

"Where We Are and How We Got Here"

Allan I. Bergman
President & CEO
Brain Injury Association

PUBLIC POLICY IS
VALUE-BASED

CIVIL RIGHTS

1848...
TO
1998

"Prejudice and superstition are an ancient disease; in some ways, they may be counted among the most distinguishing features of the Homo sapiens."

Omer Bartov
11/99

Grass Roots
Political Activity

"A popular government without popular information, or the means of acquiring it, is but a prologue to a farce or a tragedy or perhaps both. Knowledge will forever govern ignorance, and a people who mean to be their own governors must arm themselves with the power which knowledge gives."

James Madison
1822

AMERICANS
WITH DISABILITIES
ACT

A.D.A.

! Title I: Employment
! Title II: State and Local Government Services
! Title III: Public Accommodations
! Title IV: Telecommunications

A.D.A. - DISABILITY

The term "disability" means, with respect to an individual:

- ! A physical or mental impairment that substantially limits one or more of the major life activities of such individual;
- ! A record of such an impairment; or
- ! Being regarded as having such an impairment.

MAJOR LIFE ACTIVITIES

- ! Caring for oneself
- ! Performing manual tasks
- ! Walking
- ! Seeing
- ! Hearing
- ! Speaking
- ! Breathing
- ! Learning
- ! Working

ADA - NON DISCRIMINATION TITLE II

Subject to provisions of this title, no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.

ADA Integration Mandate

"A public entity shall administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities"

28 CFR Section 35.130(d)

"A public entity shall make reasonable modifications in its policies, practices, or procedures when modifications are necessary to avoid discrimination, unless...modification would fundamentally alter the nature of the services, program or activity."

29 CFR 35.130(b)(7)

LUCILLE C.
and
ELAINE W.

Olmstead v. L.C.

11th Circuit

- "...the state (Georgia) discriminated against L.C. and E.W. by confining them in a segregated institution rather than in an integrated community based program
- ...the state's actions in this case constituted discrimination...
- ...the state has violated the core principle underlying the ADA's integration mandate..."

THE QUESTION PRESENTED IN OLMSTEAD

"Does Title II of the ADA compel a State to provide treatment for mentally disabled persons in a community placement, when appropriate treatment can also be provided to them in a state hospital?"

OLMSTEAD vs. L.C. & E.W.:

1. What Did the Supreme Court Say?

A. The ADA is a fundamental civil rights statute!

B. The Court acknowledged that Congress found that discrimination against people with disabilities includes segregation, isolation and institutionalization.

OLMSTEAD vs. L.C. & E.W.:

C. Under ADA, a legal right to be served in the most integrated setting. Not open to state's discretion.

D. Unnecessary isolation and institutionalization is discrimination and requires community placement, if:

OLMSTEAD vs. L.C. & E.W.:

- "State's treatment professionals" have determined community placement appropriate for specific individuals; - Transfer to the community is not opposed by "affected individual;" and
- Community placement can be "reasonably accommodated, taking into account resources available and needs of other people with ...[]"

OLMSTEAD vs. L.C. & E.W.:

2. Court said "the reasonable-modifications standard would be met," if State has:
- A comprehensive, effectively working plan for persons [in community], and
 - a waiting list that moved at a reasonable pace not controlled [by the State]...to keep institutions fully populated..."

OLMSTEAD vs. L.C. & E.W.:

3. "Fundamental Alterations" allow state:
- To maintain a range of facilities and
 - To administer services with an even hand..."

OLMSTEAD vs. L.C. & E.W.:

E. What judgments did supreme court say show that "unjustified institutional isolation...is a form of discrimination"?

- "Institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life."
- "Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contracts, work options, economic independence, education advancement, and cultural enrichment."

...No American should have to live in a nursing home or state institution if that individual can live in a community with the right mix of affordable supports...

- Donna Shalala Secretary of Health and Human Services @ NCSL Annual Meeting. July 28, 1999

Conclusions from Olmstead:

- ADA applies to all people with disabilities across the age span - Title II is not only for Medicaid beneficiaries
- Title II is not only for Medicaid services
- Title II is really about how states organize services and supports - Title II is about informed consumer choice
- Title II does not require the closure of all institutional facilities
- Olmstead is about planning and systems change

Board of Trustees of University of Alabama vs. Garrett

- U.S. Supreme Court, February 21, 2001
- 5 to 4 Decision
- 11th Amendment expanded to preclude ADA Title I Damages Litigation against a state for employment discrimination
- Individuals can still sue states for injunctive relief under Title I of the ADA for injunctive relief
- No direct impact on Olmstead under Title II
- No impact on employment discrimination under Title I against local government and private employers

1994 Disability Survey

- New data set
- First national comprehensive disability survey
- All ages included
- Only includes community population
- Poverty and program participation data are unimputed

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Major Disability Definitions

- ! Work disability (limitations in or inability to work due to disability)
- ! Disability program recipient (SSI, SSDI, Special Education, Part H, Veterans' Day Disability Pension, Disability Retirement)
- ! Perceived disability (ADA) - ("Do you consider yourself or do others consider you to have a disability?")

Functional Disability -- Children

- ! Physical activities (e.g., running, playing, climbing stairs, ADLs)
- ! Mental activities (e.g., getting along with other children, behavioral, service use)
- ! Development in cognitive, learning, speaking
- ! Special health needs (e.g., excessive utilization, special equipment to breathe)
- ! Children under 5 (age-appropriate - sitting up, walking, talking)

Functional Disability -- Adults

- ! Functional disability includes limitation or inability to perform age-appropriate activities for at least 12 month, e.g.
- ! Physical activities (e.g., walk 3 blocks, lift 10 lbs., grasp, climb stairs)
- ! Sensory impairments (e.g., see, hear, communicate)
- ! Mental impairments (e.g., symptoms, service use, prescription drugs)
- ! Assistive devices (e.g., wheelchairs, scooters)
- ! ADL (e.g., bathe, dress, get out of bed or chair)
- ! IADL (e.g., prepare meals, manage money)

Alternative Disability Definitions: 1994 (in millions)

Functional - Work - Disability - Perceived - Functional OR Work OR Programs
OR
Disability Disability Program Disability Recipient Perceived

Long-Term Care Definition

! Needs help of another person in order to perform ADL or IADL

For under 5 - sit up by 2, walk by 3, special equipment to breathe

Disability and Long-Term Care Needs in General Population

Prevalence of Disability
47.6 million

Proportion with LTC Needs
11.6 million

Disability and Long-Term Care Needs in the Medicaid Population by Age

Percentage of U.S Population Over 65 Percentage of U.S Population Over 65 Years of Age

25

20

15

over 65

10

5

Percentage of U.S. Population

* Projections

0

1950 1970 1990 *2010 *2030 *2050 *2070

Aged Population/ Projected

1998
2000
2025
2050
2075
2100

In Millions

65 Years and over

34.9
35.3
60.7
75.3
85.8
93.2

75 Years and over

16.1
16.7
24.9
39.7
46.8
52.1

85 Years and over

4.2
4.2
6.2
14.5
16.8
20.4

SOURCE: Social Security Administration, Office of Programs: Data from the Office of the Actuary

FAMILY

CAREGIVING

ACROSS THE

AGE SPAN

ECONOMIC ISSUES

! Family Caregiving Value: \$196 Billion/yr.
! Nursing Home Care Spending: \$83 Billion (1998)
! Home Care Spending: \$32 Billion (1998)

Federal Budget Outlays
FY '99 \$1.703 Trillion

Source: OMB

Federal Budget Outlays-Mandatory Programs
FY '99 \$951.731 Billion

Source: OMB

Medicare Reform Legislation

- ! Maintain as a social insurance program and do not convert to a market driven system
- ! People with disabilities of all ages must be protected in access to health care
- ! Oppose mandatory enrollment of the "dually eligible" population into state Medicaid managed care health plans
- ! Access to affordable and appropriate prescription drug coverage
- ! Medicare is not just for Americans over 65 years of age

Medicare Homebound Clarification Act of 2001

- ! Representative Edward Markey
- ! Change antiquated home care criteria which focuses on frequency, duration and purposes under which Medicare beneficiaries may leave their home
- ! An issue of freedom and community access/ participation

ESTIMATED MEDICARE BENEFIT PAYMENTS, BY TYPE OF SERVICE, FISCAL YEAR 1999

Skilled Nursing Facilities	6%	Home Health A	6%
		Other Part B Benefits	6%
Hospital Inpatient	40%	Hospital Outpatient	8%

Physicians 15%

Home Health B 1%

Hospice 1%

Managed Care Plans 17%

Total \$212 billion*

*Exclude administrative expenses

SOURCE: Congressional Budget Office, An Analysis of the President's Budgetary Proposals for Fiscal Year 2000, April 1999.

Number of Medicare Beneficiaries
Fiscal Years 1967-2027



*Includes beneficiaries whose eligibility is based solely on end-stage renal disease (96,000 in 1997)

SOURCE: Health Care Financing Administration, Office of the Actuary, April 1998

Social Security Reform

! Trust Fund solvent until 2038

! 38% of Social Security benefits do not go to retired workers

! General Accounting Office report, January 2001 to Senator Tom Harkin

! All privatization proposals would reduce cash income for beneficiaries with disabilities compared to current law

Social Security Reform

! People with disabilities must be included in any reform proposal development and discussion.

Social Security Reform

! Individual investment accounts (IA's) would produce less for beneficiaries with disabilities because of typically shorter work histories and less time to accumulate money in their accounts.

! S.S.D.I. often is the only income source for people who have experienced a brain injury in their adult life.

TITLE XIX-GRANTS TO STATES FOR MEDICAL ASSISTANCE PROGRAMS

[42 U.S.C. Sec. 1396]

Sec. 1901. For the purpose of enabling each state as far as practicable under the conditions in such State, to furnish (1) medical assistance on behalf of families with dependent children and of aged, blind or disabled individuals, whose income and resources are insufficient to meet the costs of necessary medical services, and

(2) rehabilitation and other services to help such families and individuals attain or retain capability for independence of self-care, there is hereby authorized to be appropriated for each fiscal year a sum sufficient to carry out the purposes of this title. The sums made available under this section shall be used for making payments to Sates which have submitted, and had approved by the Secretary, State plans for medical assistance.

MEDICAL "MODEL"

VS

PSYCHOSOCIAL "MODEL"

MEDICAID EXPENDITURES BY SERVICE, 1997

	ICF/MR 6%	Mental Health 1.7%	
		Home Health 8.8%	
Nursing Facilities 20.4%		Inpatient 15.3%	
		Physician, Lab & X-Ray	
48%			
DSH Payments 9.9%		Outpatient/Clinic 7.1%	
Payments to MCOS 9.7%		Drugs 6.3%	
Payments to Medicare 2.8%		Other Acute 7.2%	
	Total = \$161.2 billion		

SOURCE: Urban Institutes Estimates, 1999.

MEDICAID ENROLLEES AND EXPENDITURES BY ENROLLMENT GROUP, 1997

Elderly 10.1%	
Payments** 9.9%	DSH

Blind & Disabled 16.8%

Elderly 27.6%

Adults 21.2%

Blind &

Disabled 37.5%

Children 51.8%

Adults 10%

Children 15%

Enrollees

Total = 40.6 million people

Expenditures*

Total = \$161.2 billion

* Total expenditures exclude administrative expenses

** Disproportionate share hospital payments SOURCE: Urban Institute Estimates, 1999.

E.P.S.D.T

This act requires that any service which you are permitted to cover under Medicaid that is necessary to treat or ameliorate a defect, physical and mental illness, or a condition identified by a screen, must be provided to E.P.S.D.T participants regardless of whether the service or item is otherwise included in your Medicaid plan.

Medicaid and Long-Term Care

! Pays for half of all nursing home spending

! Accounts for 80% of public dollars spent on nursing home care

! Pays for 15% of total home care spending

! Limited to the poor/ "spend-down

Evolution of Medicaid

Long Term "Care"

(services & supports)

1965 Title XIX Enacted with S.N.F. Entitlement

1967 I.C.F. Option

1971 I.C.F.M.R. Option

1981 Home & Community-Based Services Waiver Option

1982 Katie Beckett Waiver

1986 Home & Community-Based Services Amendments
 ! Supported Employment
 ! Respite Care

1987 Nursing Home Reform
 ! Federal Standards
 ! PASARR

1990 Community Supported Living Arrangements (CSLA) Option

1991 Frail Elderly Services Option

1992 Personal Care Amendment

1995 CSLA Expired

Medicaid Expenditures for Long-Term Care Services 1987-1997
(in thousands of dollars)

1987
1997
ACRG 1987-1997
Personal Care
1,178,031
3,207,381
10.5%
HCBS Waiver
451,061
8,107,233
33.5%
Home Health
439,655
2,189,562
17.4%
Frail Elderly
0
91,516
NA
ICF
7,599,393

SNF
5,966,181
32,532,667
18.5%
ICF-MR
5,501,832

9,996,224
6.2%
Total Long-Term Care
21,136,153
56,124,583
10.3%
Total Medicaid
46,955,851
160,256,207
13.1%

THE CHALLENGE

IS

"EQUITY"

DEVOLUTION CONTINUES:
THE CHANGING ROLES
OF FEDERAL AND
STATE GOVERNMENT

GOVERNMENT "TRENDS"
 PRIVATIZATION...
 OUTSOURCING...
 DOWNSIZING...

FROM A CONTINUUM OF
CARE TO AN ARRAY OF
INDIVIDUAL AND FAMILY
SUPPORTS

Nursing Home Residents
All families-1997
Total: 1,608,700

Age Distribution:
 Under 65 years-8.5%
 65-74 years-12.3%
 75-84 years-32.8%
 85 years and over-45.9%

Doe v. Chiles
(2/26/98)

11th CIRCUIT COURT OF APPEALS

! PROMPTNESS-WAITING LIST NO LONGER THAN 90 DAYS

! "ENTITLEMENT" TO ICF-MR

WAIT-LIST LITIGATION

! 14 filed in MR/DD Area: 5 settled

! 1 case filed in aging

RESIDENTS IN PUBLIC MR/DD INSTITUTIONS

1977-149,892

1988-91,531

1992-77,600

1996-59,726

No State Operated Large ICF's-MR

As of 6/30/99

Alaska
D.C.
Hawaii
Maine
New Hampshire
New Mexico
Rhode Island
Vermont
West Virginia

300 or Fewer Residents of State Operated Large
ICF's-MR as of 6/30/99

Arizona	92
Colorado	152
Delaware	264
Idaho	112
Michigan	272
Minnesota	72
Montana	130
Nevada	165
North Dakota	139
Oregon	173
South Dakota	195
Utah	250
Wyoming	120

ICF-MR Residents as a Proportion of All Residents of State and Nonstate Settings by Size on June 30, 1999

	1-6	7-15	16+	1-6	7-15	16+
	STATE			NONSTATE		
250000						
200000						
150000						
1000000						
5000						
0						

Federal Medicaid Expenditures for ICF-MR and HCBS Programs for Persons with MR/DD as a Proportion of All Federal Expenditures

Year	Total Federal Medicaid Expenditures	Total Federal ICF-MR and HCBS Expenditures for Persons with MR/DD	Federal iCF-MR and HCBS Expenditures for Persons with MR/DD as Proportion of All Medicaid Expenditures
1995	\$86.684 billion	\$7.5057 billion	8.7%
1996	\$88.294 billion	\$8.171 billion	9.3%
1997	\$91.826 billion	\$8.88804 billion	9.7%
1998	\$96.049 billion	\$9.762 billion	10.2%
1999	\$102.949 billion	\$10.143 billion	9.9%

SOURCE: HCFA, Office of State Financial Management

Percent of Medicaid Long-Term Care Clients Served in Community Based Care

Percent of Long-Term Care Cases by Type of Service

R.W.J. Foundation
Cash and Counseling Demonstration

! Arkansas
! Florida
! New Jersey
! New York

(University of Maryland)

ELDER PHILOSOPHY

! AUTONOMY, DIGNITY, PRIVACY
! PROMOTE AGING IN PLACE
! DECISION MAKING/ CHOICE

PERSON/ FAMILY
CENTERED
PLANNING

PRINCIPLES OF SELF DETERMINATION
(Shumway & Nerney)

! FREEDOM
 to plan a real life
! AUTHORITY
 to control a limited amount of resources
! SUPPORT
 for building a life in one's community
! RESPONSIBILITY
 to give back to one's community

Family Opportunity Act
S.231/ H.R. 600

! Senators Grassley/ Kennedy
! Representatives Sessions/ Waxman

- ! Medicaid buy-in for families with children up to age 18
- ! Incomes up to 300% Federal poverty level (approximately \$51,150/yr for a family of 4)
- ! Fund information and outreach centers for families
- ! Estimated cost, \$2 billion over 5 years

HOMEOWNERSHIP:

- ! HUD issues final regulations for use of Section 8 vouchers for homeownership
- ! Issued October 12, 2000
- ! At the discretion of local public housing authorities/agencies

Successful Community Life

- ! Housing
- ! Healthcare and Appropriate Medical Services
- ! Transportation
- ! Employment
- ! Leisure/ Recreation
- ! Friends/ Relationships
- ! Choice
- ! Community Supports
- ! System Infrastructure
- ! Quality Assurance

1992 Rehabilitation Act Amendments

- ! Presumptive Eligibility
- ! "Choice"

STATE V.R. PROGRAM

"(3) It is the policy of the United States that such a program shall be carried out in a manner consistent with the following principles:

"(A) Individuals with disabilities, including individuals with the most severe disabilities, are generally presumed to be capable of engaging in gainful employment and the provision of individualized vocational rehabilitation services can improve their ability to become gainfully employed.

"(B) Individuals with disabilities must be provided the opportunities to obtain gainful employment in integrated settings.

In The Work Force

29.4 Million Americans with Disabilities in the Work Force

Source: National Organization on Disability/

Harris Survey of Americans with Disabilities, 1998.

LIMITED USE OF SSI WORK INCENTIVES

! Only 6.2% of SSI recipients worked in June, 1999
-- 337,928 of 5,293,829 individuals
! Worker earnings remain limited
-- 71% earned below SGA (\$700/month)
-- 28% earned \$65/ month or less
! Use of Work Incentives by workers remain low
-- PASS .3%
-- IRWE 3.0%
-- BWE 1.2%

DISABILITY PROGRAMS' ESCALATING COSTS

	Disability Insurance	Supplemental Security Income	Total
1960	\$ 0.5	\$--	\$ 0.5
1970	2.8	--	2.8
1980	14.9	5.7	20.6
1990	24.4	11.5	35.9
1997	47.2	27.2	74.4
2002	68.3	36.2	104.5

S.S.A.
ESTABLISHES
OFFICE OF EMPLOYMENT
SUPPORT PROGRAMS

THE GOOD NEWS: Integrated Employment is Rising

THE BAD NEWS: Facility-Based
& Non-Work Services Keep Rising

Ticket to Work
And
Work Incentives Improvement
Act of 1999

Initial "Ticket" States
February 2001

! Arizona
! Delaware
! Illinois
! Massachusetts
! Oklahoma
! South Carolina
! Wisconsin
! Colorado
! Florida
! Iowa
! New York
! Oregon
! Vermont

Unemployment rate: 3.9%
April 2000
Lowest since January 1970
(peaked @ 7.8%-Mid 1992)

Increase the minimum wage

EXPANDED AND ENHANCED ROLE OF AND FOR TECHNOLOGY

ACCOUNTABILITY FOR VALUED OUTCOMES

DATA ARE ESSENTIAL

Health Outcomes

! Health Status

- ! Functional Capacities
- ! Community Participation
- ! Quality of Life
- ! Consumer Satisfaction

"All providers, regardless of size, must be able to say this is what we do, this is how we do it, and here is the durability of the outcome."

Christine MacDonell
CARF

"QUALITY"

MALCOLM BALDRIGE AWARDS

- ! LEADERSHIP 110 POINTS
- ! STRATEGIC PLANNING 80 POINTS
- ! CUSTOMER FOCUS/
SATISFACTION 80 POINTS

"QUALITY"

MALCOLM BALDRIGE

AWARDS

(CONTINUED)

- ! INFORMATION ANALYSIS 80 POINTS
- ! HUMAN RESOURCES 100 POINTS
- ! PROCESS MANAGEMENT 100 POINTS
- ! BUSINESS RESULTS 450 POINTS

President George W. Bush's
New Freedom Initiative

- ! February 1, 2001
- ! "I am committed to tearing down the remaining barriers to equality that face Americans with disabilities today."
- ! Spoke positively about his commitment to the ADA and to IDEA

Competing Priorities for "Surplus"

- ! Tax Cuts
- ! Save Social Security and Medicare
- ! Pay down national debt
- ! Increase spending

Political-Economic Context
State Government

! Congressional redistricting based on 2000 Census
! Surpluses are over
! 20 states face revenue shortfall
! States provided tax cuts of \$34 billion from 1995-2000
! Medicaid budgets soaring
! National Governors' Association debates Medicaid reform and institutional bias

MICASSA-S. 1935
Senators Harkin and Specter

"Medicaid Community Attendant Services and Support Act of 1999"

"...and who requires such community attendant services and supports based on FUNCTIONAL need and WITHOUT regard to age or disability,"

DISABILITY POLICY FOR THE NEW MILLENIUM

RIGHTS

RESPONSIBILITIES

"(3) disability is a natural part of the human experience and in no way diminishes the right of individuals to-

"(A) live independently;

"(B) enjoy self-determination;

"(C) make choices;

"(D) contribute to society;

"(E) pursue meaningful careers; and

"(F) enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society

New Opportunities for the Disability Community in 2001

! \$50 million in "Real Choice" grants to states
! \$20 million in nursing home transition grants
! \$50,000 starter grants to states
! TWWIIA Regulations
! HUD Section 8 vouchers for homeownership
! Older Americans Act (PL 106-501)
! National Family Caregivers Support Program
! New Office of Disability Employment Policy at the Department of Labor

*INNOVATION

*CREATIVITY

*INITIATIVE

*FLEXIBILITY

*RISK

ACTION STEPS

*Clarify Your Values

*Become Market Driven

*Be Customer Responsive

*Fund Strategies and Activities

*Implement the Values

*Measure Outcomes

collaboration.

1. to work together, especially in some literary, artistic, or scientific understanding:

2. to cooperate with an enemy invader.

WEBSTER'S NEW WORLD DICTIONARY

BELONGING

be-long, v. 1: to feel and be a part of ...i.e. of a community, a workplace, a neighborhood or school 2: to enjoy a sense of contribution, value, self-worth 3: to truly believe one is a natural and equal part of the whole 4: comfortable, safe, cared for, welcome.

OPPORTUNITY IS MISSED BY MOST PEOPLE BECAUSE IT IS DRESSED IN OVERALLS AND LOOKS LIKE WORK

Thomas Edison

"If you can't afford to leave the public housing project, you're not free. If you don't know how to find a job and you don't know how to create a job, you are not free. If you can't find a place that'll educate you, you're not free..."

Speaker of the House Newt Gingrich

January 4, 1995

Acceptance speech in House of Representatives

Freedom-

(1) the condition of being free of restraints; (2) liberty of the person from slavery; oppression or incarceration; (3) profession of civil rights; (4) immunity from the arbitrary exercise of authority; (5) the capacity to exercise choice or free will; (6) the right of enjoying all of the privileges of membership or citizenship.

The American Heritage Dictionary

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