data indicating that it costs relatively little to

incorporate accessibility features into the construction of new housing, and that accessible housing will be increasingly needed as the Nation's population ages, the Council advocated the broad application of housing accessibility requirements. Such requirements would call for universally accessible housing units that can be easily adapted to meet the needs of individuals with parucular disabilities.

Some progress has been made in expanding the application of Federal housing accessibility requirements. In addition to the Uniform Federal Accessibility Standards (UFAS) that had previously created accessibility and adaptability requirements for housing constructed by Federal agencies, similar requirements are now proposed for recipients of Federal housing grants. Proposed regulations of the Department of Housing and Urban Development under Section 504 of the Rehabilitation Act of 1973 (to be discussed in connection with recommendation number 6) require that federally assisted housing projects shall contain no fewer than five percent of units that are accessible to persons with mobility impairments and no fewer than two percent that are accessible for persons with hearing or vision impairments.

Concepts of universal accessibility features have also been incorporated in the proposed Fair Housing Amendments Act and in the Council's proposed comprehensive equal opportunity law. Based upon the Council's concern that fair housing for persons with disabilities include, at a minimum, an accessibility requirement for new housing constructfon, the Senate version of the Fair Housing bill (S.558) was modified in the Judiciary Committee in June 1987 by a Kennedy/ Specter substitute bill. In addition to other types of discrimination prohibited under the proposed statute, the language of the substitute

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bill as adopted by the Judiciary Committee makes it an unlawful act of discrimination to design and construct multifamily dwellings 30 months after the date of enactment of the Act that fail to meet the following standards:

(i) the public use and common use portions of such dwellings are readily accessible to and usable by handicapped persons;

(ii) all the doors into and within all premises within such dwellings are sufficiently wide to allow passage by persons

in wheelchairs: and

(iii) all premises within such dwellings contain basic universal features of adaptive design.

These standards apply to all the floors of buildings having elevators and to the ground floor of buildings without elevators. The same standards are included in the proposed "Americans with Disabilities Act," the Council's comprehensive equal opportunity proposal.

3. Congress should direct the Department of Housing and Urban Development that programs to provide rent subsidies for persons with disabilities through both Section 8 certificates and the housing voucher program should be made permanent and given a high priority.

# N Accomplishments

The Council considers both the Section 8 certificates program and the housing voucher program to be effective means for providing housing opportunities for persons with disabilities who are unable to afford appropriate housing without assistance. While Congress has not yet expressly made the voucher program a permanent Federal program, it has continued to provide funding for expansion of the voucher program as a demonstraffon project within the Secffon 8 program.

4. Congress should direct the Department of Housing and Urban Development to reorganize the Section 202 program to provide a range of housing options for persons with disabilities, and to include a program of demonstration grants to agencies such as Independent Living Centers to develop model housing options, including transitional living programs, group residences, and other alternatives.

# N Accomplishments

The Section 202 program provides direct, long-term Federal loans to eligible private nonprofit organizations to finance new construction or

substantial rehabilitation of rental or cooperative housing for elderly persons or people with disabilities. At the time *Toward Independence* was issued, funding for the Section 202 housing construction program was in a moratorium, and there was some question as to whether the Section 202 program would be continued. The Council felt that, with some modifications, the Section 202 program was a useful means for addressing the shortage of housing construction appropriate for persons with disabilities. It recommended continuation of the program, with changes in focus designed to increase social integration and ageappropriateness for tenants with disabilities. The Section 202 program has been continued. In Fiscal Year 1987, the Department of Housing and Urban Development provided some \$556.7 million in loans under Section 202 to finance 12,689 rental units for low-income elderly and disabled households. Loans were awarded to 384 nonprofit groups in for-Ly-three States, the District of Columbia, Puerto Rico, and the Virgin Islands. Approidmately \$122.6 million of these funds are earmarked to finance 2,928 units for persons with disabilities.

# 5. Offices responsible for disability issues should be established within HUD's Fair Housing and Equal Opportunity Division and within the Office of Policy Development and Research.

# N Accomplishments

Consistent with the Council's recommendation, a Section 504 Unit has been established within the Fair Housing and Equal Opportunity Division of the Department of Housing and Urban Development (HUD). Its mission statement is the following:

The Section 504 Unit is responsible for the implementation and enforcement of Section 504 of the 1973 Rehabilitation Act, as amended. The Section 504 Unit provides administrative oversight and technical support in regard to Sections 501 and 502 of the 1973 Rehabilitation Act, the Architectural Barriers Act of 1968, and other laws affecting disabled persons. The combined effect of these activities will be to ensure that HUD's programs and activities are carried out in a manner which neither discriminates against nor has the effect of excluding participation by disabled persons.

Although administratively created and functioning, the Section 504 Unit has not yet been fon-nally incorporated as a permanent part of the HUD structure and organizational chart.

No action has been taken regarding the Council's other recommendation for creating an office responsible for disability issues within HUD's Office of Policy Development and Research.

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6. Congress should direct IIUD to issue appropriate regulations for the implementation of Section 504 of the Rehabilitation Act of 1973.

#### Accomplishments

As a result of a lawsuit, Wilson v. Pierce, (Civil No 82-288 TUC RMB (Order of June 22, 1983)), the Department of Housing and Urban Development has been ordered to issue its Section 504 regulations on a prompt basis, and the Court is monitoring its progress monthly. A current version of the proposed regulations, incorporating many of the changes recommended by the Council is, as this report goes to press, the subject of negotiations between HUD and the Department of Justice.

# 7. Additional programs should be initiated to leverage existing private sector funding and to provide incentives and financial resources for the development of housing opportunities for people with disabilities.

## N Accomplishments

The Federal tax deduction available to businesses for the removal of architectural barriers has been made a permanent part of the Tax Code and has been increased from \$25,000 to \$35,000. Apart from this and the Section 202 program discussed previously, little has been made available in the way of increased resources to provide for housing opportunities for persons with disabilities. The Department of Housing and Urban Development has contracted with the United Cerebral Palsy Associations, Inc. to develop reports in the area of housing for persons with disabilities. One of these reports, issued in August 1987, focused on the feasibility and usefulness of establishing a National Center on Housing for Persons with Disabilities. Another, issued in April 1987, presented six case studies representing a range of approaches to the provision of housing for persons with disabilities; its conclusion was as follows:

While these cases represent organizations along a continuum of public/private partnership in the development of housing for disabled persons, it is clear that the promise of the future is in private financing, a heavier reliance on private providers, and an ongoing search for incentives for investors and small community based living situations. All of the programs considered envision expanded development of housing in the future and there is no indication that the need for housing for disabled persons is even close to being met. Because of the shrinking public dollars and a future trend towards private investment, the pressure is on to expand creative financing schemes and turn any stone which may hide ari investor incentive.

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These findings underscore the importance of the Council's proposals of additional programs to leverage existing private sector funding and provide additional resources for housing opportunities for persons with disabilities.

In the fall of 1987, HUD awarded a two-year grant to the National Association of Homebuilders National Research Center (NAHBNRC) in collaboration with the Association for Retarded Citizens of the United States (ARC) to review financing mechanisms and accessibility design issues in housing development for people with disabilities, and to provide technical assistance in regard to such financing and design issues.

8. HUD and the private sector should be encouraged to develop training grants, supplemental teaching positions, awards, and other innovative programs for promoting architectural planning that incorporates the concept of universal accessibility.

Accomplishments

The Council is not aware of any major Federal training grants focusing specifically on accessibility in architectural design, although several schools of architecture in various parts of the country have made courses on accessibility a mandatory part of their curriculums.

One of the major undertakings of the HUD-funded grant project (NAHBNRC/ARC) discussed previously is to provide technical assistance in regard to accessible design.

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# Community-Based Services for Independent Living

In 1983, the Council in its National Policy for Persons with Disabilities defined independent living as "control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities." The independence defined here implies an optimally responsible and productive exercise of the power of choice. It implies that each disabled person, regardless of his or her mental or physical ability, should be encouraged and assisted to achieve maximum levels of quality of life, independence, and productivity in the least restrictive environment and with due respect for cultural or subcultural affiliation.

According to the Research and Training Center on Independent

Living (ILRU) in Houston, Texas: "Independent living centers are operated primarily by people with disabilities who have been successful in establishing independent lives. Centers offer a wide variety of services, including: information and referral; independent living skills training; peer counseling; advocacy; and others." ILRU estimates that there are approximately 150 independent living centers and over 320 independent living programs in this country. In 1984, according to the Rehabilitation Services Administration, 86 grants were awarded to 160 independent living projects throughout the country. In 1987, 136 grants were awarded to 170 independent living projects. The increase in independent living centers and programs is indicative of their increasing importance in the lives of persons with disabilities.

# N Recommendations from Toward independence

1. Congress should require the agency in each State designated to administer Title VII, Part A of the Rehabilitation Act to allocate no less than 50% of available funds to purchase services from independent living centers that meet the standards approved by the National Council on the Handicapped. No more than 10% of available funds should be used for administrative purposes. The remaining funds should be used at the discretion of the administering agency in any way that assists people with severe disabilities to achieve independence and productivity in their communities.

Accomplishments

According to Senate Conference Report (99-388), which accompanied the Rehabilitation Act Amendments of 1986, the Congress has been

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impressed with the overall accomplishments of independent living programs. Several additions were made to the Rehabilitation Act Amendments of 1986 to strengthen the philosophical integrity of the independent living program. The basic principles of consumer involvement and consumer control, which are fundamental to the concept of independent living, were stressed.

In Toward Independence, the Council recommended that funding for Part A be continued as a means of ensuring that community-based services are made available to persons with severe disabilities. The Rehabilitation Act Amendments of 1986 retained this provision. The 1986 Amendments also mandated the establishment of State Independent Living Councils which would serve three purposes:

1) provide guidance for the development and expansion of

independent living programs and concepts on a statewide basis;

2) provide guidance to State agencies and to local planning and administrative entities assisted under the Rehabilitation Act; and

3) prepare and submit to a designated State agency a five-year plan addressing the long-term goals and recommendations for the need for independent living services and programs within the State.

The Council views the establishment of State Independent Living Councils as a positive step in strengthening the independent living movement and in enabling persons with disabilities to live and work more productively in their communities.

2. Congress should provide core funding under Title VII, Part B of the Rehabilitation Act for independent living centers that meet the standards approved by the National Council on the Handicapped. Such centers should be allowed to apply and compete for this funding on an equal basis with State vocational rehabilitation agencies.

# N Accomplishments

The Congress has reaffin-ned the importance of the standards established by the Council in 1985 for independent living centers. In Senate Report 99-388, the Congress indicated that the appropriate Federal role with respect to independent living centers is to ensure the provision of a foundation of support for these independent living centers that will enable them to attract additional public and private support at Federal, State and local levels. Continued funding for centers operating according to prescribed standards and principles of good business assures that these centers will be able to attract the additional

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support required to expand programs to meet the needs of all severely disabled people in the communities which they serve.

The evaluation standards for independent living services developed by the Council have been endorsed by the Rehabilitation Services Administration. RSA is currently organizing an advisory group to develop measurable criteria based on the Council standards. These criteria are expected to be published in the Federal Register in July 1988.

3. Congress should require the Health Care Financing Administration to study the institutional bias within its programs for persons with disabilities and to develop appropriate measures for eliminating such biases. The criteria should be developed in consultation with the National Council on the Handicapped and be reported in hearings before Congress within one year from the date of enactment of this requirement.

Accomplishments

An extraordinary amount of the Medicaid funds administered by the Health Care Financing Administration (HCFA) is spent on nursing homes and other long-term institutions that primarily provide custodial maintenance for disabled individuals. The Council believes that strictly maintenance-oriented institutional programming is indefensible and unnecessary. Wherever possible, institutions should be transitional and foster independence. The majority of available funding should be directed toward assisting all individuals with severe disabilities to achieve self-direction and independence to the mwmum extent possible, in the most dignified and least restrictive environment.

The Council continues to cooperate with HCFA to develop criteria to determine to what extent Medicaid and other programs administered by the HCFA promote community-based services and discourage placements in institutions. Steady progress in this area is expected as independent living concepts gain acceptance.

4. Congress should amend the Internal Revenue Code to establish a tax credit for taxpayers with disabilities who incur unreimbursed expenses directly related to independent nving, employment, and efforts to secure employment, including personal assistant services, special transportation, assistive devices, and other support services.

## N Accomplishments

The number of tax deductions allowable under the medical category conffnues to grow. Recently enacted tax legislation, for example, per-

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mits a disabled employee to deduct the full cost of attendant services and other services necessary to enable the employee to work. Capital expenditures to accommodate a personal residence now also constitute medical expenses eligible for deductions. However, regulations governing many non-medical, disability-related services remain unclear and impose unfair restrictions on disabled persons. The Council intends to continue its efforts to clarify tax legislation and regulations and to include services that enable individuals with disabilities to engage in productive activity.

# Educating Children With Disabilities

Few would argue with the premise that education is a key to success in our society. The same holds true for children with disabiliffes- education helps disabled children develop the skills they need to live as independently as possible when they reach adulthood.

In Toward Independence, the Council placed education of children with disabilities among its ten prioriffes. The Council has heard about needs and issues related to the education of children with disabilities from hundreds of parents, disabled persons, and service providers from around the country. Moreover, this issue is close to the hearts of many Council members either because they are parents of children with disabilities or because they, as disabled persons, vividly remember their ov,7n educaffonal difficulties.

Although special educational services have progressed greatly in the twelve years since the passage of Public Law 94-142, the full promise of the mandate has not yet been fulfilled. The Council made four recommendations relating to the education of disabled children.

The first two recommendations are related directly to the Education for All Handicapped Children Act (EHA). The Council believed that the Act should be amended to extend the mandate to birth. The Education of the Handicapped Act Amendments of 1986 extend the mandate. The recently enacted legislation creates an Early Intervention Program to serve disabled infants from birth through age two. In addition, the legislation included significant improvements in services which are provided for threeto five-year-old children with disabilities.

The second recommendation relates to one of the central principles of the EHA- the least restrictive environment (LRE). Th ' e Council identified LRE as an issue that requires standards for clarification. To help in this process the Council developed a draft policy statement on least restrictive environment.

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The last two recommendations have national significance. One suggests the development of a national technical assistance center to help parents and State and local education agencies plan and develop educational options for children with special needs. The other calls for the establishment of a National Commission for the Study of Excellence in Special Education.

One final activity not menffoned in *Toward* Independence is the Council's iniffation of a third Louis Harris poll that will survey parents, educators, and children with disabilities to more closely examine the

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status of education for children with disabilities in this country. The results of the poll will be of immense value to the Council, the Congress, and others in the development of the best educational policy to meet the needs of disabled children and youth.

# N Recommendations from Toward Independence

1. Congress should amend the Education for All Handicapped Children Act to encourage States to make available a free appropriate public education to every disabled child from birth through age twenty-one.

# 9 Accomplishments

Young children with disabilities are particularly vulnerable. Research indicates that early intervention services greatly enhance the developmental and educational potential of these youngsters. Furthermore, the provision of early intervention services which benefit children and their parents result in significant tax savings in the long run because of reduced special education expenditures in later years.

Public Law 99-457, the Education of the Handicapped Act Amendments of 1986, enacted into law on October 10, 1986, extends services to children from birth to age three, significantly expands services to preschoolers ages three to five, and contains a number of important provisions regarding the education of children with disabilities.

The new legislation, a result of the combined efforts of the Council and many parents and advocacy groups, creates a program which will provide enhanced services to infants and toddlers with disabilities and their families. A State-wide system which will provide comprehensive services to these young children and their parents is an essential ingredient of the new program. Through the development of an Individualized Family Service Plan, each child will receive a multi-disciplinary assessment which will identify his or her unique needs and assure that appropriate services are delivered. Additionally, States may choose to serve those children who are 'at risk- in developing a disability.

Another provision of the new law addresses concems raised in *Toward* Independence regarding the lack of coordination of funds for services rendered to young disabled children. The major thrust of this payor of last resort- provision is that monies provided for this program may not be used to pay for services which would have been provided through another public or private source.

The Amendments also made significant improvements in services which are provided to three- to five-year-old children. This new man-

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date effectively extends the mandate of Public Law 94-142, the Education for All Handicapped Children Act, to serve all disabled children at three years of age by 199 1. The Amendments repeal the eldsting Preschool Incentive Grant program but increase the financial incentives for serving disabled preschoolers. By school year 1990-199 1, if appropriations are made at the authorized levels contained in the Amendments, States will be required to serve all disabled children aged three to five. EHA funds for preschoolers, including incentive grants and discretionary funds, will be withheld from States not in compliance with the service mandate.

Finally, the new law adds several other provisions designed to assure that children and youth with disabilities receive appropriate educational and related services.

2. Congress should direct the Department of Education to promulgate and enforce standards for the application of the least restrictive environment requirement; such standards should clarify that the primary determinant of which educational setting is least restrictive is the educational appropriateness of the program.

## Accomplishments

The least restrictive environment mandate is a major component of the right to a free appropriate public education for children with disabilities. The principle has not, however, always been appropriately applied by State and local education agencies. In some instances, least restrictive environment has not been vigorously applied and children with disabilities continue to be unnecessarily segregated. Additional guidance and clarification should be provided so that this principle can be realized.

In order to address the multiple issues which are involved in educating youngsters with disabilities in the LRE, the Council has adopted a draft policy statement with a broad-based, comprehensive approach. Issues discussed in the draft document include the need for monitoring and data collection on LRE; the parental role in LRE; technical assistance to State and local education agencies; and personnel development and funding issues. The Council believes that these and other issues must be thoughtfully considered if the vision of educating children in the least restrictive environment is to be fully realized.

A Council task force will be convened within the next few months to finalize the policy statement on LRE. After this has been completed the full Council will consider this policy for adoption and dissemination.

# 3. Congress should direct the Office of Special Education Programs to fund a national technical assistance center to help parents and State and local education agencies plan and develop educational options for children with special needs. N Accomplishments

The Council has long recognized the need for greater emphasis on the provision of services to parents of children with disabilities. Many gaps e2dst in the provision of information and referral sources for parents. The feasibility of a centralized information-based system with nationwide access is being considered.

In its special report on the Education for All Handicapped Children Act, the Council provided testimony to Congress on the need for a national technical assistance center. Senator Paul Simon further explored this concept with Chairperson Parrino during the hearing. The Council will continue to advocate the establishment of a parental assistance system.

# 4. Congress should direct the Secretary of Education and the Chairperson of the National Council on the Handicapped to establish a National Commission for the Study of Excellence in Special Education. N Accomplishments

The Council has been impressed with the variety of new and innovative approaches adopted in special education programs. Called "best practices," they include team and shared teaching, itinerant teachers and resource persons working with the regular educator, and physical, speech and occupational therapists working with classroom teachers to "transfer" their professional knowledge from isolated settings into the regular educatfon environment. These practices reinforce the Council's belief that a comprehensive approach to personnel development will enhance the collaborative efforts among all professionals involved in the education of children with disabilities.

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While members of the Council are excited about new techniques emerging in the education of children with disabilities, it is nonetheless disturbing that so much remains to be done. In 1982, the Commission on Excellence in Education issued a report titled A Nation at Risk, which cited many problems faced by the American educational system. The report, however, did not attempt to address the special needs of students with disabilities and their families. Therefore, the Council believes that this unmet need must be fulfilled. Moreover, twelve years have passed since the enactment of Public Law 94-142, and the Council sees value in assessing the progress of the implementation of the law to date. Therefore, the Council recommends the establishment of a National Commission on the Study of Excellence in Special Education. Such a commission would evaluate the progress and recommend future directions geared toward enhancing the educatfon of children with disabilities.

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# Personal Assistance: Attendant Services,, Readers,, and Interpreters

Personal assistance is one key to independence for thousands of Americans with disabilities. Without question, personal assistance by readers, interpreters, and advocates is one of the single most important unmet needs for disabled persons.

According to *Toward* Independence, personal assistance, as rendered by attendants who assist with routine activities of daily living, when provided in conjunction with other community-based services, can be an effective and economical means for reducing the Nation's reliance on institutions. Effective and efficient personal assistance services can enable most persons with disabilities to live independently in settings of their choice. The goal should be to establish personal assistance services, self-directed when feasible, as one component of a comprehensive array of community-based services that should be available to people with disabilities. In order for an acceptable system to be developed, many complex funding, policy, and legislative issues must be addressed.

While some progress has been made at the Federal, State, and local levels toward providing personal assistance services, the stark reality is that for most disabled Americans, these services are, at best, difficult to acquire. And for most these services are unavailable, leaving countless disabled persons to live lives of dependency. This situation often puts an untoward burden on families and friends, or means that the disabled person must reside unnecessarily in an institution or nursing home.

The World Institute on Disability (WID), an internationally knov,7n organization comprised primarily of disabled consumers, has recently released a study entitled, "Attending to America." That study further underscores the critical need for attendant services in this country.

The Council has sought input regarding attendant services from

WID, the National Council on Independent Living, and many other organizations and individuals. In addition, because the Council places such a high priority on personal assistance, it has brought together experts from the disability community to form a task force on this issue to develop recommendations for a comprehensive legislative agenda. A legislative workplan is currently being developed which recommends amendments to legislation, and includes proposals to fill service gaps in developing coordination of personal assistance services.

The Council reaffirms its commitment to the development of a neitional policy on personal assistance for all persons with disabilities

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and to the connection between such a policy and the goal of independence for persons with disabilities.

# N Recommendations from Toward Independence

1. Congress should establish a national policy that defines personal assistance and should require the development of national standards for the delivery of personal assistance services.

## N Accomplishments

As the Council examined the development of a national policy on personal assistance services, one fact was clear: this is a complex policy matter, one that requires careful thought and deliberation. First, while there are some programs currently funded through the Federal Government, eligibility requirements often limit these services based on age or income. Second, even when these services are funded, they are often on a time-limited basis. For example, someone who has recently been discharged from a hospital might only have attendant services available during the recovery period, even though that individual might need more Finally, these services are generally extensive services. rendered through a "medical model" which does not usually promote optimum independence or choice for individuals with disabilities. These and many other factors enter into the development of a comprehensive public policy on personal assistance senices for persons with disabilities.

Some of the options discussed by the Council include: amendments to Medicaid and/or Medicate to mandate personal assistance services for persons with disabilities; amendments to Title II of the Social Security Act (SSDI) to allow attendant services; and amendments to Medicate to also increase the availability of these services. Additionally, the Council has initiated tracking of major legislative options. Although there is no broad Federal policy regarding personal assistance services, scattered Federal attempts to provide these services can be found under Medicaid; Title XX, Social Service Block Grants: the Older Americans Act, Title III; and State initiatives. Because of the wide range of government agencies involved, as well as the wide range of age groups and disability populaffons needing personal assistance services, the process of developing personal assistance program legislation is exceptionally complicated. Overcoming these obstacles necessitates a proposal that **fills** in the gaps regarding populations or services not included in other legislation.

In addition to establishing a Council task force for the development of a legislative package for a national personal assistance program, the

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Council has consulted with leaders in the field and many organizations throughout the country, including the World Rehabilitation Fund, the National Council on Independent Living, and the World Institute on Disability. A legislative workplan is currently being developed, and future task force meetings are expected to provide results which will reflect enhanced coordination of personal assistance services.

Although the number of qualified interpreters for people who are deaf has expanded in recent years, the demand for competent interpreters far exceeds availability. Section 315 of the Rehabilitation Act of 1973, as amended, authorizes the Commissioner of the Rehabilitation Services Administraffon to award grants to States for the establishment of interpreter service programs. This section includes a requirement that interpreters participating in such programs meet minimum standards. Because Section 315 has not been funded by the Congress, no interpreter standards have been established. However, the Arkansas Research and Training Center on Deafness and Hearing Impairment is currently conducting a national survey from which specific recommendations can be developed regarding needed interpreter competencies. The study, which has surveyed professional interpreter trainers, vocational rehabilitation counselors, deaf consumers, providers of interpreter services, and others in the field of deafness, is expected to be completed by September 1988.

2. Congress should require the Social Security Administration (SSA), in consultation with the National Council on the Handicapped, to implement a series of projects, using SSA demonstration authority and targeting currently available funds, to develop and demonstrate a cost-effective process and mechanisms for the support of community-based personal assistance services for persons with severe disabilities.

# N Accomplishments

As progress is achieved in the development of a workplan on personal assistance policy, it is anticipated that cooperaffve negotiations between SSA and the Council will yield detailed steps for the effective provision of personal assistance services. The Council believes that a more centralized process of providing personal assistance services can be developed with the assistance of SSA subsequent to the completion of the task force workplan. The Council remains confident that the SSA is sensitive to the need for increased community-based personal assistance programs and that future funding priorities will reflect this commitment.

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# Coordination

In addition to the recommended legislaffve changes in each of the nine substantive areas, the need for coordination of services, programs, and funding is also criffcal. "Coordinated services" describes the ideal results of a wide range of interactfons among persons active in policy and program development. Although these interactions take place every day, their purpose, frequency, and effectiveness vary greatly from program to program, community to community, and State to State. Many instances of gaps in services, as well as duplicative services, are evident across the country. Coordinated efforts could resolve some of these problems.

The Council advocates frequent interaeffon at the national level of all parties involved in policy decisions that affect services to people with disabilities. To that end, the Council has maintained its information base with consumer organizations around the country while strengthening interaction on coordinaffon with national, State and I,:)cal policy makers, disability organizations, Congress, and the Administration.

Several examples of coordinated efforts in disability policy stand out, but activities in the area of prevention best exemplify the advantages of a coordinated approach. In conjunction with the Office of Disease Prevention and Health Promotion, a series of meetings of various Federal agencies were convened which focused on the prevention of disability. Another example entails coordination with the Department of Transportation in the development of regulations pursuant to the Air Carrier Access Act of 1986. Knov,7n as "regulatory negotiation," this process involves a team of individuals representing different areas of concem, ranging from a particular disability, such as blindness or mobility impairments, to a sector of the air transportation industry, such as airport operators or flight attendants.

The Council also has supported coordination efforts by cosponsoring a conference with the Office of Special Education and Rehabilitative Services and by submitting congressional testimony advocating coordination of services to very young children with disabilities.

## N Recommendation from Toward Independence

1. Congress should require State and local agencies that receive Federal funds for services for people with disabilities to participate in the development of coordinated service delivery plans.

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#### N Accomplishments

During the past few years, the Council has actively engaged in efforts that have fostered coordination at the Federal, State and local levels. Examples of these efforts include the establishment of a Federal ad hoc group on prevention, parucipation in the regulatory negotiation process for the Air Carrier Access Act of 1986, cosponsorship of a conference with the Office of Special Education and Rehabilitative Services, and recommendations in testimony for the Education of the Handicapped Act Amendments of 1986.

One of the most significant contributions at the Federal level is the ad hoc group which the Council convened in conjunction with the Office of Disease Prevention and Health Promotion. Comprised of fifteen Federal agencies, the committee meets bimonthly to promote the coordination of services for the prevention of disabilities. Representatives on the committee include the Council, the Administration on Developmental Disabilities, the Rehabilitation Services Administration, the President's Committee on Mental Retardation, the Centers for Disease Control, the Matemal and Child Health Program, and the National Institute on Disability and Rehabilitation Research. The committee has two functions: one, to exchange information and coordinate efforts among these agencies on the prevention of disability; and two, to develop a national plan on the prevention of both primary and secondary disabilities. The national plan will be the first of its kind and will greatly enhance

coordination efforts around the country. (see also "Prevention of Disabilities')

Another example of coordination at the Federal level is one in which the Council has been an observer and supporter in the Department of 'ftansportation's "regulatory negotiation" process to develop regulations pursuant to the Air Carrier Access Act of 1986. This process involves a team of fifteen individuals, each representing a different area of concem, ranging from a particular disability, such as blindness or mobility impairments, to a sector of the air transportation industry, such as the airport operators or flight attendants. The intent of the process is to create a forum in which divergent views can be aired and a consensus can emerge. In November 1987, after a series of twentyfive meetings, a report detailing areas of agreement and disagreement will be submitted to the Department of Transportation so that a proposed rule can be published in the Federal Register for public comment. (see also "Transportation")

In March 1987, the Council cosponsored a conference with the Office of Special Education and Rehabilitative Services and the President's Committee on Employment of the Handicapped regarding the transition of disabled youth from school to work settings. This

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conference was unique in that it brought together disabled youth, parents, employers, and rehabilitation professionals to discuss problems faced by disabled Americans leaving school and seeking their rightful place in the work force. (see also "Employment")

Finally, the Council's commitment to the coordination of services also has been demonstrated in its written testimony on August 12, 1986, to the House Subcommittee on Select Education regarding the Education of the Handicapped Act Amendments of 1986. In that testimony, the Council supported the creation of Early Intervention Councils to assure that services to very young children with disabilities are adequately coordinated.

In testimony submitted to the Senate Subcommittee on the Handicapped in April 1987 regarding the Developmental Disabilities Act, the Council reinforced the coordinated approach taken by the Development Disabilities State Councils. Furthermore, the Council emphasized that Federal programs must maintain a certain degree of flexibility so that they can be coordinated with other programs to meet the unique needs of State and local communities.

The Council is also exploring the work of the Advisory Council on Intergovernmental Relations to identify data being gathered regarding coordination efforts at the State and local levels. Biographies of Members of the National Council on the Handicapped

## Sandra Swift Parrino

Sandra Swift Parrino, of Briareliff Manor, New York, was appointed Chairperson of the National Council on the Handicapped in 1983 by President Reagan. She has been actively involved in issues conceming disabled people for many years. Her 22-yearold son, Paul, has been severely disabled for most of his life. She is best known as a spokesperson for parents of disabled children and as a panelist, lecturer, lobbyist, and organization official.

Mrs. Parrino serves on numerous boards and councils. She has been director of the Office of the Disabled in Ossining and Briarcliff Manor, New York; she has served on the board of Westchester County Homes for the Retarded; and she is a member of the New York State Assembly Task Force on the Disabled, which reviews pending legislation in the State of New York. Through her efforts, many local advances have been made to improve accessibility for disabled people, such as setting up transportation services and installing voting machines for disabled persons, fund-raising to provide interpreter services for deaf people, and supervision of the school district's compliance with Federal regulations. Mrs. Pan-ino has been instrumental in the inception of the Council's comprehensive equal opportunity proposal which promotes independence and equality for people with disabilities.

Mrs. Parrino is also a member of the board of Parent Chain, and has served as an American Representative to the United Nations and LJNICEF for the Intemational Year of Disabled Persons. She is currently the North American vice president of Rehabilitation Intemational, a worldwide service, information, and advisory organization. She has also been asked by the Department of Health and Human Services to co-chair an ad-hoc committee on the prevention of disabilities.

#### John S. Erthein

John S. Erthein lives in Los Angeles, Cahforriia, where he is president of John S. ErLhein and Associates, Inc., a public relations firm with offices in Los Axigeles and Washington, D.C. The firm's clients include the AMDAHL Corporation; CBS, Inc.; Arts and Entertainment Network; Forum Home Video; Insight Magazine; Dart Drug; and the Chicago Board of 'ftade. Mr. Erthein has produced and marketed home video cassettes including 'How To Benefit From Tax Reform- and Charleton Heston's "Television's Vietnam.'

Mr. Erthein was the founding president of the American Paralysis Association, an organization whose primary objective is to fund research to find a cure for spinal cord injuries. He is a graduate in marketing from Columbia University, served as an officer in the United States Coast Guard and was Security Officer and Public Information Officer for his unit in New York.

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He was assistant for finance for Citizens for the Republic when Ronald Reagan chaired that organization. Subsequently, he assisted in setting up the fundraising organization for the 1980 Reagan Presidential campaign.

#### Theresa Lennon Gardner

Theresa Lennon Gardner of Washington, D.C., was nominated by President Reagan to the National Council on the Handicapped after more that two decades of professional service as an educator and volunteer working with disabled youngsters.

Mrs. Gardner began her efforts with disabled children in the early 1960s, when she worked at the D.C. Society for Crippled Children. At that time, Mrs. Gardner was successfully completing her degree work at the Washington Montesorri Institute. Mrs. Gardner's commitment to quality education for our younger student population was evidenced in 1966, when she founded the Georgetown Montessori School in Washington. For twelve years, Mrs. Gardner administered the sixty-student Montessori preschool which educated children of diverse socioeconomic backgrounds in the Nation's Capital. She also founded and funded an inner-city Montessori facility near the Capitol which later became a model for Washington's Head-Start program.

As a mother of two daughters, Mrs. Gardner has been active in a variety of cultural and social enrichment programs for Washington area youngsters. As a member of the Women's Heart Board of Washington, D.C., Mrs. Gardner chaired the Children's Heart Party. She also has taught therapeutic riding to multi-disabled youngsters from numerous Washington area residential fadities.

In addition to her civic responsibilities, Mrs. Gardner currently attends TYinity College in Washington, where she is scheduled to receive a degree in education in the spring of 1988. Mrs. Gardner is also a frequent visitor to educational and disabledperson facilities throughout United States, Europe and Africa. In 1982, Mrs. Gardner served as the official U.S. hostess to thousands of Kenyan school children who visited the U.S. exhibit on telecommunications while her husband was serving as President Reagan's ambassador to a United Nations' Conference in Nairobi.

## Marian North Koonce

Marian North Koonce, of Santa Barbara, California, is the mother of six children. Two are physically handicapped from birth and a third contracted multiple sclerosis as a young adult. Along with the great amount of time and attention she gives to her family, she has held many administrative and leadership positions in business, most recently, as chairman of the board of a Santa Barbara independent bank.

She is involved in numerous local and national organizations. She was chair-man of the Santa Barbara County Reagan-Bush '84 Committee. She served as a delegate to the Republican National Conventions of 1976, 1980, and 1984. From 1980 to 1981, Mrs. Koonce was vice president of recording for the Blind Auxiliary. She serves on the boards of the Santa Barbara Symphony Association, the Las Positas Park, and the University of California, Santa Barbara. She is also chairman of the Channel Islands chapter of the National Multiple Sclerosis Society.

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#### Leslie Lenkowsky, Ph.D.

Dr. Leshe Lenkowsky is the president of the Institute for Educational Affairs, a nonprofit organization in Washington, D.C., devoted to encouraging innovative thinking in higher education, philanthropy, and public affairs. He is also an adjunct professor of public policy at Georgetown University and an adjunct scholar for public policy research for the American Enterprise Institute where he specializes in social policy issues. He is also a director of the Foreign Policy Research Institute and a member of the board of advisors to the president of the Naval War College.

From 1976 to 1983, Dr. Lenkowsky was the director of research at the Sniith Richardson Foundation in New York. He has served as a consultant to Senator Daniel Patrick Moynihan and was an assistant to the Secretary of the Pennsylvania Department of Public Welfare. He has also been deputy director of the United States Information Agency and a member of the National Voluntary Service Advisory Board.

Dr. Lenkowsky completed his undergraduate education at Franklin and Marshall College, Lancaster, Pennsylvania. His doctoral degree was awarded from Harvard University. Dr. Lenkowsky is the author of many books and articles. He lectures frequently on philanthropy, social policy, and other issues.

#### Nanette Fabray MacDougall

Nanette Fabray MacDougaH, a resident of Pacific Palisades, California, is a renowned actress who developed a progressive hearing disability. Following four operations, the condition that had threatened her with total deafness was cured. She has continued to be active in organizations benefiting hearing-impaired and other disabled persons.

Mrs. MacDougall was regional chairperson of the National Easter Seal Society and the National Mental Health Association. She is past chairperson of the National Advisory Conunittee for Education of the Deaf. She currently serves on the board of the National Captioning Institute and the Better Hearing Institute in Washington, D.C., as well as the House Ear Institute and the Museum of Science and Industry.

Among the many awards she has received are the President's Distinguished Service Award (1 97 1), the Eleanor Roosevelt Humanitarian Award (1 964), and the Screen Actors Guild's Humanitarian Award (1986) for outstanding service. Mrs. MacDougaU and Helen Keller are the only two women ever to have received the annual Public Service Award of the American Academy of Opthalmology and Otolaryngology. She has three honorary doctoral degrees, from Gallaudet College, Westem Maryland CoHege, and MacMurray CoHege. She was one of the original members of the National Council on the Handicapped, and was reappointed by President Reagan.

#### Robert S. Muller

Robert Muller of GrandviHe, Michigan, joined Steelcase Inc. in 1966 and is currently in administration. He is an adjunct assistant professor in the Department of Psychology at Aquinas College and in the Department of Education at Calvin College in Grand Rapids, Michigan. He serves on the board of trustees for Hope Rehabilitation

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Network in Grand Rapids, which serves 1,400 adults with disabilities. In April of 1981, he received an honorary degree in educational psychology from the Free Uriiversity in Amsterdam, the Netherlands. Mr. Muller holds a B.S. degree in business administration from Aquinas College and in 1978 was voted Outstanding Alumnus of the Year. Mr. Mulier has lectured at several colleges and universities, both nationally and internationally. He is a board member of a number of national, State and local organizations.

In May 1987, he and his wife, Carol, hosted a first-time event at the V%Thite House with the Vice President. The 'Celebration of Disabled Americans at Work' was cosponsored by several major corporations throughout the United States. He presently serves as chairman of the National Roundtable on Corporate Development for Americans with Disabilities. In May 1985, Mr. Muller was awarded the Liberty Bell Award by the Grand Rapids Bar Association for his work toward 'Liberty and Justice for All.-

#### Brenda Premo

Brenda Premo is a native of Southem California and currently resides in Stanton, California. Ms. Premo has a small fraction of the vision many people take for granted. She is legally blind, one of the characteristics of albino persons, along with pale sldn and snow white hair.

Ms. Premo received her bachelor of arts degree in psychology from California State University at Long Beach. VIhfle attending college, she became acquainted with other disabled students and became part of an activist group that helped to found the Disabled Students Services at the Urjiversity. After college, while working for the Orange County Department of Education, Ms. Premo became part of a task force which surveyed disabled persons in Orange County and called for an independent living center to provide information and services to people of all disabilities. The Dayle McIntosh Center was launched in November 1977 with Ms. Premo, age 25, as its first director.

She was asked to go to Washington, D.C., on a peer review team evaluating other independent living centers, was active on the State Independent Llving Advisory Committee, served as vice president of the California Association of the Physically Handicapped, and served two years as chairperson of the California Coalition of Independent Living Centers. In 1981, she chaired the Orange County Task Force on the Intemational Year of Disabled Persons. Ms. Premo was recently elected president of the Califon-iia Foundation of Independent Living Centers.

Ms. Premo has been the recipient of many awards for her outstanding service to the disabled community. She received the Handicapped Californian Award from the California Association of the Physically Handicapped (1978); the regional Service to Mankind Award from Sertoma Intemational (1987); and the California Professional Handicapped Woman of the Year Award from the Pilot Club (1987).

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## Father Haney J. Sutcliffe, D.D.

Father Hariy J. Sutcliffe resides in Brooklyn, New York. He has been totally blind since infancy and received his early education from the New York Institute for Education of the Blind. He earned a bachelor of arts degree, Magna Cum Laude, from Wittenberg University, a masters of divinity form the Mount Aily Theological Seminary and a doctor of divinity from the Episcopal'Meological Seminary, both with honors.

Father Sutcliffe is the founder of the Episcopal Guild for the Blind and has served as its director since 1959. He also is employed as a classical language and sacred studies instructor with the Hadley School for the Blind, Winnetka, Illinois. The Hadley School operates the only home study program in the world for blind individuals, having an enrollment of more than 6,000 students representing all of the continents. The school offers over 100 courses in academics, independent living, and homemaker skills.

He is involved in many local and national organizations, including the American Association for Education and Rehabilitation of the Blind and Visually Impaired Individuals, American School of Oriental Studies, Society of Biblical Literature, Republican Presidential Task Force and State and national Republican Committees.

Father Sutcliffe has received numerous awards for his outstanding service, including the B'nai B'rith Man of the Year Award (1 959) in recognition of his interfaith activities, particularly the teaching of Hebrew and Hebrew Braille to blind persons of the Jewish faith; the Private Sector Initiative Commendation, given by the President of the United States in recognition of exemplary community service (1986); and the Excellence Award from the Hadley School for the Blind (1986).

Father Sutcliffe serves as a strong advocate, not only for persons who are blind, but for all persons with disabilities.

#### Joni Eareckson Tada

Joni Eareckson Tada is a resident of Woodland Hills, Cahfomia. Mrs. Tada was paralyzed from the shoulders down by a diving accident in 1967, at the age of 17. She developed a latent artistic talent by painting with her mouth during two years of rehabilitation. Her experiences were catalogued in an autobiography that has been translated into 35 languages.

As founder and president of the Christian Fund for the Disabled, Mrs. Tada's goal is to help churches reach out and meet the spiritual and practical needs of persons with disabilities. This is accomplished through books, films, record albums, videos, tapes, printed materials, seminars, and workshops. Also a five-minute radio program, Joni and Friends, is aired every weekday over 400 religious stations in the United States. Among the many awards she has received are the Golden Plate (1979) from the American Academy of Achievement; Penwoman of the Year (1980) from the National

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League of American Penwomen; Layperson of the Year (1985) from the National Association of Evangelicals; The Courage Award (1985) from the Courage Rehabilitation Center; and the Excellence and Accomplishment Award (1985) from the Patricia Neal Rehabilitation Center.

#### Roxanne S. Vierra

Roxanne S. Vierra, of Littleton, Colorado, has been actively involved in business as well as in community and political affairs. Her son, Steven, had brain damage from birth. His disability gave her insight into the needs of mentally retarded individuals. This insight caused her to develop Retarded Unlimited, Inc., an organization designed to establish business ventures owned and operated by mentally retarded persons. Her objective is to make mentally retarded people more self-sufficient and less dependent on government funds. Steven is an example of what a mentally retarded individual can do: He lives in his own apartment, works as a courtesy clerk at a grocery store, and is relatively independent.

Mrs. Vierra serves as an officer of the Children's Diabetes Foundation, which is dedicated to finding a permanent cure for diabetes in children. She is on the board of directors of the American Lung Association, and is past president of the board of Childhelp USA, a national organization to prevent child abuse. She has campaigned for and organized numerous activities in national elections, including fundraising in President Reagan's campaign. In the business world, Mrs. Vierra has been a broker associate for the Devonshire Company, selling residential property for the past eight years.

#### Alvis Kent Waldrep, Jr.

Alvis Kent Waldrep, Jr. of Plano, Texas, is the president and chief executive officer of the Kent Waldrep National Paralysis Foundation, a nonprofit organization dedicated to finding a treatment and cure for paralysis caused by spinal cord injury. He is responsible for all phases of daily operations including fundraising, budgeting, and public awareness, through its national office in Dallas. From September 1982 to June 1985, Mr. Waldrep was president of the American Paralysis Association.

From June 1979 to December 1981, Mr. Waldrep founded and served as chief executive officer of the Kent Waldrep Intemational Spinal Cord Research Foundation, Inc., a nonprofit organization which became the American Paralysis Association. He was responsible for planning and implementing all programs designed to meet the objectives and goals of the Foundation.

Mr. Waldrep served as assistant sports information director for Texas Christian University from April 1977 to June 1979. There, he assisted the sports infor-rnation director with all sports promotion programs, including media conimuriication, brochure preparation, and compilation of statistics and advertising sales. This followed three years of intensive physical therapy for a cervical spinal cord injury from a football injury in 1974, which resulted in quadriplegia with paralysis from the neck down.

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He is a member of several community and professional groups, including the board of the Dallas Rehabilitation Institute and the National Society for Fundraising Executives. He has been the recipient of many awards for his achievements in the area of disability. Mr. Waldrep was selected by the United States Jaycees as one of the ten outstanding young men in America for 1985. Mr. Waldrep was recently named chairman of the Texas Govemor's Conunittee on Disabled Persons.

#### Phyllis D. Zlotnick

Phyllis Zlotrjick of West Hartford, Connecticut, has been employed by the Office of Protection and Advocacy for Handicapped and Developmentally Disabled Persons in Hartford, since 1983. Bom with Spinal Muscular Atrophy, Ms. Zlotnick is widely recognized as a successful advocate for the rights inherent with full citizenship for all disabled people. As a highly respected lobbyist in Connecticut, she is responsible for changes Ln the State Building Code; removal of architectural barriers; access to pubhe transportation, housing, education, voting, employment, and parking; and handicapped driver training programs. She has lectured, published articles, received numerous awards, and served on many boards and advisory councils.

Ms. Zlotnick formerly was the Director of Extemal Affairs for the Easter Seal Society of Connecticut and later, an aide to the former Speaker of the House in the State and General Assembly. Presently, she is a legislative consultant to the Protection and Advocacy Office in Connecticut and the chairperson of the State Personal Care Assistance Advisory Council.

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