

coleman institute
for Cognitive Disabilities
University of Colorado System


“PAST--PRESENT--FUTURE--”

DEVELOPMENTAL DISABILITIES IN ILLINOIS AND THE UNITED STATES

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Associate Vice President, University of Colorado System &
Executive Director, Coleman Institute for Cognitive Disabilities



Arc of Illinois State Convention
LISLE, ILLINOIS
APRIL 25, 2012

PAST--PRESENT--FUTURE 

-- ARC CHANGED AMERICA

I. THE PAST--
THE INSTITUTIONAL ERA, ITS DECLINE, AND THE RISE OF COMMUNITY, FAMILY AND INDIVIDUAL

II. THE PRESENT--

- OVERVIEW OF IDD SERVICES IN ILLINOIS AND THE U.S.
- ECONOMIC UNCERTAINTY IN THE STATES AND **THE GREAT RECESSION**

III. THE FUTURE--


- EMERGING TECHNOLOGIES
- GROWING INEQUALITY & THE AMERICAN PROMISE

2

Elizabeth Boggs 






Arc Advocacy Changed America 

ARC INVOLVEMENT IN CLASS ACTION LITIGATION IN HIGH RANKING STATES IN COMMUNITY SERVICES FISCAL EFFORT IN FY 2009

Rank	State	Class Action Litigation and Year Filed	State Arc Involvement
1	New York	New York State ARC v. Rockefeller (1973) filed 1972	Plaintiff
2	Maine	Wuori et al. v. Zitnay (1978) filed 1975	No Official Role
3	Minnesota	Welsch v. Likins (1974) filed 1972	Plaintiff
4	Connecticut	Connecticut ARC v. Thorne (1993) filed 1978	Plaintiff NARC was Amicus Curiae
5	Vermont	In re R.B. (Judicial Review) (1980) filed 1978	No Official Role
6	Rhode Island	Iasimone v. Garrahy (1982) filed 1977	Court Monitor
7	North Dakota	ARC of North Dakota v. Olson (1982) filed 1980	Plaintiff
8	District of Columbia	Evans v. Washington filed 1976	Plaintiff
9	West Virginia	Medley v. Ginsberg (1980) filed 1980	Plaintiff
12	New Mexico	Lewis et al. v. NM Dept of Health et al. (2000) filed 1999	Plaintiff

Source: Braddock, D., State of the States in Developmental Disabilities, 2011.

The Arc Makes a Proven Difference 

Hierarchical Regression for Community Services Fiscal Effort

Correlates	R ² Change	Beta	F	Equation
Population	0.0055	-0.0195		0.256
Wealth	0.0728	-0.115		1.912
Federal assistance	0.0014	-0.0932		1.270
Civil Rights Innovativeness	0.2413	0.537		5.083*
Arc Advocacy	0.200	0.4541		9.121**
Total R²	0.5206			

*p<.01. **p<.001

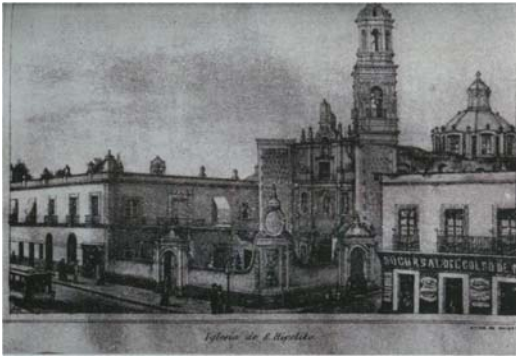
Braddock & Fujiura (1991). Politics, public policy and the development of community mental retardation services in the United States. *AJMD*, 95(4), 369-387.

I. THE PAST: INSTITUTIONAL ERA: 1403-1960

- FIRST MENTAL DISABILITY INSTITUTIONS**
- BETHLEHEM, LONDON, ENGLAND (1403)**
- VALENCIA, SPAIN (1409)**
- ZARAGOZA, SPAIN (1425)**
- SEVILLE, SPAIN (1436)**
- VALLADOLID, SPAIN (1436)**
- PALMA MAJORCA, SPAIN (1456)**
- TOLEDO, SPAIN (1480)**
- GRANADA, SPAIN (1527)**
- SAN HIPOLITO, MEXICO CITY (1566)**

7

**HOSPITAL E IGLESIA DE SAN HIPOLITO
MEXICO CITY (1566) – 1ST IN NORTH AMERICA**



D. Braddock, University of Colorado, 2005.

8

**ERA OF INSTITUTIONALIZATION -
NEW BETHLEM HOSPITAL IN MORE FIELDS: 1725**



9

STATE INSTITUTION FOR FEEBLE MINDED-CHILDREN SYRACUSE, NEW YORK (1851)



D. Braddock, University of Colorado, 2005.

10

GOVERNOR DUNCAN HOME, JACKSONVILLE, ILLINOIS (1865): FIRST I/DD INSTITUTION



D. Braddock, University of Colorado, 2005.

11

ILLINOIS INSTITUTION FOR THE EDUCATION OF THE DEAF, JACKSONVILLE (1851)



D. Braddock, University of Colorado, 2005.

12

**LINCOLN STATE SCHOOL AND COLONY
LINCOLN, ILLINOIS (1877) (CLOSED 2004)**

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MAIN BUILDING, LINCOLN STATE SCHOOL AND COLONY, LINCOLN, ILL.

D. Braddock, University of Colorado, 2006. 13

**HOME FOR THE FEEBLE-MINDED
FORT WAYNE, INDIANA (1879)**

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Home for the Feeble-Minded, Fort Wayne, Ind.

D. Braddock, University of Colorado, 2006. 14

**KANSAS STATE IMBECILE ASYLUM,
WINFIELD, KANSAS (1881)**

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D. Braddock, University of Colorado, 2006. 15

**NEW YORK STATE CUSTODIAL ASYLUM
FOR WOMEN, NEWARK (1885)**



Main Building of the New York State Custodial for Feeble-minded Women, Newark, N. Y.

D. Braddock, University of Colorado, 2006.

16

**PENNHURST INSTITUTION FOR FEEBLE MINDED AND
EPILEPTICS, SPRING CITY, PENNSYLVANIA (1903)**



Main Building Eastern Penn. State Institution for Feeble Minded and Epileptics,
Spring City, Pa.

D. Braddock, University of Colorado, 2006.

17

VIRGINIA TRAINING CENTER, LYNCHBURG (1912)



2011 CENSUS: 384

D. Braddock, University of Colorado, 2006.

18

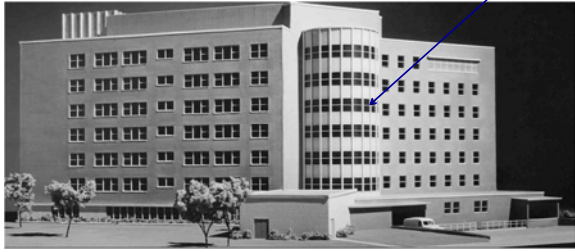
ILLINOIS INDUSTRIAL COLONY FOR IMPROVABLE EPILEPTICS, DIXON, ILLINOIS (1918) (CLOSED 1987)



HOSPITAL BUILDING - DIXON STATE HOSPITAL - DIXON, ILL.

D. Braddock, University of Colorado, 2006; Abraham Lincoln Pres. Library. 19

ILLINOIS STATE PEDIATRIC INSTITUTE, CHICAGO (1961)



D. Braddock, University of Colorado, 2005; Abraham Lincoln Pres. Library. 20

MURRAY DEVELOPMENTAL CENTER, CENTRALIA, ILLINOIS (1964)



D. Braddock, University of Colorado, 2005; Illinois DMH. 21

FOX DEV. CENTER, 1965 (BUILT AS KEELEY ALCOHOLISM CENTER, 1879), DWIGHT, ILLINOIS



U. S. Veterans' Hospital,
Dwight, Illinois

D. Braddock, University of Colorado, 2005.

22

BOWEN CENTER, HARRISBURG, ILLINOIS (1966)



- Closed 1982
- Current use: Correctional Center for youth

D. Braddock, University of Colorado, 2005.

23

**LUDEMAN DEVELOPMENTAL CENTER
PARK FOREST, ILLINOIS (1972)**



D. Braddock, University of Colorado, 2005, Google Earth.

24

**HOWE DEVELOPMENTAL CENTER,
TINLEY PARK, ILLINOIS (1973) (CLOSED 2010)**



D. Braddock, University of Colorado, 2005; Google Earth.

25

**SHAPIRO DEV. CTR. (1974) (FORMERLY
KANKAKEE STATE HOSPITAL, 1879)**



D. Braddock, University of Colorado, 2005.

26

**KILEY DEVELOPMENTAL CENTER,
WAUKEGAN, ILLINOIS (1975)**



D. Braddock, University of Colorado, 2005; Illinois DMH

27

JACKSONVILLE MH/DD CENTER (1975) (1st ILLINOIS STATE MH HOSPITAL, 1851) (CLOSED 2012)



D. Braddock, University of Colorado, 2005; Abraham Lincoln Pres. Library. 28

“THE SHAME OF THE STATES”



Page 8 The CINCINNATI SUN

High Costs and Crowded Institutions Create Great Problems for Mentally Retarded

(Third of series on Mental Retardation) denied both of the aforementioned; were Mrs. Harold J. Moss, Mrs. ed rights—attendance in a public Lucius Riggs and Mrs. Elias Torf.

January 4, 1952

Source: D. Braddock, University of Colorado, 2012. 29

WHILE WASHINGTON SLEPT KENNEDY FOUNDATION DID NOT



Kennedy Foundation Gives \$1,250,000 To Aid Chicago Home for Retarded Boys

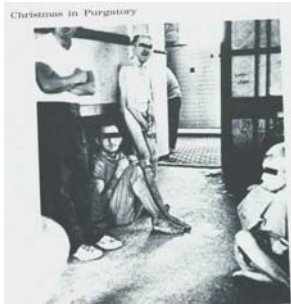
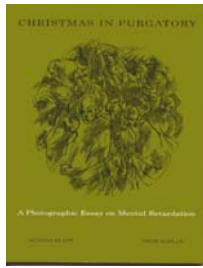
Special to THE NEW YORK TIMES.

CHICAGO, Feb. 20—The Joseph P. Kennedy Jr. Foundation has donated \$1,250,000 toward the completion of a new home and school for mentally retarded boys, Cardinal Stritch, Archbishop of Chicago, announced today. three years ago and receives annually 150 applications for admission. All buildings will be on one level and joined by underground tunnels. No structure will have more than one step to ease the movement of children incapable of

February 20, 1952

Source: D. Braddock, University of Colorado, 2012. 30

**FAST FORWARD TO NEW YORK STATE
INSTITUTION, 1960s**



Source: D. Braddock, University of Colorado, 2012.

31

PENNHURST STATE SCHOOL, 1960s

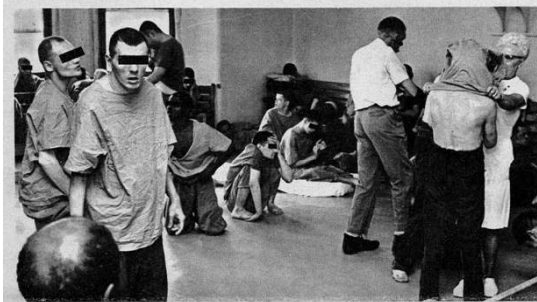


Photo by the Philadelphia Inquirer

DAY ROOM ACTIVITY—Residents in a ward for profoundly retarded males at Pennhurst (Pa.) State School pace aimlessly or lie dejectedly against wood benches. A nurse (right) replaces a resident's shirt.

Source: D. Braddock, University of Colorado, 2012.

32

**PROGRESS STIMULATED BY THE
PRESIDENT'S PANEL: 1961**



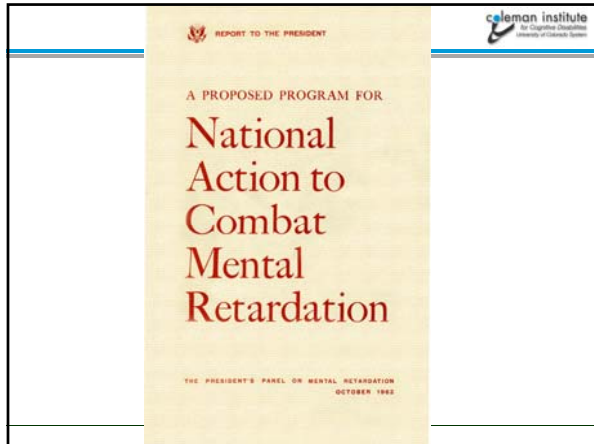
PRESIDENT KENNEDY (left) with four members of Panel on Mental Retardation at White House. Third from left is Abraham Ribicoff, Secretary of Health, Education and Welfare. Next to Ribicoff is Dr. Leonard May, chairman of Panel. Partially hidden behind Ribicoff is Dr. Elizabeth Boggess.

Kennedy Action Makes History

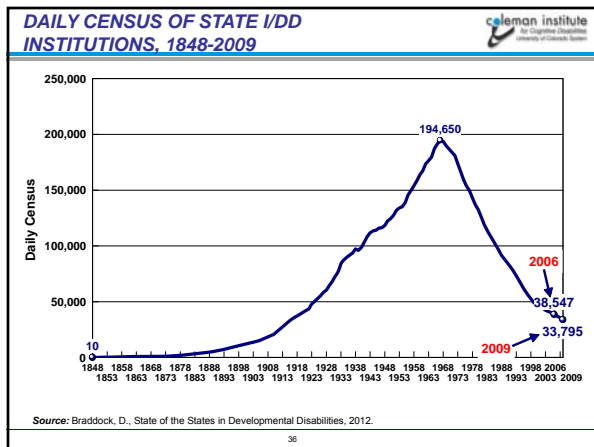
President Kennedy's announcement during his press conference, Oct. 11, of the Panel on Mental Retardation which coincided with the opening day of the NARCA's 11th annual convention, injected an added excitement and enthusiasm into the annual meeting.

Source: D. Braddock, University of Colorado, 2012.

33



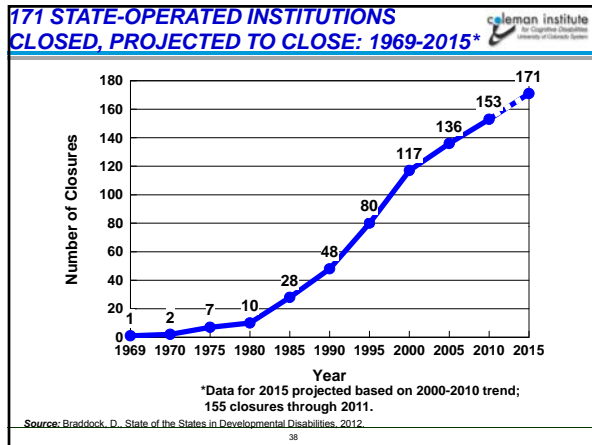


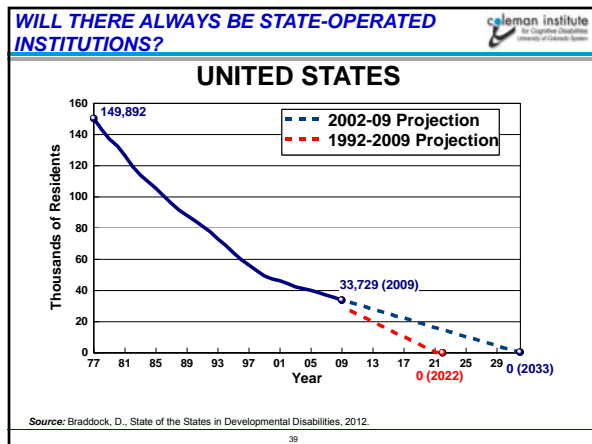


14 STATES WITHOUT STATE-OPERATED /IDD INSTITUTIONS: 2012

1. DISTRICT OF COLUMBIA (1991)
 2. NEW HAMPSHIRE (1991)
 3. VERMONT (1993)
 4. RHODE ISLAND (1994)
 5. ALASKA (1997)
 6. NEW MEXICO (1997)
 7. WEST VIRGINIA (1998)
 8. HAWAII (1999)
 9. MAINE (1999)
 10. MICHIGAN (2009)
 11. OREGON (2009)
 12. ALABAMA (2012)
 13. MINNESOTA (2000)*
 14. INDIANA (2007)*

37





WHO'S NEXT?

SMALLEST INSTITUTIONAL CENSUS, 2009 (RED 2011 DATA)	
1 Nevada	48
2 Montana	51
3 Delaware	68
4 Wyoming	82
5 Idaho	96
6 Arizona	111
7 North Dakota	123
8 South Dakota	146
9 Colorado	160
10 Utah	206

Source: Braddock, D. State of the States in Developmental Disabilities, 2012.

40

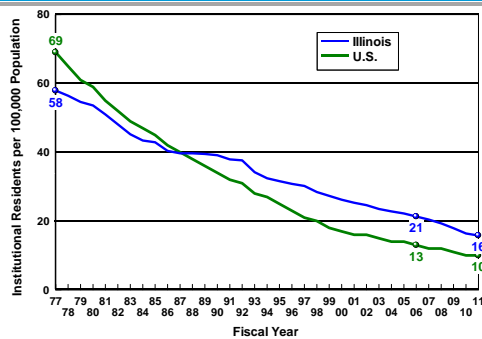
WHO'S NOT?

LARGEST CENSUS, 2009 (RED 2011 DATA)		
1 Texas		4,899
2 New Jersey	2,703	2,649
3 Illinois	2,308	2,034
4 California	2,194	1,774
5 North Carolina	1,638	1,572
6 New York		1,492
7 Mississippi		1,371
8 Ohio	1,423	1,228
9 Pennsylvania	1,253	1,174
10 Virginia	1,184	1,105

Source: Braddock, D. State of the States in Developmental Disabilities, 2012.

41

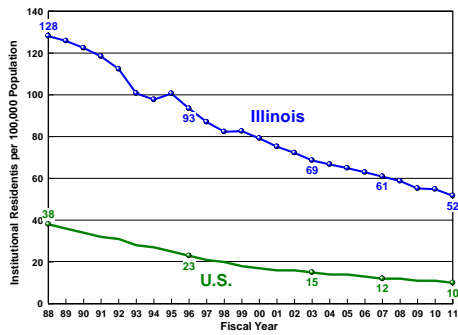
INSTITUTIONAL UTILIZATION IN ILLINOIS ABOVE U.S. RATE 1988-2011



Source: Braddock, D. State of the States in Developmental Disabilities, 2012.

42

ILLINOIS PUBLIC/PRIVATE 16+ UTILIZATION
1988-2011: 5 TIMES THE U.S. RATE in 2011



Source: Braddock, D., State of the States in Developmental Disabilities, 2012

43

II. THE PRESENT: I/DD SERVICES IN ILLINOIS AND THE U.S.



- STRUCTURE AND FINANCING OF INTELLECTUAL/DEVELOPMENTAL DISABILITY (I/DD) SERVICES
- MEASURING STATE COMMITMENT TO I/DD SERVICES: FISCAL EFFORT
- RECENT TRENDS IN FAMILY SUPPORT, SUPPORTED EMPLOYMENT AND AGING CAREGIVERS

44

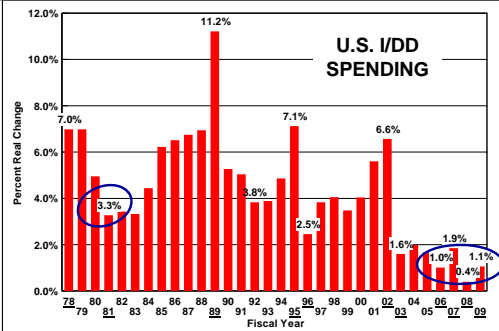
FINANCING I/DD SERVICES



- DURING 2006, 2008 AND 2009, AGGREGATE PUBLIC NATIONWIDE I/DD SPENDING GREW BY THE SMALLEST AMOUNTS WE HAVE OBSERVED IN 32 YEARS.

45

ANNUAL % CHANGE IN TOTAL INFLATION-ADJUSTED I/DD SPENDING IN THE U.S.: 1978-09



Source: Braddock, D., State of the States in Developmental Disabilities, 2012

NUMBER OF STATES WITH INFLATION-ADJUSTED CUTS IN I/DD SPENDING : 1978-2009



1978 - 8	1989 - 5	2000 - 6
1979 - 6	1990 - 4	2001 - 10
1980 - 18	1991 - 6	2002 - 3
1981 - 15	1992 - 11	2003 - 20
1982 - 14	1993 - 18	2004 - 16
1983 - 17	1994 - 8	2005 - 22
1984 - 10	1995 - 6	2006 - 21
1985 - 5	1996 - 10	2007 - 16
1986 - 5	1997 - 8	2008 - 23
1987 - 7	1998 - 4	2009 - 23
1988 - 6	1999 - 10	

Source: Braddock, D., State of the States in Developmental Disabilities, 2012

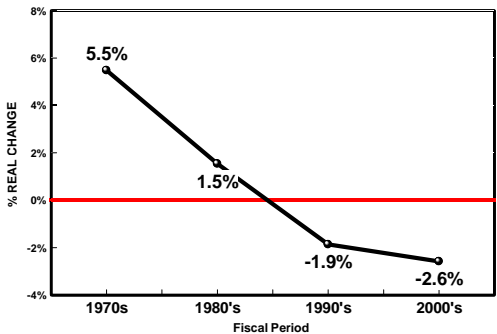
23 STATES REDUCED INFLATION ADJUSTED I/DD SPENDING IN FY 2009; ILLINOIS + 2%



State	% Change	State	% Change	State	% Change
Oregon	12%	Illinois	2%	Kentucky	-1%
District of Columbia	11%	Delaware	2%	Michigan	-2%
Louisiana	10%	West Virginia	2%	Missouri	-2%
North Dakota	10%	Utah	2%	Alabama	-2%
Nevada	9%	Mississippi	2%	Indiana	-3%
Alaska	8%	New Mexico	2%	Maryland	-4%
Washington State	7%	Virginia	1%	Iowa	-4%
North Carolina	6%	Massachusetts	1%	New Jersey	-4%
Arkansas	5%	Maine	1%	Hawaii	-5%
Arizona	4%	Kansas	1%	Montana	-6%
California	4%	South Dakota	0%	Georgia	-6%
New York	4%	Minnesota	-0.3%	Texas	-7%
Connecticut	4%	Nebraska	-1%	Florida	-8%
New Hampshire	3%	Wyoming	-1%	Idaho	-9%
Colorado	3%	Ohio	-1%	Rhode Island	-10%
Pennsylvania	3%	Wisconsin	-1%	South Carolina	-11%
Vermont	3%	Tennessee	-1%	Oklahoma	-12%
				UNITED STATES	1.1%

Source: Braddock, D., State of the States in Developmental Disabilities, 2012

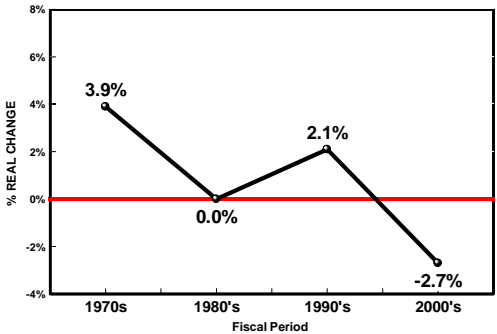
U.S. INSTITUTIONAL SPENDING DECLINED RAPIDLY OVER THE LAST TWO DECADES



Source: Braddock, D. State of the States in Developmental Disabilities, 2012

49

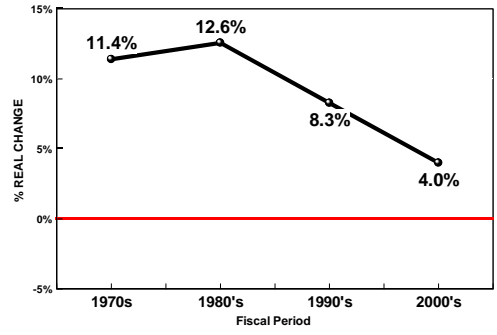
ILLINOIS INSTITUTIONAL SPENDING DECLINED 1980s and 2000s



Source: Braddock, D. State of the States in Developmental Disabilities, 2012

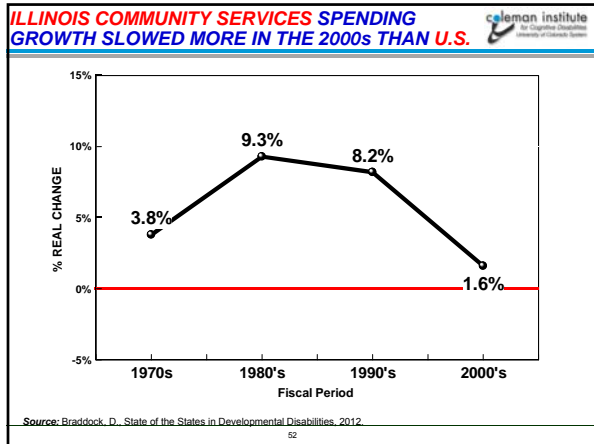
50

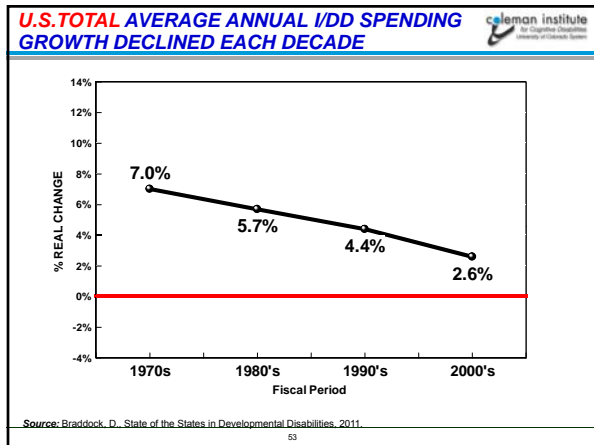
U.S. COMMUNITY SERVICES SPENDING GREW RAPIDLY THROUGH 1990'S, THEN SLOWED DOWN

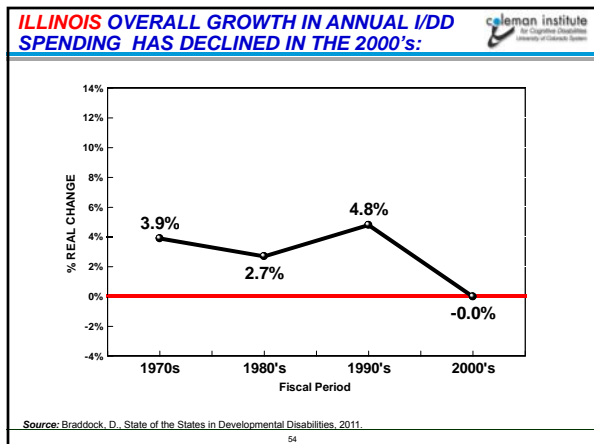


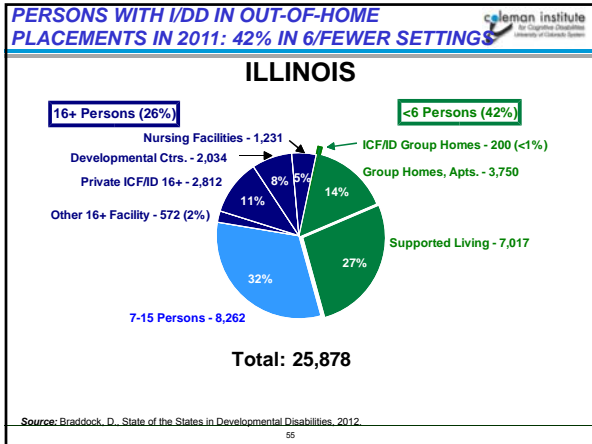
Source: Braddock, D. State of the States in Developmental Disabilities, 2012

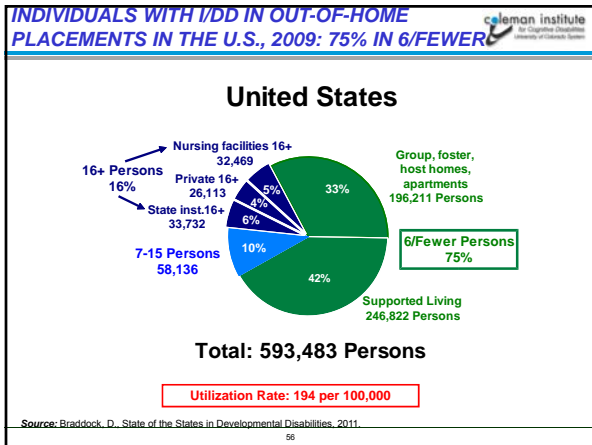
51

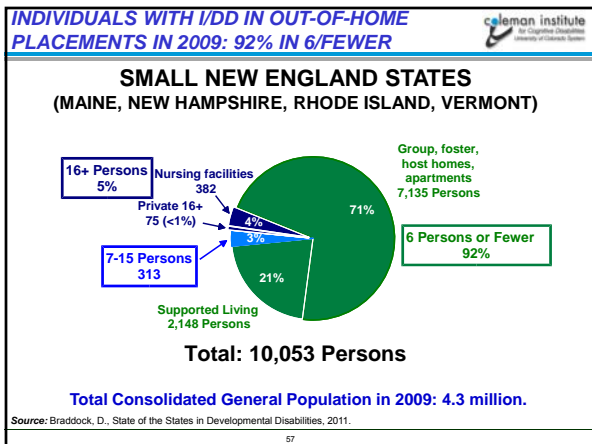




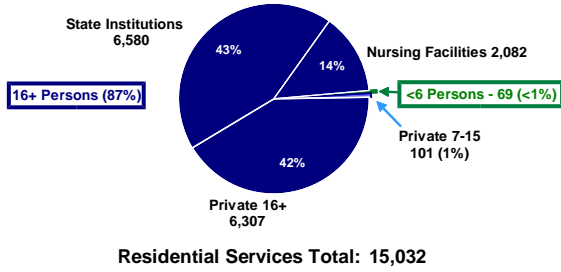








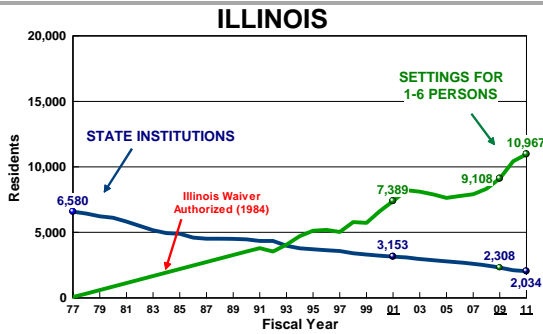
INDIVIDUALS WITH I/DD BY SIZE AND TYPE OF SETTING IN ILLINOIS: 1977: 1% IN 6/FEWER



Source: Braddock, D., State of the States in Developmental Disabilities, 2012

58

SUMMARY: INSTITUTIONS DECLINE, SETTINGS FOR 6 OR FEWER PERSONS GROW



Sources: [1-6 person settings] 1977-90 (Prouty, Smith, & Lakin, 2002); 1991-2011 (Braddock et al., 2012). (State institutions) (Braddock et al., 2012)

59

ILLINOIS DEVELOPMENTAL CENTERS AND MH/DD UNITS: 2011



Facility/Unit	Location	Year Facility Opened	Year Closed	FY 2011 Average Daily Census
Adler MH/DD	Champaign	1967	1982	
Alton MH/DD	Alton	1916	1995	
Anna/Choate MH/DD Anna	Anna	1875		155
Bowen	Harrisburg	1966	1982	
Dixon	Dixon	1918	1987	
Elgin MH/DD	Elgin	1971	1988	
Fox Dwight	Dwight	1965		117
Galesburg MH/DD	Galesburg	1950	1985	
Howe	Tinley Park	1973	2010	
Illinois Pediatric	Chicago	1961	1974	
Jacksonville	Jacksonville	1975		197
Kiley	Waukegan	1975		218
Lincoln	Lincoln	1877	2004	
Ludeman	Park Forest	1972		414
Mabley	Dixon	1987		91
Meyer MH/DD	Decatur		1991	
Murray	Centralia	1964		279
Shapiro	Kankakee	1974		563
Singer MH/DD	Rockford	1966	2003	
TOTAL AVERAGE DAILY CENSUS				2,034

Sources: Braddock et al., 2012; Hemp and Braddock, 1986.

60

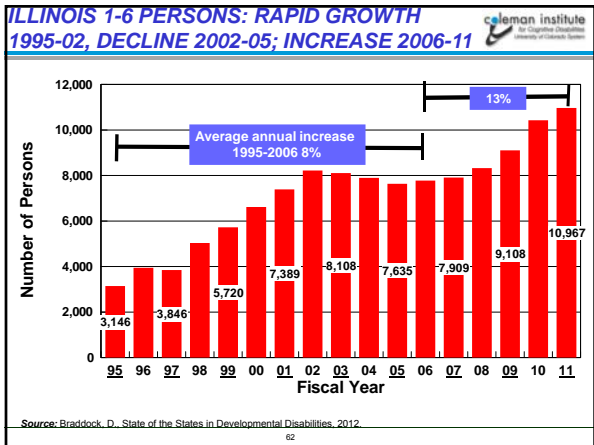
MOST EXTENSIVE UTILIZATION OF 7-15 PERSON SETTINGS * (2009; 2011 for IL)

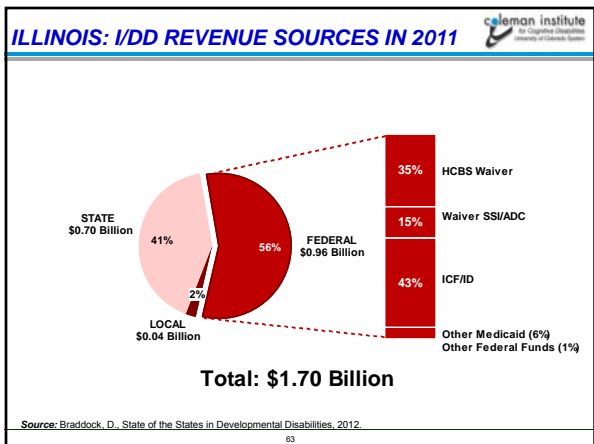
Source: Braddock, D., State of the States in Developmental Disabilities, 2011.

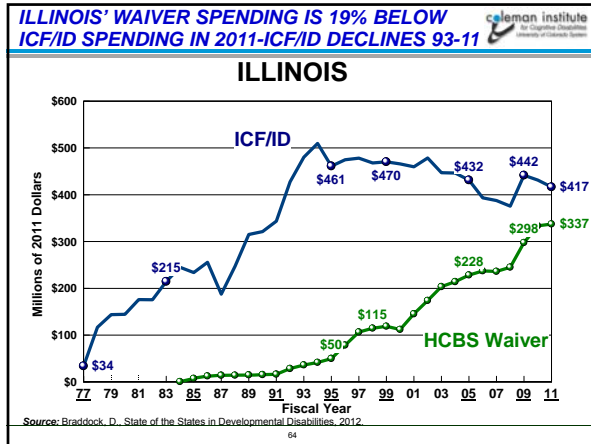
1 New York	29%
2 Illinois	28%
3 South Dakota	22%
4 North Dakota	22%
5 Montana	20%
6 Indiana	20%
Small New England States	3%
UNITED STATES	10%

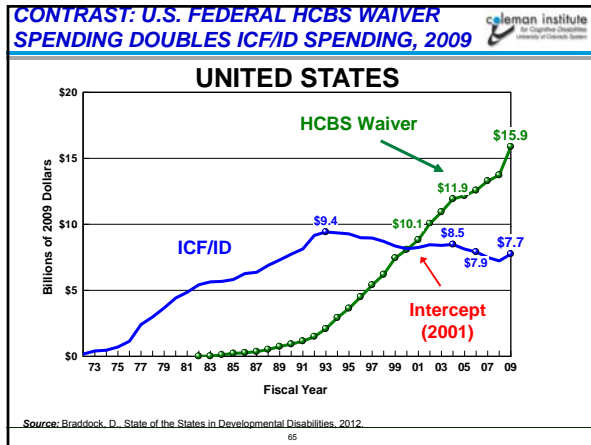
*Percentage of total served in out-of-home residential services

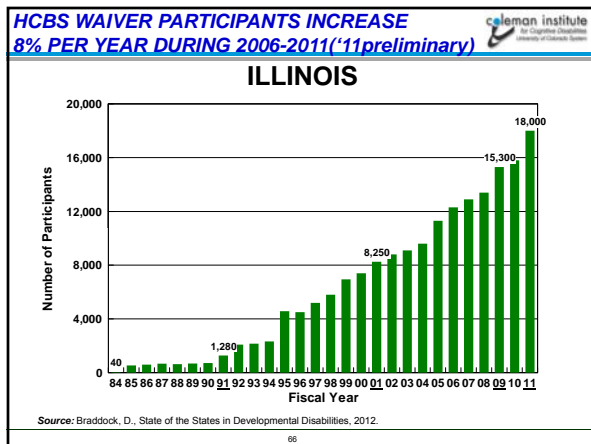
61











STATES RANKED BY HCBS WAIVER UTILIZATION IN FY 2009*



1 New York	\$247	18 South Dakota	\$113	35 Oklahoma	\$63
2 Maine	\$230	19 Wisconsin	\$106	36 New Jersey	\$57
3 Rhode Island	\$214	20 Kansas	\$104	37 Virginia	\$56
4 Minnesota	\$211	21 Delaware	\$100	38 Alabama	\$54
5 Vermont	\$205	22 Nebraska	\$93	39 California	\$52
6 District of Colum	\$203	23 Maryland	\$91	40 North Carolina	\$51
7 Wyoming	\$178	24 Tennessee	\$90	41 South Carolina	\$51
8 New Mexico	\$139	25 Iowa	\$89	42 Florida	\$47
9 Connecticut	\$133	26 Massachusetts	\$88	43 Utah	\$47
10 Pennsylvania	\$131	27 Hawaii	\$82	44 Arkansas	\$45
11 North Dakota	\$131	28 Michigan	\$80	45 Idaho	\$44
12 West Virginia	\$127	29 Ohio	\$79	46 Kentucky	\$42
13 New Hampshire	\$124	30 Washington	\$76	47 Illinois	\$38
14 Alaska	\$124	31 Montana	\$72	48 Georgia	\$34
15 Oregon	\$121	32 Indiana	\$72	49 Texas	\$28
16 Louisiana	\$119	33 Missouri	\$66	50 Nevada	\$27
17 Arizona	\$115	34 Colorado	\$63	51 Mississippi	\$13

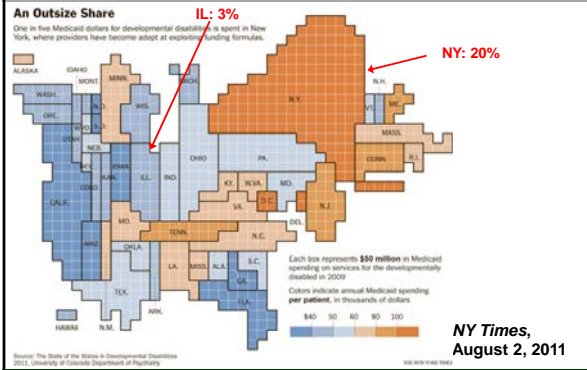
UNITED STATES \$82

* Federal-State HCBS Waiver spending per citizen of the general population.

Source: Braddock, D. State of the States in Developmental Disabilities, 2011.

67

NEW YORK RECEIVES 20% OF NATION'S I/DD MEDICAID FUNDING--ILLINOIS 3%



68

ILLINOIS HCBS WAIVER SERVICES



- Case management
- Companion, Homemaker, Personal Assistance
- Habilitation
- Pre-Vocational
- Assistive Technology and Environmental Mod
- Clinical and Therapeutic Services
- Nursing and Home Health
- Crisis Services, Family Training & Counseling
- Transportation
- Residential Habilitation
- Supported Employment
- Adult Day Health
- Personal Emergency Response System (PERS)

69

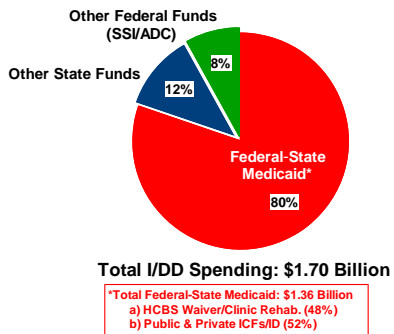
ILLINOIS HCBS WAIVER SERVICES (Continued)



- AMONG THE HCBS WAIVER SERVICES NOT PROVIDED:**
- Private duty nursing
 - Nutritional counseling
 - Chore services
 - Communication devices
 - Community integration training
 - Family/caregiver supports, and
 - Independent living skills training.

70

ILLINOIS I/DD SPENDING IN 2011: MEDICAID IS 80%



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado (2012).

71

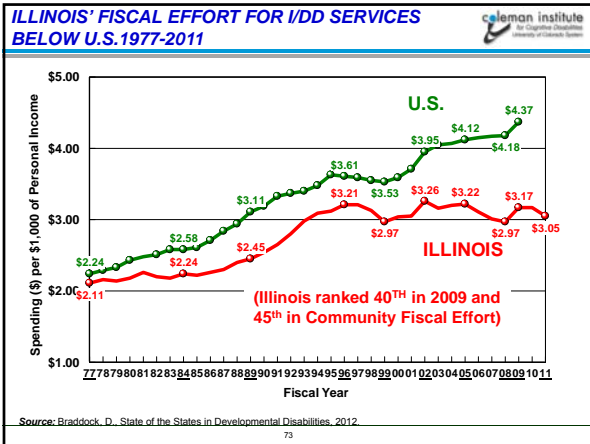
MEASURING STATE COMMITMENT TO I/DD SERVICES: FISCAL EFFORT

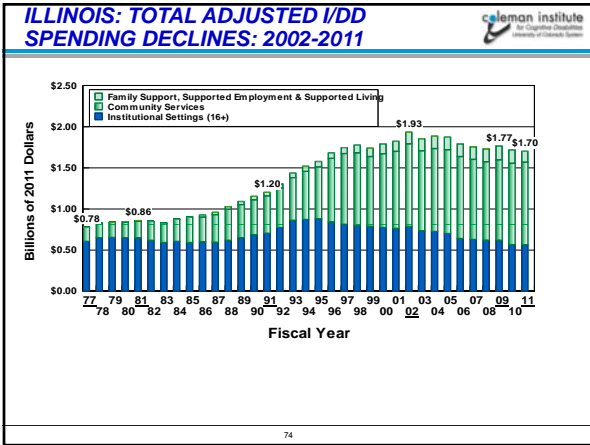


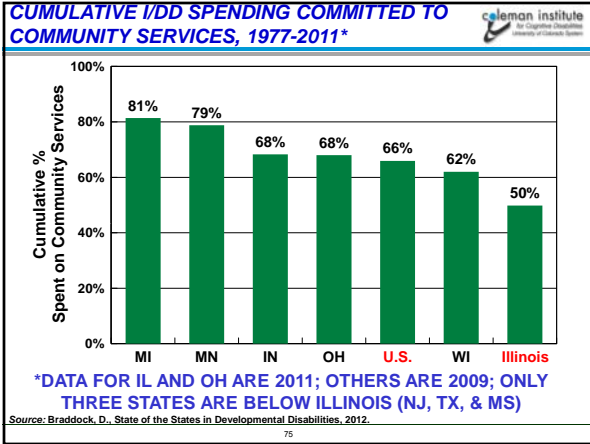
Fiscal effort is a ratio that can be utilized to rank states according to the proportion of their total statewide personal income devoted to the financing of I/DD services.

Fiscal effort is defined as a state's spending for I/DD services per \$1,000 of total statewide personal income.

72







RECENT TRENDS IN COMMUNITY SUPPORTS 

- FAMILY SUPPORT
- SUPPORTED LIVING
- SUPPORTED EMPLOYMENT
- IMPACT OF AGING CAREGIVERS

76

FAMILY SUPPORT DEFINED 

FAMILY SUPPORT INCLUDES

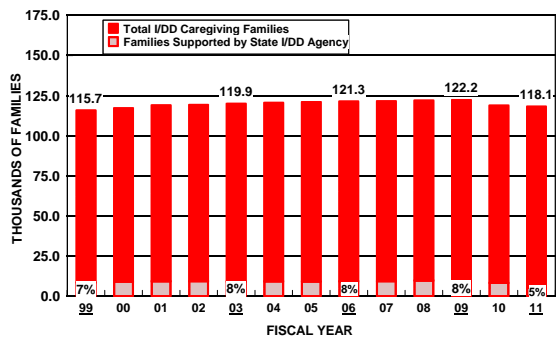
- Respite
- Family counseling
- Architectural adaptation of the home
- In-home training, education, behavior management
- Sibling support programs, and
- Purchase of specialized equipment

“CASH SUBSIDY FAMILY SUPPORT” INCLUDES:

Payments or vouchers directly to families;
families determine what is purchased

77

FAMILIES SUPPORTED IN ILLINOIS ARE 5% OF ESTIMATED I/DD CAREGIVING FAMILIES IN STATE 



Source: Braddock, D. State of the States in Developmental Disabilities, 2012.

78

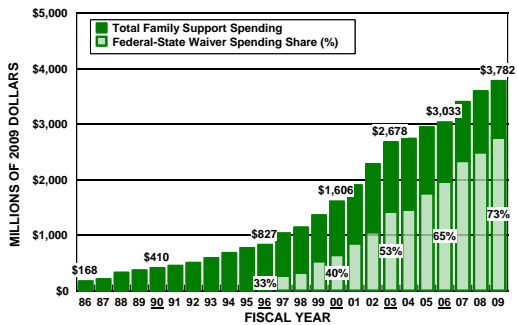
FAMILIES SUPPORTED: ILLINOIS FELL BELOW THE U.S. AVERAGE IN 2009



State	Families Supported % of All Caregiving Families	National Rank
UNITED STATES	17%	
New York	33%	3
Pennsylvania	21%	18
Ohio	20%	19
Texas	12%	31
Florida	10%	35
Illinois	8%	46

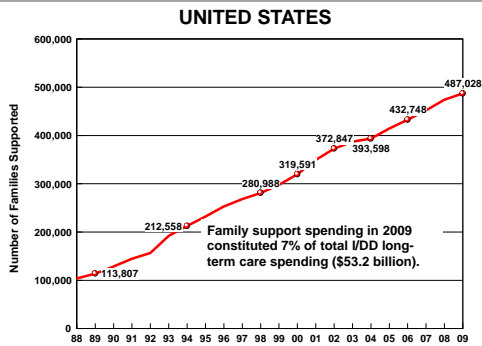
Source: Braddock, D. State of the States in Developmental Disabilities, 2012.

HCBS WAIVER PROVIDED 73% OF I/DD FAMILY SUPPORT SPENDING IN U.S., 2009

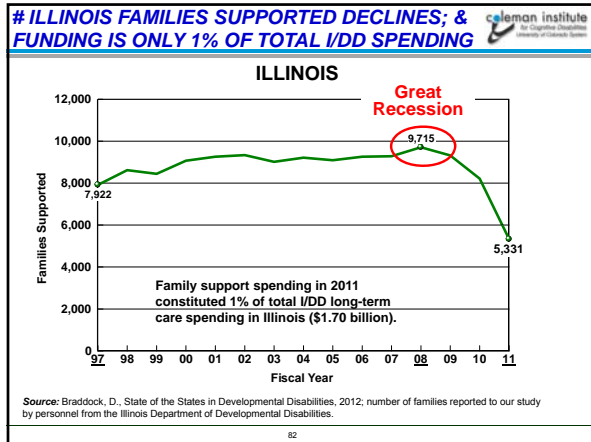


Source: Braddock, D. State of the States in Developmental Disabilities, 2011.

NUMBER OF U.S. FAMILIES SUPPORTED GROWS: FS Spending is 7% OF TOTAL I/DD Spending



Source: Braddock, D. State of the States in Developmental Disabilities, 2012.



22 STATES HAD CASH SUBSIDIES FOR FAMILIES IN 2009—ILLINOIS HIGH IN \$\$ PER FAMILY, NOT#

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The Cognitive Disabilities
University of Chicago System

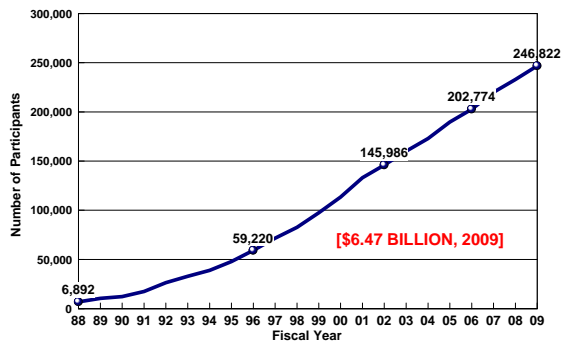
Rank	State	Subsidy Per Family	Rank	State	Families Supported
1	Utah	\$10,299	1	Michigan	7,125
2	Illinois	\$6,950	2	New Jersey	5,685
3	Minnesota	\$6,811	3	South Carolina	3,627
4	North Dakota	\$5,571	4	Connecticut	3,578
5	Nevada	\$4,502	5	Tennessee	3,403
6	New Mexico	\$4,337	6	Texas	3,060
7	Iowa	\$4,249	7	Minnesota	2,781
8	Florida	\$3,908	8	Washington State	2,311
9	Delaware	\$3,294	9	Oklahoma	2,299
10	Louisiana	\$3,272	10	Louisiana	1,523
11	Rhode Island	\$3,261	11	Kansas	1,418
12	Michigan	\$2,598	12	Maine	545
13	Oklahoma	\$2,588	13	Nevada	492
14	Kansas	\$2,516	14	Iowa	353
15	Arizona	\$2,509	15	Illinois	299
16	Texas	\$1,870	16	Arizona	181
17	Washington State	\$1,711	17	New Mexico	164
18	Tennessee	\$1,429	18	North Dakota	95
19	New Jersey	\$1,315	19	Florida	85
20	South Carolina	\$1,134	20	Delaware	54
21	Maine	\$1,101	21	Rhode Island	50
22	Connecticut	\$917	22	Utah	6
	U.S.	\$2,328		U.S.	39,248

Source: Braddock, D., State of the States in Developmental Disabilities, 2012.

83

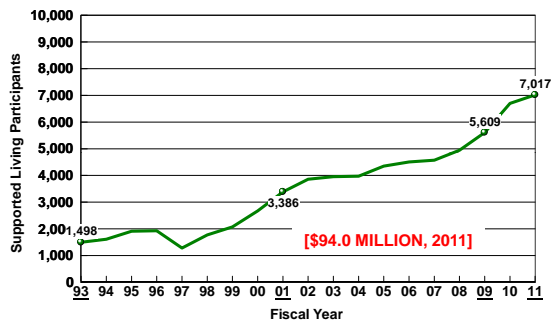
- SUPPORTED LIVING**
- coleman institute
The Cognitive Disabilities
University of Chicago System
- ✓ **CHOICE**
 - Where to live, with whom and which lifestyle
 - ✓ **OWNERSHIP BY OTHER THAN THE SERVICE PROVIDER**
 - Individual owns or rents;
 - Family owns or holds lease;
 - Housing cooperative owns
 - ✓ **INDIVIDUAL SUPPORT**
 - Focus on individual's changing needs over time;
 - Individualized support plan or support contract
- Source: Braddock, D., State of the States in Developmental Disabilities, 2011.
- 84

STATES REPORT CONTINUING GROWTH IN SUPPORTED LIVING PARTICIPANTS: 1988-09



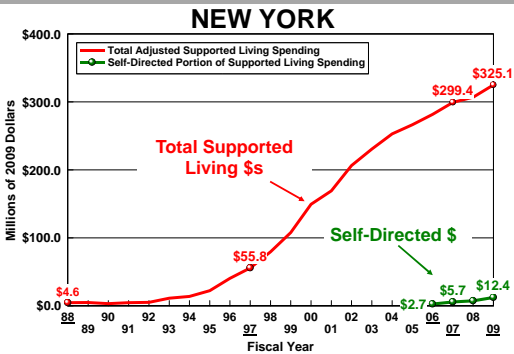
85

THERE'S GROWTH IN SUPPORTED LIVING PARTICIPANTS IN ILLINOIS TOO :1997-11



86

SELF-DIRECTED COMPONENT OF SUPPORTED LIVING GROWS IN NEW YORK STATE:1988-09



Source: State of the States/NASDDDS pilot study of individual and family support, 2010.

87

SUPPORTED EMPLOYMENT



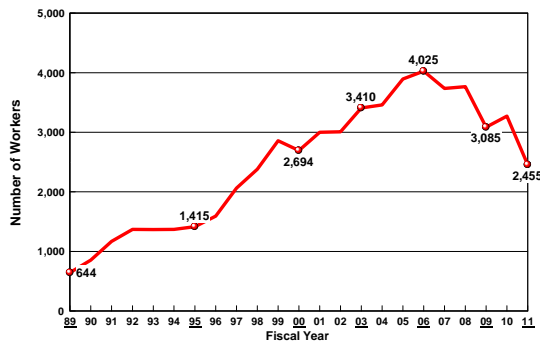
➤ “While supported employment has made significant gains since its formal introduction in 1984 (P.L. 98-527), segregated services continue to outpace the growth of supported employment nationally.”

➤ True in 2004 and true today.

(Rusch & Braddock, *Research and Practice for Persons with Severe Disabilities*, 2004)

88

I/DD SUPPORTED EMPLOYMENT WORKERS IN ILLINOIS PEAK IN 2006, THEN DECLINE TO '11



Source: Braddock, D., *State of the States in Developmental Disabilities*, 2012

89

PER CAPITA* SUPPORTED EMPLOYMENT WORKERS IN ILLINOIS RANKED IN BOTTOM 4th OF STATES, 2009

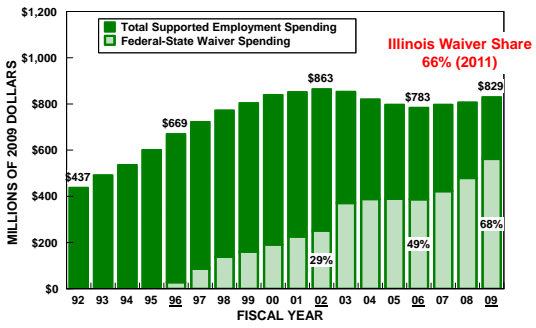


National Rank	State	Workers per Capita (General Population)
1	Vermont	146
2	Connecticut	129
3	Iowa	111
4	Oklahoma	93
5	South Dakota	90
6	Maine	87
7	Maryland	82
8	Pennsylvania	75
9	Alaska	71
10	District of Columbia	71
17	Ohio	54
39	Illinois	19
49	Texas	3
50	Louisiana	2
	UNITED STATES	34

*Per 100,000 of General Population

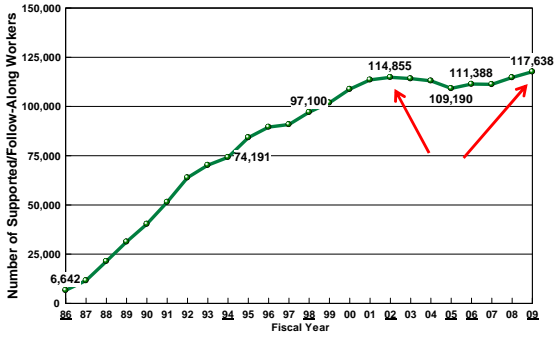
90

THE HCBS WAIVER PROVIDED 68% OF U.S. I/DD SUPPORTED EMPLOYMENT SPENDING IN 2009 



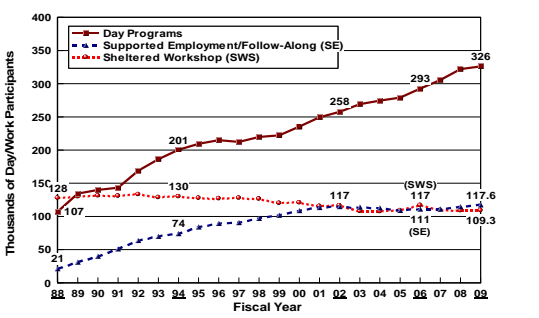
Source: Braddock, D. State of the States in Developmental Disabilities, 2011.

SUPPORTED/FOLLOW-ALONG WORKERS IN THE U.S. INCREASES ONLY 2%, 2002-09 




Source: Braddock, D. State of the States in Developmental Disabilities, 2011.

DAY PROGRAM, SHELTERED WORKSHOP & SUPPORTED EMPLOYMENT PARTICIPANTS: U.S. 




Source: Braddock, D. State of the States in Developmental Disabilities, 2011.

SUMMARY: ILLINOIS' COMMUNITY RANKINGS IN 2009 


- 45th in community fiscal effort, 44% below the U.S. State average
- 50th in the percentage of total I/DD resources financing 6/fewer community residential services
- 50th in the proportion of consumers in 6/fewer settings.
- 47th in federal-state Waiver spending per capita of the general population (\$38 vs. \$82/U.S.); 33rd in supported living spending per capita and 36th in SL participants
- 45th in the percentage of total day/work participants in supported employment (11% vs. 21% in the U.S.)

94

AGING CAREGIVERS 

- LONGEVITY OF PERSONS WITH I/DD IS INCREASING
- AMERICA IS AGING
- FAMILY CAREGIVERS ARE AGING

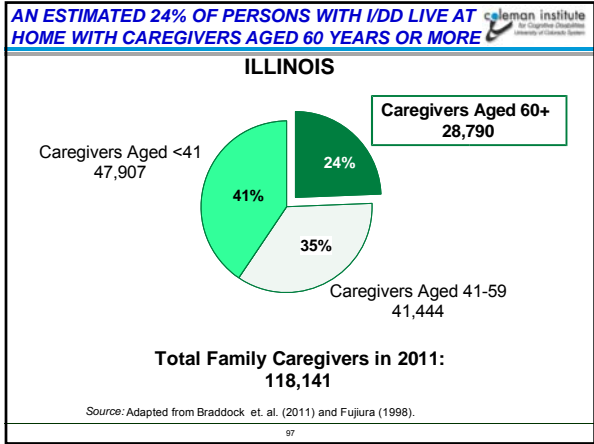
95

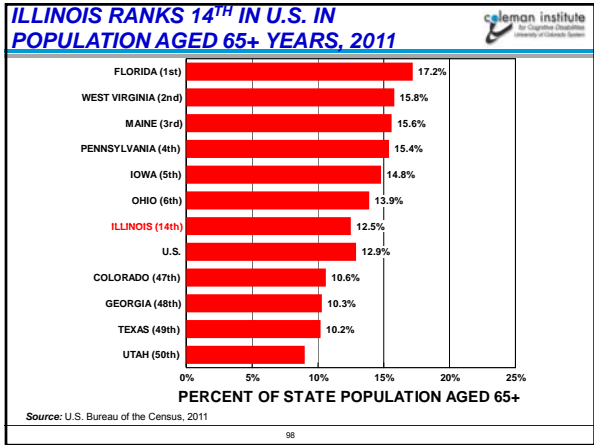
LONGEVITY INCREASES FOR PERSONS WITH AN INTELLECTUAL DISABILITY 

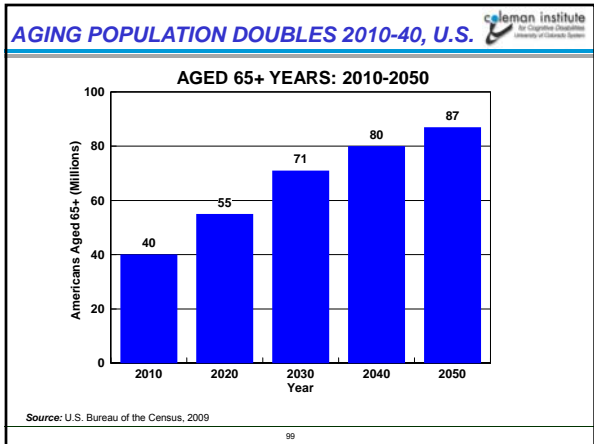
- 1970s: 59.1 years
- 1993: 66.2 years
- U.S. General Population: 70.4 years
- In the future "...those without severe impairment can be expected to have a life span equal to that of the general population."

Source: M. Janicki, (1996), Rehabilitation Research and Training Center on Aging and Mental Retardation, University of Illinois at Chicago.

96







**THANKS TO A VITAL COMPONENT OF THIS STUDY:
ILLINOIS STATE PERSONNEL WHO PROVIDE DATA**



- Thank you Dan Blair, Chris Council and Reta Hoskin for reporting Illinois data we requested in this 2012 update of the State of the States in Developmental Disabilities Project. The study is funded by the U.S. Administration on Developmental Disabilities. We thank ADD as well.
- Special thanks to Illinois DD State Director Kevin Casey's commitment to Illinois participating in this study.
- Our Project is responsible for any errors or omissions contained in this presentation. We appreciate any errors or omissions in data reported being brought to our attention.

100

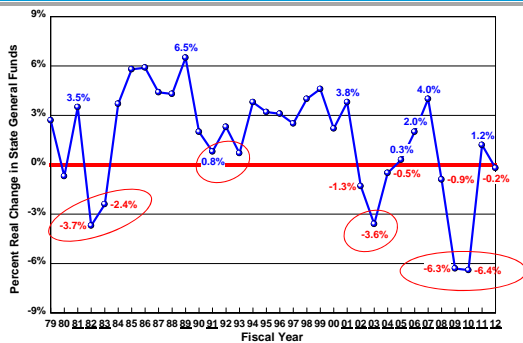
ECONOMIC UNCERTAINTY



**ECONOMIC UNCERTAINTY IN
THE STATES AND
THE GREAT RECESSION**

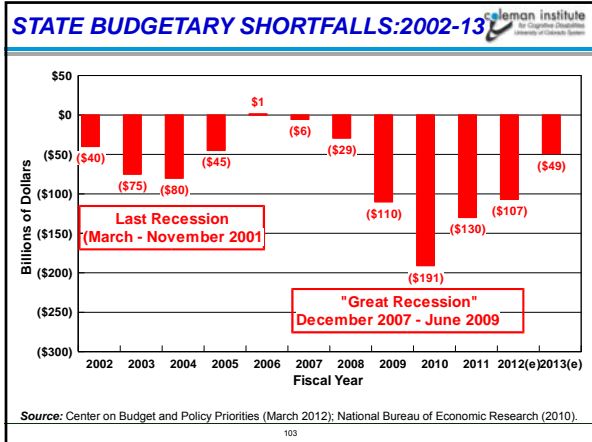
101

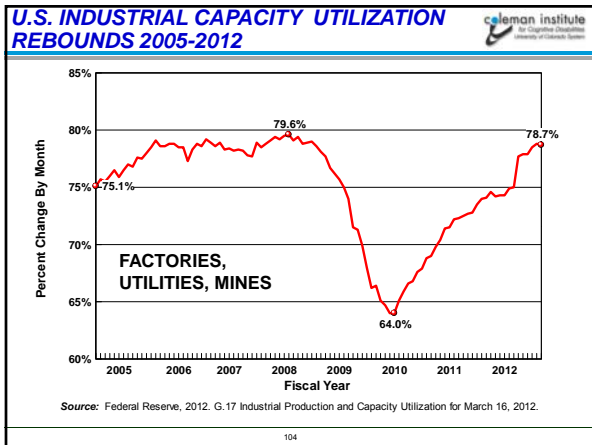
**FOUR US RECESSIONS: AGGREGATE
STATE GENERAL FUNDS DROP**

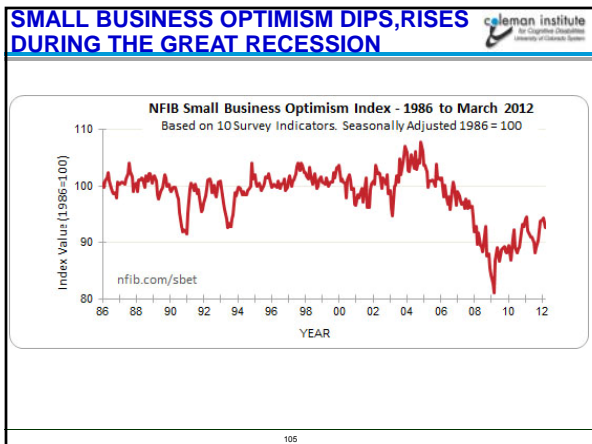


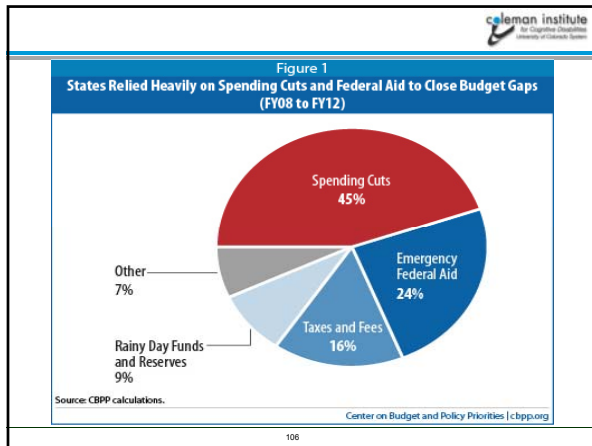
Source: National Governors Association and National Association of State Budget Officers (Fall 2011)
79-10 are "actual" state expenditures; 2011 is "preliminary actual" and 2012 is "appropriated."

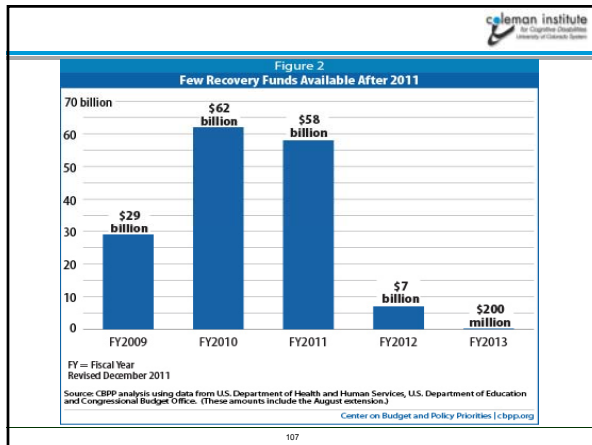
102

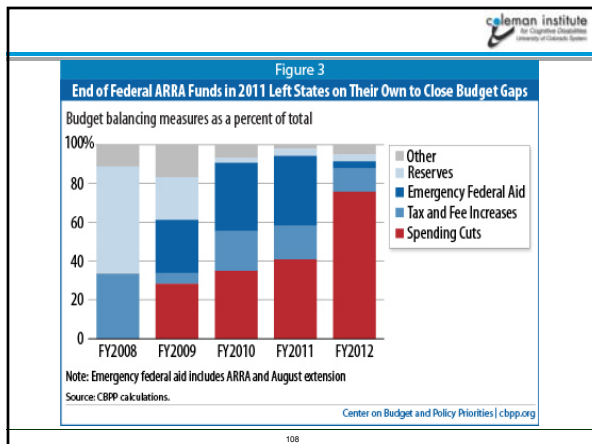


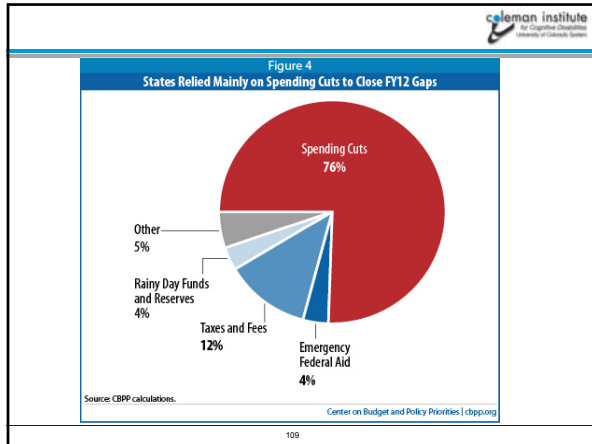


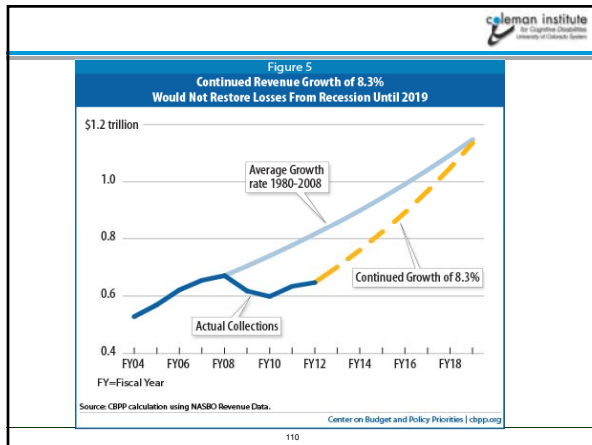


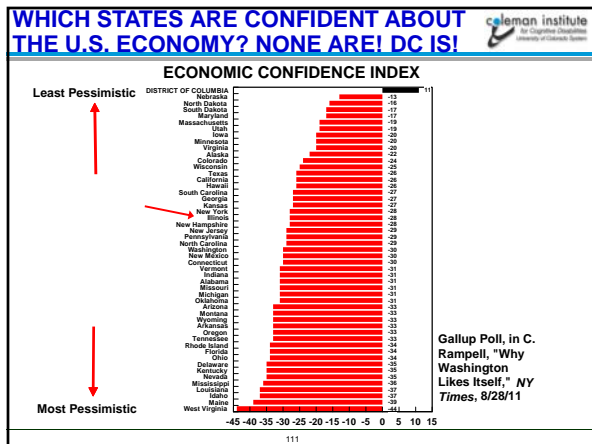












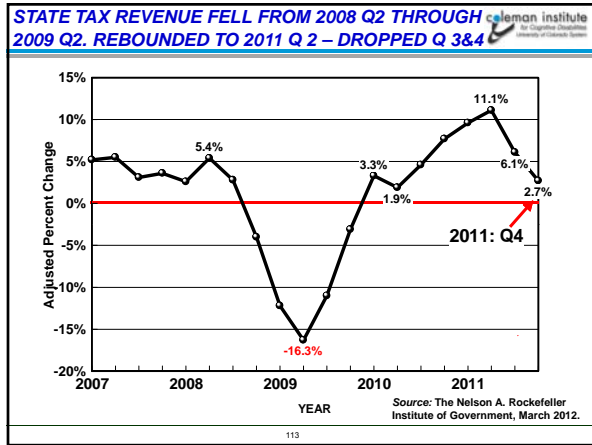
STATE BUDGET SHORTFALLS FOR FY 2013*

42 STATES PROJECT BUDGET GAPS: 2013

State	Percent of 2012 State Budget	State	Percent of 2012 State Budget	State	Percent of 2012 State Budget
Nevada	37.0%	Ohio	10.8%	Kentucky	4.0%
New Jersey	36.0%	North Carolina	10.2%	Massachusetts	4.0%
Oregon	24.0%	Missouri	10.0%	Idaho	3.6%
Texas	20.4%	Nebraska	10.0%	Michigan	3.6%
New Hampshire	20.0%	California	9.8%	New York	3.5%
Washington	19.8%	Alabama	9.4%	Pennsylvania	2.7%
Arizona	17.0%	Oklahoma	9.0%	Iowa	2.4%
Maine	15.5%	Hawaii	8.9%	District of Columbia	0.8%
Connecticut	14.4%	Colorado	8.4%	Alaska	na
Vermont	14.3%	Florida	8.4%	Arkansas	na
Mississippi	13.8%	New Mexico	8.3%	Delaware	na
Virginia	12.3%	Kansas	8.1%	Indiana	na
Wisconsin	12.3%	Utah	8.0%	Montana	na
Minnesota	11.6%	Georgia	7.6%	North Dakota	na
South Carolina	11.5%	Maryland	6.9%	Tennessee	na
South Dakota	11.0%	Illinois	5.2%	West Virginia	na
Louisiana	10.8%	Rhode Island	4.6%	Wyoming	na
				TOTAL	9.3%

Source: McNichol, Cliff, & Johnson, Center on Budget and Policy Priorities, March 21, 2012.

*2013 Shortfall as percent of 2012 state budgets

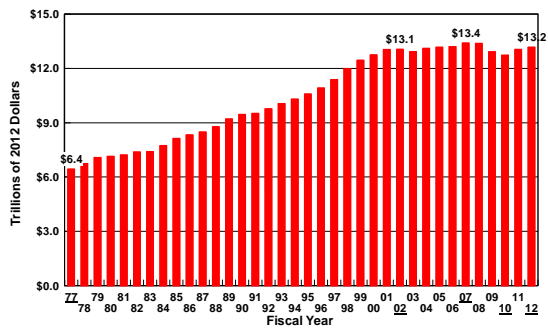


GOOD NEWS: ILLINOIS LEADS IN STATES' TAX REVENUE GROWTH IN 4th QUARTER, '11

Illinois	24.1%	Pennsylvania	3.3%
Connecticut	21.9%	Florida	2.6%
Arizona	19.9%	Alabama	2.3%
Oklahoma	19.7%	Hawaii	2.3%
North Dakota	18.5%	Kentucky	2.3%
Montana	12.7%	Rhode Island	1.8%
Texas	11.4%	Virginia	1.7%
Tennessee	10.0%	Mississippi	1.6%
Ohio	9.3%	Wisconsin	1.6%
Kansas	8.9%	Maine	1.2%
Oregon	7.8%	Missouri	1.1%
Nebraska	7.7%	West Virginia	1.0%
Indiana	7.3%	Delaware	0.7%
Minnesota	6.7%	New York	0.5%
Maryland	6.4%	New Mexico	0.3%
Iowa	6.1%	South Dakota	0.2%
South Carolina	6.1%	Alaska	0.0%
Wyoming	5.6%	Washington	-0.1%
Colorado	5.0%	North Carolina	-0.9%
Arkansas	4.9%	Massachusetts	-1.3%
Nevada	4.7%	Vermont	-1.5%
Idaho	4.2%	Utah	-1.7%
New Jersey	3.8%	New Hampshire	-4.5%
Georgia	3.5%	Louisiana	-5.1%
Michigan	3.3%	California	-8.9%
		UNITED STATES	2.7%

Source: The Nelson A. Rockefeller Institute of Government, March 2012, (Personal and Corporate Income, Sales Taxes)

AGGREGATE U.S. PERSONAL INCOME GREW 3.4% 2010-12, BUT REMAINS BELOW 2005 LEVEL



Source: Bureau of Economic Analysis, U.S. Department of Commerce (2012).

115

ECONOMIC MOMENTUM IN THE STATES: TOP FIVE AND BOTTOM FIVE—ILLINOIS 36TH



INDEX OF ECONOMIC MOMENTUM¹ IN SELECTED STATES: MARCH 2012

U.S.		
RANK	STATE	INDEX
1	North Dakota	2.68
2	Texas	1.28
3	Oklahoma	0.84
4	Utah	0.83
5	Colorado	0.64
46	Delaware	-0.76
47	Wisconsin	-0.77
48	Rhode Island	-0.84
49	Alabama	-0.94
50	Mississippi	-1.01
UNITED STATES		0.00

¹Weighted average growth in personal income, employment and population (Federal Funds Information for States, March 2012).

116

INDEX OF ECONOMIC MOMENTUM¹ IN THE STATES: MARCH 2012



U.S.			U.S.		
RANK	STATE	INDEX	RANK	STATE	INDEX
1	North Dakota	2.68	26	Michigan	-0.16
2	Texas	1.28	27	Massachusetts	-0.21
3	Oklahoma	0.84	28	Ohio	-0.29
4	Utah	0.83	29	Pennsylvania	-0.31
5	Colorado	0.64	30	Minnesota	-0.31
6	Iowa	0.38	31	Connecticut	-0.32
7	Washington	0.37	32	New Hampshire	-0.33
8	Tennessee	0.37	33	New Mexico	-0.34
9	Louisiana	0.32	34	South Dakota	-0.4
10	Wyoming	0.31	35	Oregon	-0.43
11	Maryland	0.29	36	Illinois	-0.43
12	Arizona	0.24	37	Kansas	-0.45
13	Kentucky	0.19	38	Hawaii	-0.46
14	Idaho	0.05	39	Nebraska	-0.47
15	South Carolina	0.03	40	Vermont	-0.47
16	New York	0.00	41	Montana	-0.48
17	West Virginia	-0.03	42	Arkansas	-0.52
18	Indiana	-0.03	43	Nevada	-0.65
19	North Carolina	-0.06	44	Missouri	-0.67
20	California	-0.08	45	Maine	-0.69
21	New Jersey	-0.09	46	Delaware	-0.76
22	Georgia	-0.10	47	Wisconsin	-0.77
23	Florida	-0.11	48	Rhode Island	-0.84
24	Virginia	-0.13	49	Alabama	-0.94
25	Alaska	-0.13	50	Mississippi	-1.01
UNITED STATES		0.00			

¹Weighted average growth in personal income, employment and population (Federal Funds Information for States, March 2012).

POPULATION MIGRATION IN THE STATES: 2006-09

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OUT-MIGRATION: TOP 5 STATES	
California	(793,578)
New York	(639,918)
Michigan	(356,139)
New Jersey	(229,605)
Illinois	(229,524)
IN-MIGRATION: TOP 5 STATES	
Texas	644,310
North Carolina	373,278
Arizona	298,480
Georgia	298,235
South Carolina	183,159

Source: Federal Funds Information for States (2009). State Policy Reports, Vol. 27, No. 21.

118

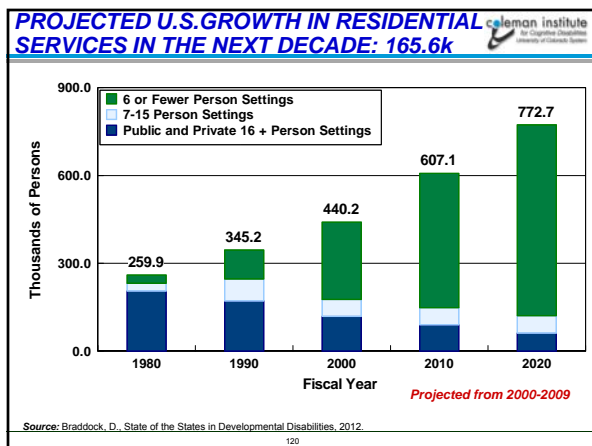
III. THE FUTURE: EMERGING TECHNOLOGIES

coleman institute
for Cognitive Disabilities
University of Colorado System

“I think we can do a ‘virtual nursing home’ with technology”...

Andy Grove
Co-Founder, Intel Corp.
In *USA Today*, 2006

119



**INTEGRATED WIRELESS
SENSOR NETWORKS**



IN THE FUTURE:

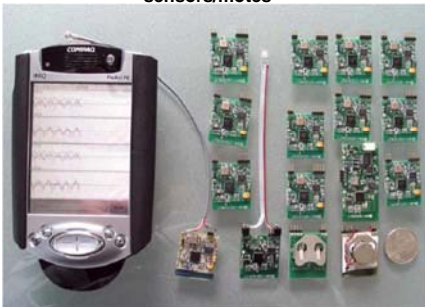
- A combination of wireless cell phone, Internet, and sensor technology will connect people, objects, and events.
- Smart homes/care will play key roles in assisted living for persons with I/DD, allowing seamless connectivity between clients, caregivers/health care providers, and parents.

121

MIT PLACELAB - BEHIND THE SCENES



Context-aware PDA with wireless sensors/motes



Source: MIT PlaceLab website at http://architecture.mit.edu/house_n/placelab.html

122

U.S. SMART HOME SERVICE PROVIDERS FOR PERSONS WITH ID



- **IMAGINE!
BOULDER AND LONGMONT
COLORADO**
- **REST ASSURED, LLC.**
- **SOUND RESPONSE,
MADISON, WISCONSIN**

Source: Braddock, D., Coleman Institute, University of Colorado, 2010.

123

**IMAGINE! SMART HOME, BOULDER,
COLORADO: COMPLETED 2009**



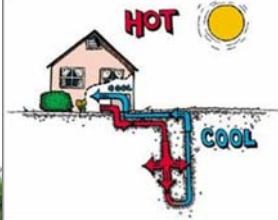
Imagine! Smart Homes in Boulder and Longmont, Colorado
<http://www.imaginesmarthomes.org/>

124

**IMAGINE! SMART HOME, BOULDER,
COLORADO: GREEN TECHNOLOGIES**



Photovoltaic cells
generate electricity



Geothermal systems heat
and cool the home

125

**IMAGINE! SMART HOME, LONGMONT, CO,
OPENED MAY 2010**



Imagine! Smart Homes in Boulder and Longmont, Colorado
<http://www.imaginesmarthomes.org/>

126

FUNDING FOR HOMES



- Private donations
- HUD
- Cities of Boulder and Longmont
- State of Colorado/Medicaid

127

IMAGINE! SMART HOMES, BOULDER/LONGMONT



STAFF SYSTEMS

- Employee/manager portal for centralized information collection and reporting
- Web-based medication prompt system
- Location based activity prompting/logging
- Web based training courses
- Lifelogging of resident histories
- Family portal for daily activities and health status with text and picture-sharing

128

IMAGINE! SMART HOMES, BOULDER/LONGMONT



CONSUMER, ENVIRONMENTAL AND COMMUNICATIONS ADAPTATIONS

- Accessible control of environment and appliances
- Accessible, safe kitchen and bathroom
- Cameras monitor high-risk areas
- Automated windows and doors
- Task prompters and reminders
- Specialized, accessible PC, Internet, journaling and web conferencing

129

REST ASSURED PROGRAM



© 2005 by Wabash Center, Inc.

Staff person monitors several apartments simultaneously.

130

REST ASSURED PROGRAM



- Uses PTZ (Pan, Tilt, Zoom) **cameras** for monitoring in high risk areas like the kitchen
- Remote supervision via two-way audio/video communication with caregiver
- Motion, temperature, carbon monoxide, and door brake sensors used in, in addition to a Personal Emergency Response System
- Consumers report increased independence; caregiver is not a constant physical presence in the house
- Reduced overall cost of care
- Currently used primarily for third-shift support

Source: Rest Assured, Wabash, Indiana.

131

REST ASSURED PROGRAM-ATTRIBUTES



- Developed in collaboration with EPICS (Engineering Projects In Community Service) at Purdue University
- Serves consumers with ID
- Nearly 300 homes and apartments with over 400 consumers served in eight states: FL, GA, IL, IN, KS, MD, OH, & WI

Source: Dustin Wright, General Manager, Rest Assured LLC, Wabash, Indiana.

132

Monitoring Station



- Professional Monitors
- Communication between Monitor and staff/ individuals served
- Access to protocols and personal intervention strategies
- Provider agency back-up
- Individualized alarm readings
- Generates reports

133

- Completely Wireless in the Home
- Cellular Transmission- No Phone or Internet Connection is Required
- 2-Way Communication
- Event Sequencing
- Data Tracking
- Portable and Adaptable to People's Homes and Abilities

134

NQSS

“We can alleviate some of the demand for Direct Support Professionals (DSPs) by identifying new service options for people who do not need intensive DSP support.

The system is tailored to the needs of each person who uses it and has been shown to improve personal independence, as well as alleviating the needs for a direct support professional where one is not needed.”

Mitch Daniels, Governor, State of Indiana
The Arc of Indiana, Meet the Candidates, Summer 2008

135

STATES WITH MEDICAID SUPPORT FOR SMART HOME TECHNOLOGIES



MEDICAID WAIVER AMENDMENT APPROVED

- INDIANA, KANSAS, LOUISIANA, OHIO*, WEST VIRGINIA

STATES EXPRESSING INTEREST

- KENTUCKY, MASSACHUSETTS, NEW JERSEY

* Ohio's Individual Options Waiver includes payment for equipment used to operate systems such as live video feed, live audio feed, motion sensing system, radio frequency identification, web-based monitoring system...and equipment used to engage in live two-way communication with the individual being monitored...Ohio will collect data to determine if the proposed amount is reasonable.

136

PDA TASK PROMPTING SOFTWARE



Visual Assistant (Prompting System)



Source: Ablelink Technologies, Colorado Springs (Terry & Jonathan).

137

VISUAL ASSISTANT



□ A pocket personal computer with an integrated PC-slot digital camera;

□ Staff/caretakers take pictures of—and narrate—the steps in a task;



□ The verbal instructions and images guide users through the steps:
– Grocery shopping
– Medications
– Personal hygiene
– Using public transportation, etc.

SOURCE: Ablelink Technologies, Colorado Springs.

138

ADAPTED WEB BROWSER AND E-MAIL

Adapted Web Browser



The Web Trek adapted web browser improves access to the World Wide Web for people who have difficulty with reading and writing.

Adapted E-mail Program



Web Trek Connect's picture-based inbox and interface for automated recording and sending of audio email.

SOURCE: Ablelink Technologies, Colorado Springs.

139

ROCKET READER AUDIO BOOKS



Source: Ablelink Technologies, Colorado Springs; www.ablelinktech.com

140

LOCATION TRACKING

- Nextel mobile locator:
http://www.nextel.com/en/services/gps/mobile_locator
- Wherifone:
<http://www.wherify.com/wherifone/>
- Accutacking:
<http://www.accutacking.com/>
- 911 to go:
<http://www.travelbygps.com/articles/tracking.php/>
Contact your cell phone provider for phones/services



141

TREKKER BREEZE GPS

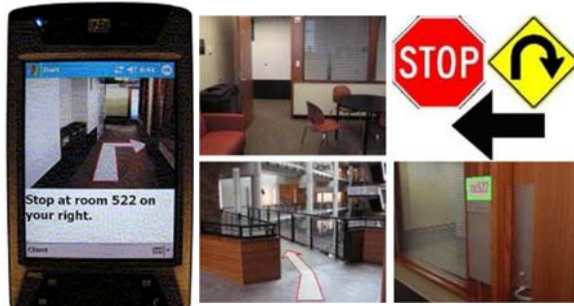


Verbally announces the names of streets, intersections and landmarks as you walk.

Source:
<http://www.visibilitystore.org/browse.cfm/trekker-breeze-gps/>

142

INDOOR WAYFINDING SUPPORT



SOURCE: http://cognitivetech.washington.edu/assets2006_liu.pdf [In Development]

143

GROWING INEQUALITY AND THE AMERICAN PROMISE

“... inequality is the ill that underlies all the others...”

Between 1979 and 2006, middle-class incomes after taxes increased by 21%

The poorest saw their incomes rise by only 11 percent.

The top one percent saw their incomes increase by 256%.

George Packer
The Broken Contract: Inequality and American Decline
Foreign Affairs, November/December 2011.

144

THE AMERICAN PROMISE IS BROKEN coleman institute
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“...Some argue that this inequality was an avoidable result of deeper shifts: global competition, cheap goods made in China, technological changes....Book after book by economists and other scholars over the past few years has presented an airtight case: over the past three decades, the government has consistently favored the rich. This is the source of the problem: our leaders, our institutions.

George Packer
The Broken Contract: Inequality and American Decline
Foreign Affairs, November/December 2011.

145

AMERICA'S TAX BURDEN IS AMONG THE SMALLEST IN THE DEVELOPED WORLD coleman institute
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Turkey	42.7%	Czech Republic	27.1%
Sweden	42.4%	United Kingdom	27.1%
Poland	42.1%	Portugal	26.6%
France	41.7%	Japan	24.9%
Belgium	40.3%	Slovak Republic	23.2%
Hungary	39.9%	Canada	21.5%
Greece	39.2%	Switzerland	18.6%
Finland	38.4%	Mexico	18.2%
Germany	35.7%	Korea	16.2%
Austria	35.5%	Australia	16.0%
Italy	35.2%	New Zealand	14.5%
Spain	33.4%	Luxembourg	12.2%
Denmark	29.6%	UNITED STATES	11.9%
Norway	29.6%	Iceland	11.0%
Netherlands	29.1%	Ireland	8.1%

Organisation for Economic Co-operation and Development (OECD). (2008).
Tax burden: Personal income, employee and employer social security contributions, and payroll taxes as a % of GDP (households of married couples, two children).

146

AVERAGE TAX BREAK FOR THE WEALTHY IS 25 TIMES THE POOREST coleman institute
for Corporate Development
University of Colorado Denver

Distribution of tax breaks 2011 est.
Tax breaks include the various exemptions, deductions and tax credits allowed to individual taxpayers, like the home mortgage interest deduction and the lower tax rates allowed on capital gains and dividends.**

AVERAGE BENEFIT PER TAXPAYER BY INCOME GROUP

Income Group	Average Benefit per Taxpayer	Share of Total	Total (\$ Billions)
LOWEST FIFTH	\$1,110	4%	\$40
SECOND-LOWEST FIFTH	2,149	7	74
MIDDLE FIFTH	2,707	8	91
SECOND-HIGHEST FIFTH	5,021	14	152
HIGHEST FIFTH	24,693	67	723

AVERAGE/TAXPAYER →

SHARE OF TOTAL →

TOTAL (\$ BILLIONS) →

Source: Eduardo Porter, A nation of too many tax breaks, NY Times, 3/12/12, p. B1

147

SPEAKING OF "WELL-BEING..."



PHYSICAL ACTIVITY & HEALTH PROMOTION MOVEMENT:

EXERCISE WORKS

IT'S THE MOST COST-EFFECTIVE "MEDICINE" YET INVENTED

151

PHYSICAL ACTIVITY AND INTELLECTUAL DISABILITY: BENEFITS

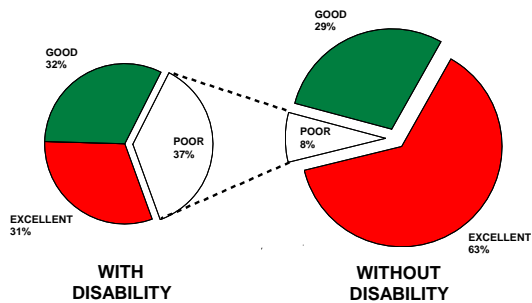


- PHYSICAL ACTIVITY HAS SUBSTANTIAL BENEFITS IN IMPROVING THE HEALTH OF PEOPLE WITH INTELLECTUAL DISABILITIES BY:
- REDUCING THE INCIDENCE OF DISEASES (E.G. TYPE 2 DIABETES, HEART DISEASE, OBESITY)
- IMPROVING SECONDARY CONDITIONS ASSOCIATED WITH DISABILITIES (E.G. WEAKNESS, FATIGUE, REDUCED MOBILITY, JOINT STIFFNESS, SOCIAL ISOLATION, DEPRESSION);
- AND ALLOWING INDIVIDUALS TO MAINTAIN A HIGHER LEVEL OF INDEPENDENCE IN PERFORMING ACTIVITIES OF DAILY LIVING
- STAFF MUST BE ROLE MODELS

Source: Rimmer (2007); Rimmer, Riley, Wang, Rauworth, & Jurkowski (2004).

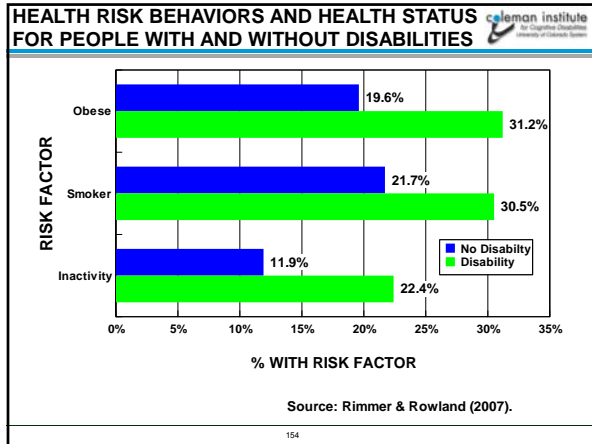
152

SELF-REPORTED HEALTH STATUS



Source: Rimmer & Rowland (2007).

153



COLEMAN INSTITUTE CONFERENCE, NOVEMBER 2012 IN WESTMINSTER, CO

THE STATE OF THE STATES IN COGNITIVE DISABILITY AND TECHNOLOGY: 2012 ANNUAL REVIEW AND FORECAST

WILLIAM POUND, Executive Director, National Conference of State Legislatures: *The State of the States in the Great Recession and It's Aftermath.*

DAVID BRADDOCK, PhD, Chair of Conference, Associate VP, University of Colorado: *The State of the States in Developmental Disabilities: 2012.*

BILL COLEMAN, Silicon Valley Entrepreneur, Founding Donor of the Coleman Institute, Partner, Alsop-Louie Partners, San Francisco: *Cloud Computing and its Implications for Disability*

PETER BLANCK, PhD, JD, Chairman, Burton Blatt Institute, Syracuse University: *Is There a Right to Technology Access for People with IDD?*

TAMAR HELLER, PhD, Director, Institute on Disability and Human Development, University of Illinois at Chicago

MIKE WEHMEYER, PhD, Director, Schiefelbusch Life Span Institute, University of Kansas

SUE SWENSON, Deputy Assistant Secretary, Office of Special Education and Rehabilitative Services, U.S. Department of Human Services

ColemanInstitute.org

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