

# 150 Years of Movement Toward Community in the United States

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The Center for Outcome Analysis

[www.eoutcome.org](http://www.eoutcome.org)

# History

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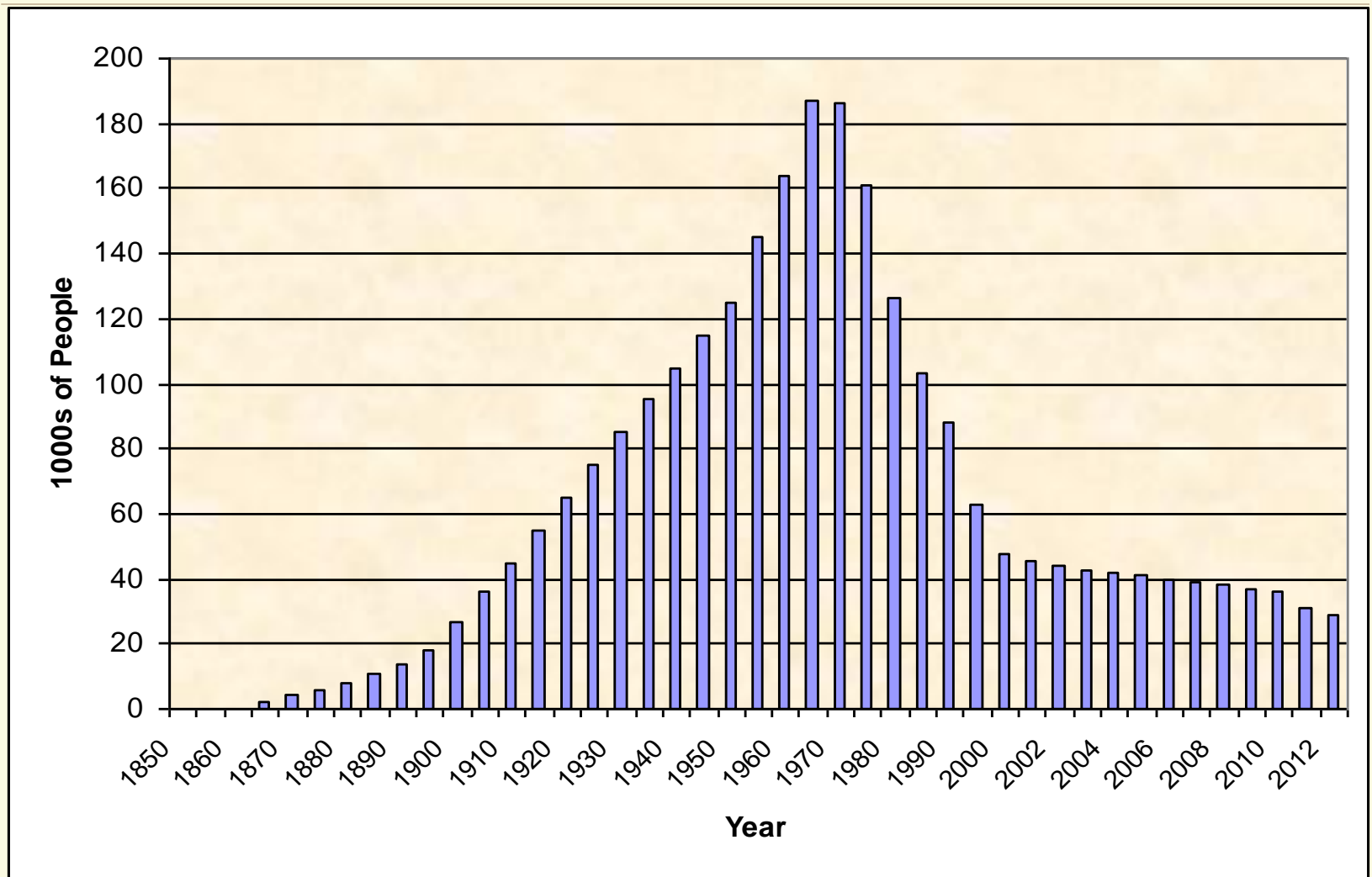
 History is important

 Those who ignore history are doomed to...

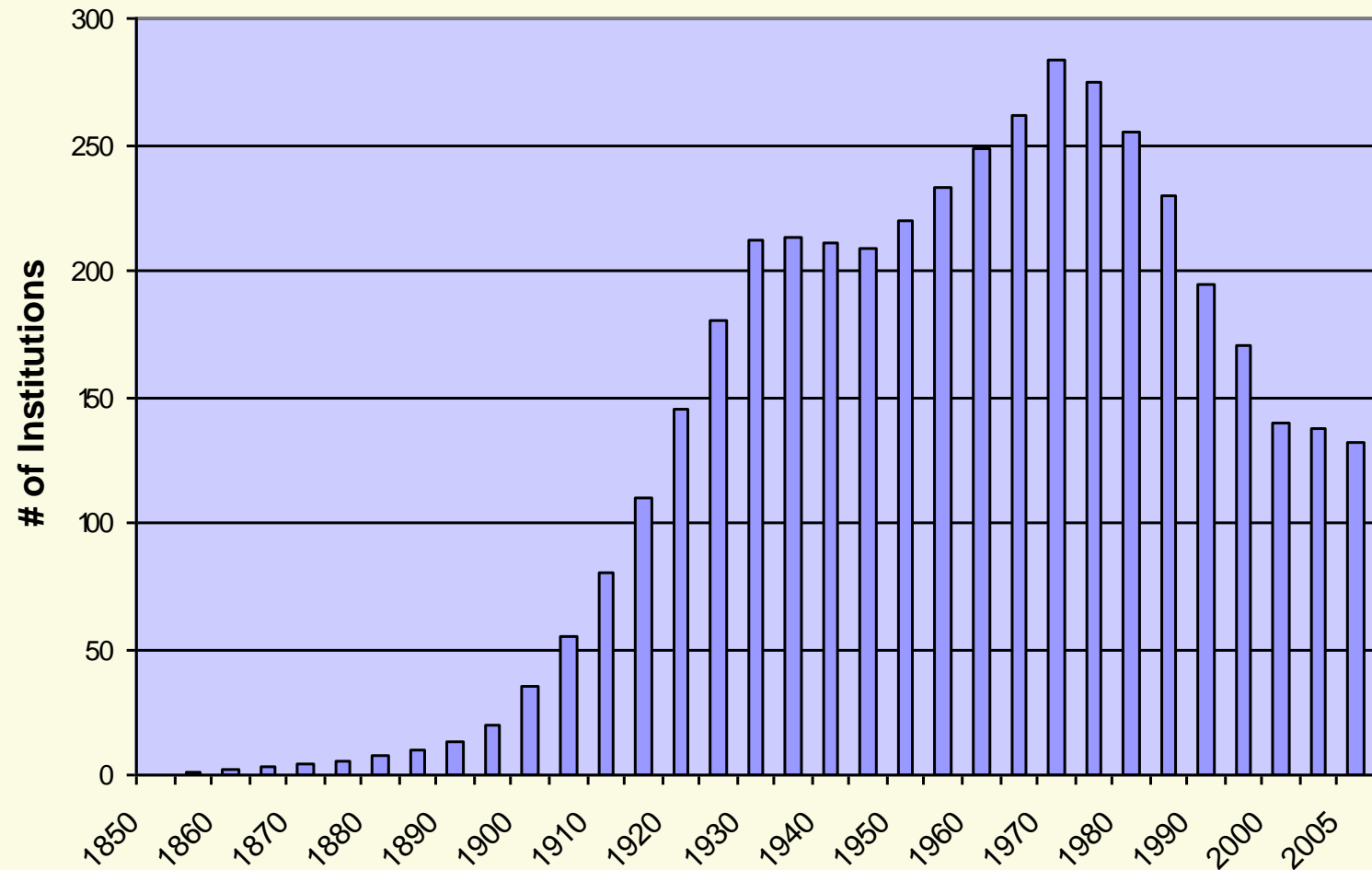
A spiral-bound notebook with a textured, light brown cover. The spiral binding is on the left side. The text "Not Know Much About History" is written in a red, serif font in the center of the cover.

Not Know Much About History

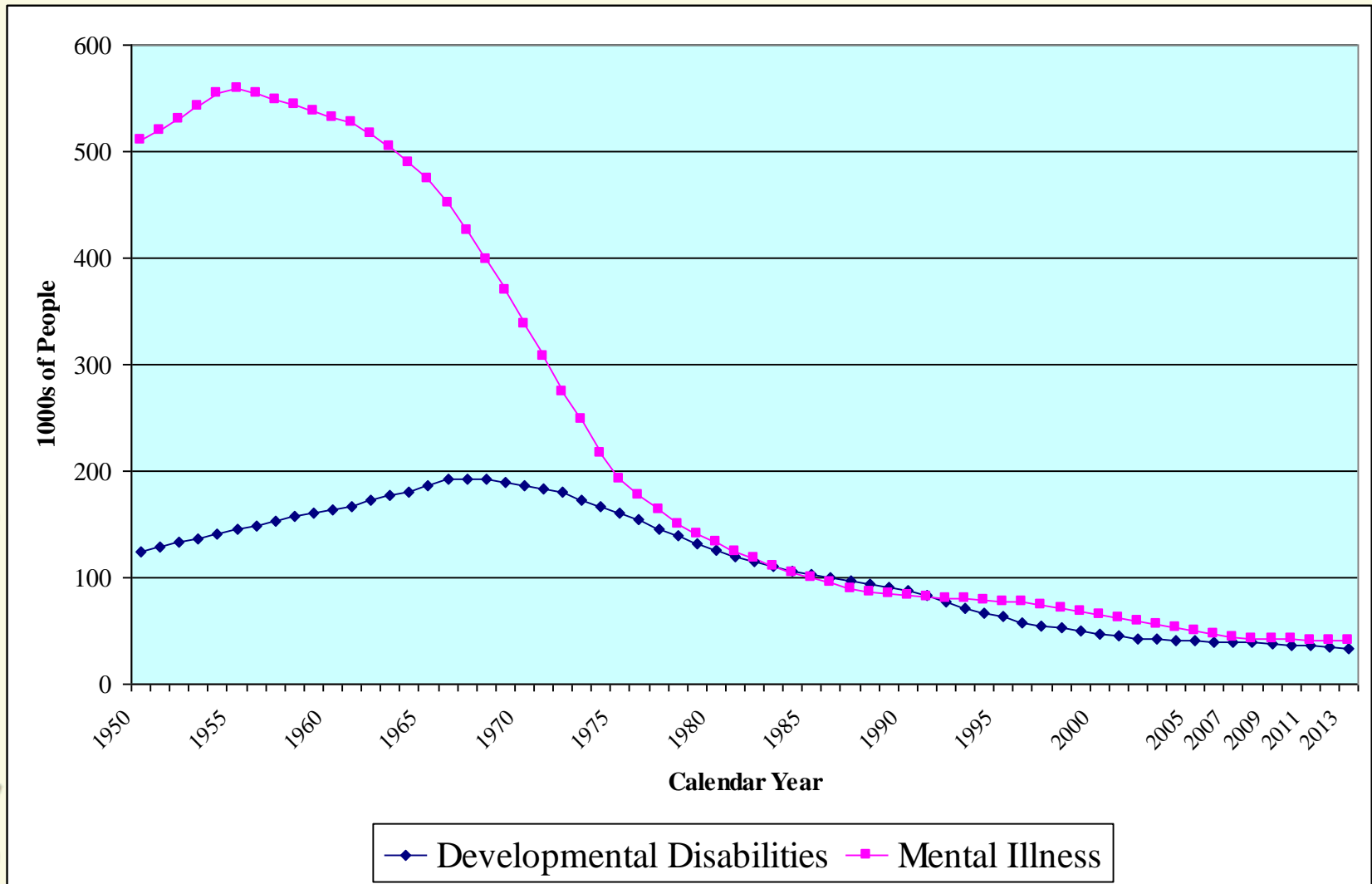
# 150 Years of Institutionalization



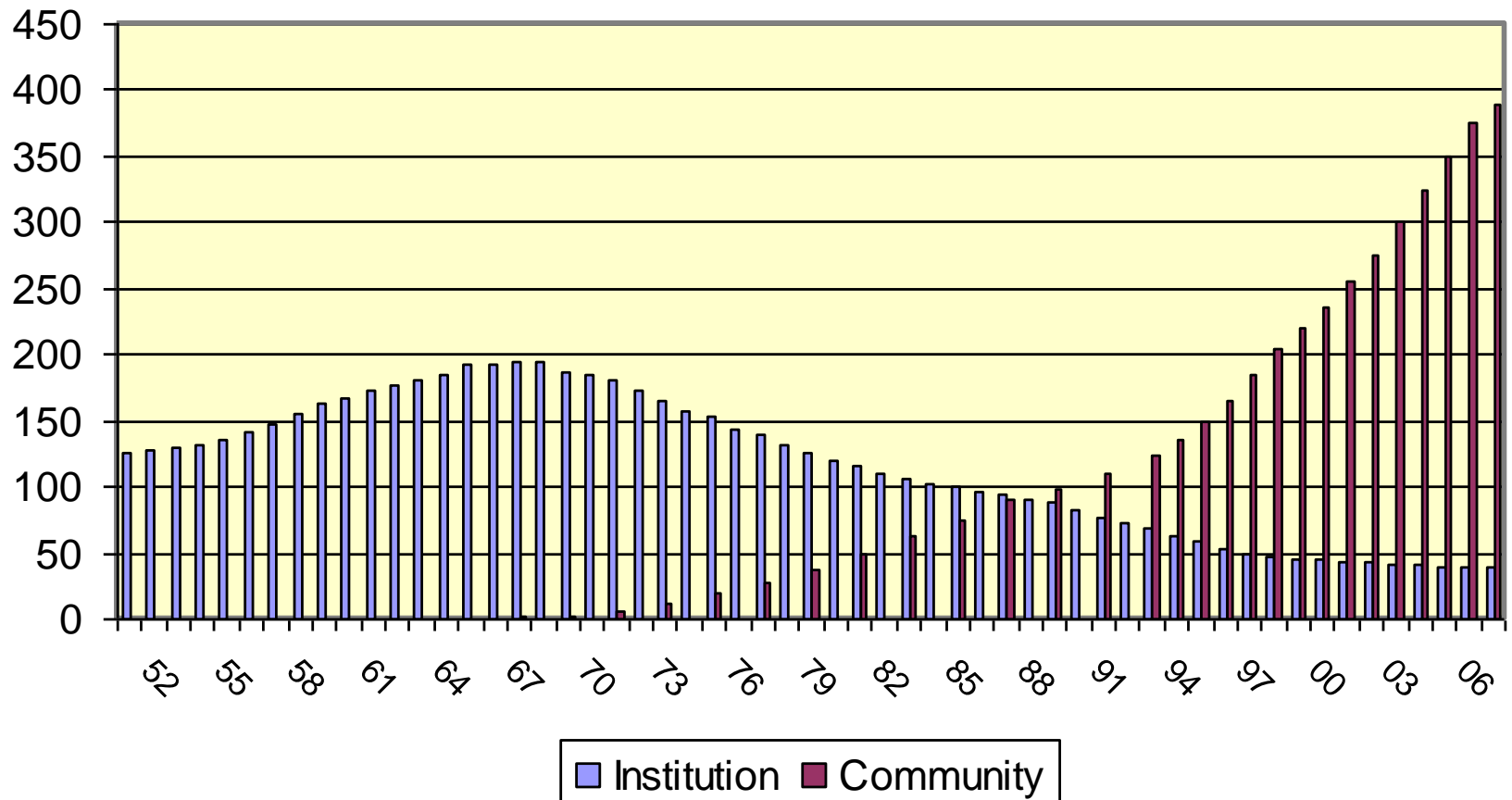
# Number of Public Institutions



# U.S. Deinstitutionalization – Developmental Disabilities Versus Mental Illness

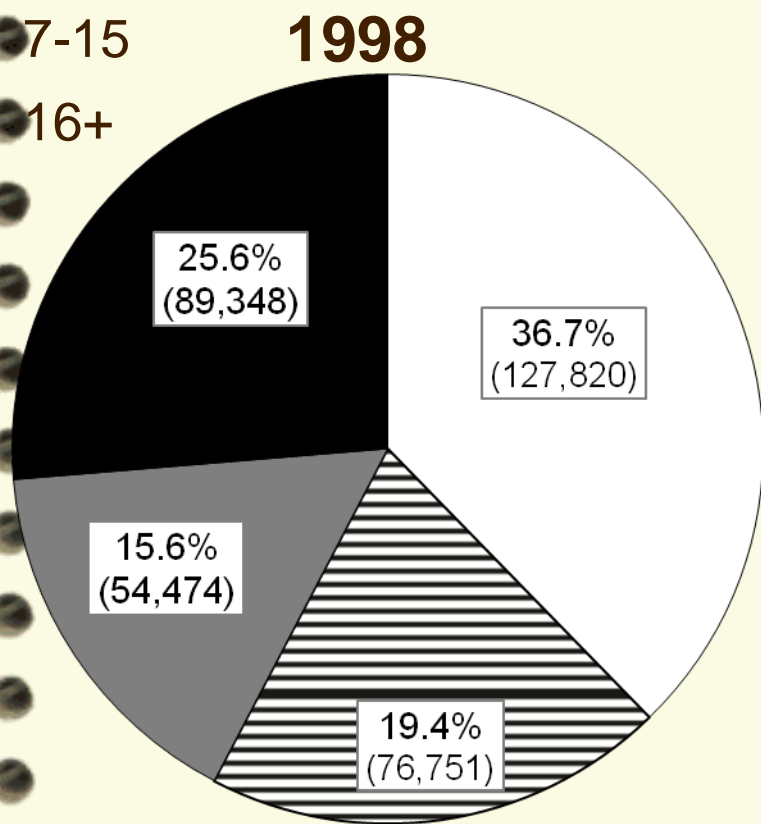


## Number of People in Institutional and Community Homes (DD)

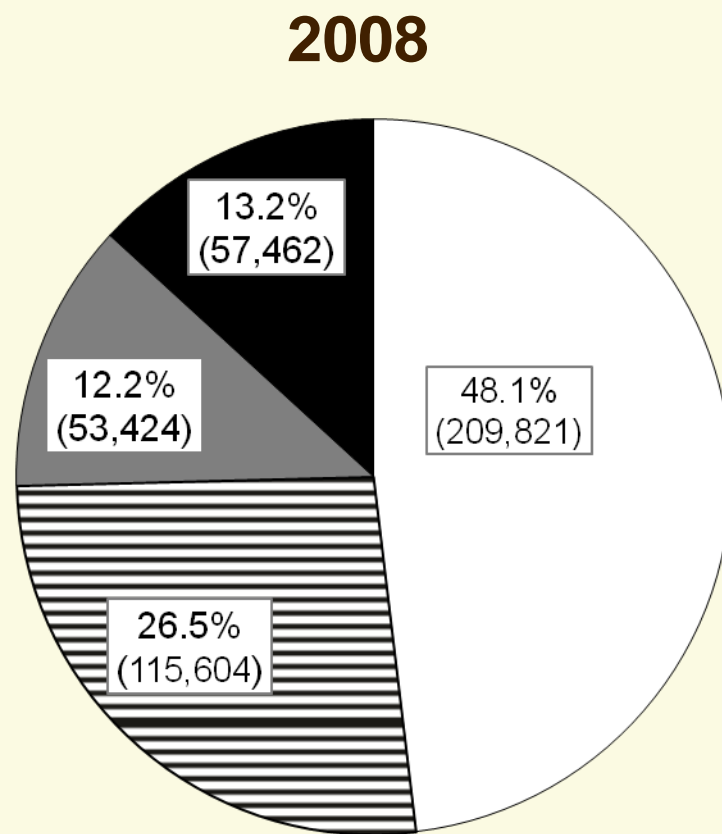


# We've Moved People Out of Institutions to the Community...But Not All

(NASDDDS & U of Minnesota)



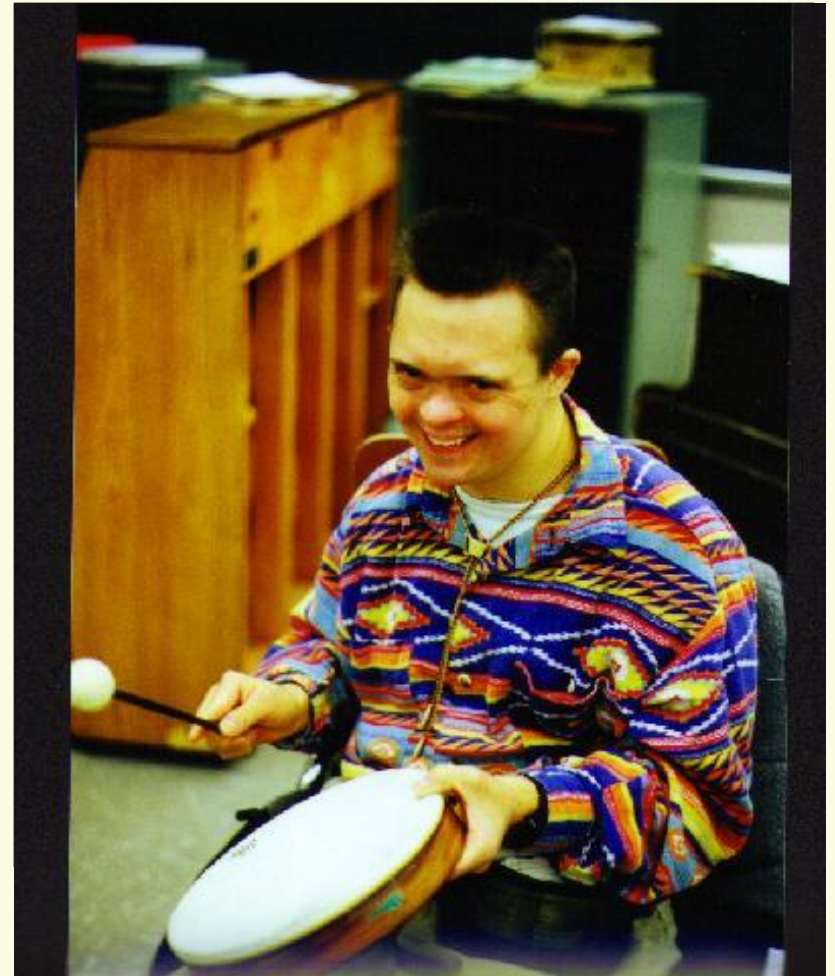
**1998**  
Total = 348,393



**2008**  
Total = 436,311

# For 100+ Years, What Did America Do With People Like Mike?

- Diagnose him
- Exclude him from school
- Tell his parents that he needed medical care
- That he could never learn and would bring no joy to the family
- That he needed to live in a large facility

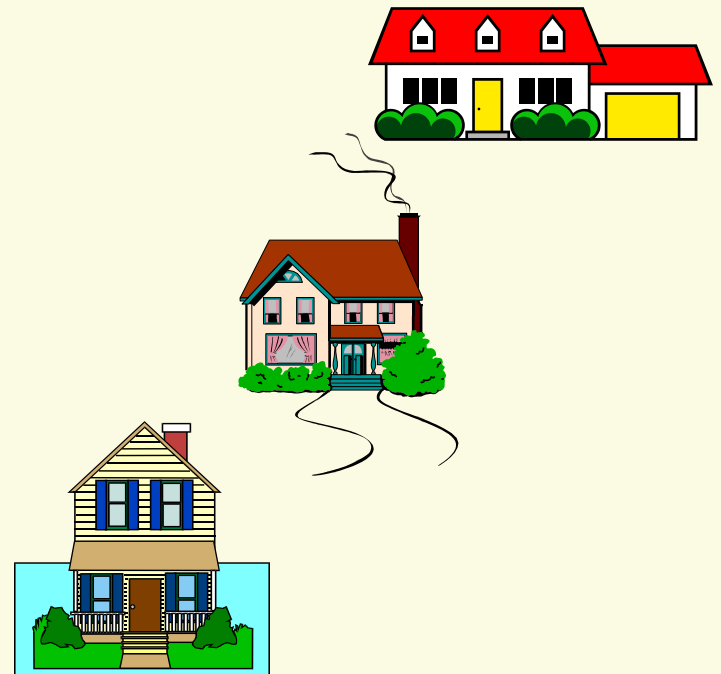


# Movement from Institution to Community

From large, segregated,  
historically state of the  
art settings



To small, integrated,  
more recent models of  
what a “home” means



# Very Big – Versus Small

## “Institution versus Community”

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# Why Did Parents Do This?

- Because professionals told them to
- Primarily doctors
- Doctors had authority
- Knew “what’s best”
- With the best intentions



# Source of The Institutional Model

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- 📄 Brought to the U.S. in 1848
- 📄 By Samuel Gridley Howe
- 📄 From a “model program” in Germany
- 📄 The vision was a self-sufficient agrarian community
- 📄 Free from pressures of normal life
- 📄 Protected, safe, healthy




# Acceptance of the Institutional Model

- First publicly funded facilities ---
- 1848 Fernald Center, Massachusetts
- 1849 Dorothea Dix Center, North Carolina
- 1849 California Prison Ship, San Francisco Bay – 30 inmates – Stockton 1851




# By 1866, Samuel Gridley Howe Said This:


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-  "Grave errors were incorporated into the very organic principles of our institutions ...
-  which make them already too much like asylums;
-  which threaten to cause real asylums to grow out of them, and to engender other evils.

## And This (In 1866!):

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 “... all such institutions are unnatural, undesirable, and very liable to abuse.


 We should have as few of them as is possible, and those few should be kept as small as possible.”


 Such persons [with disabilities] ... should be kept diffused among sound and normal persons.

# We Did Not Stop There

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 We adopted and spread the “eugenics scare” period of human history

 1880-1920

 America decided “These people are inferior”

 They cannot be permitted to breed

 They should be isolated from society for that and other reasons

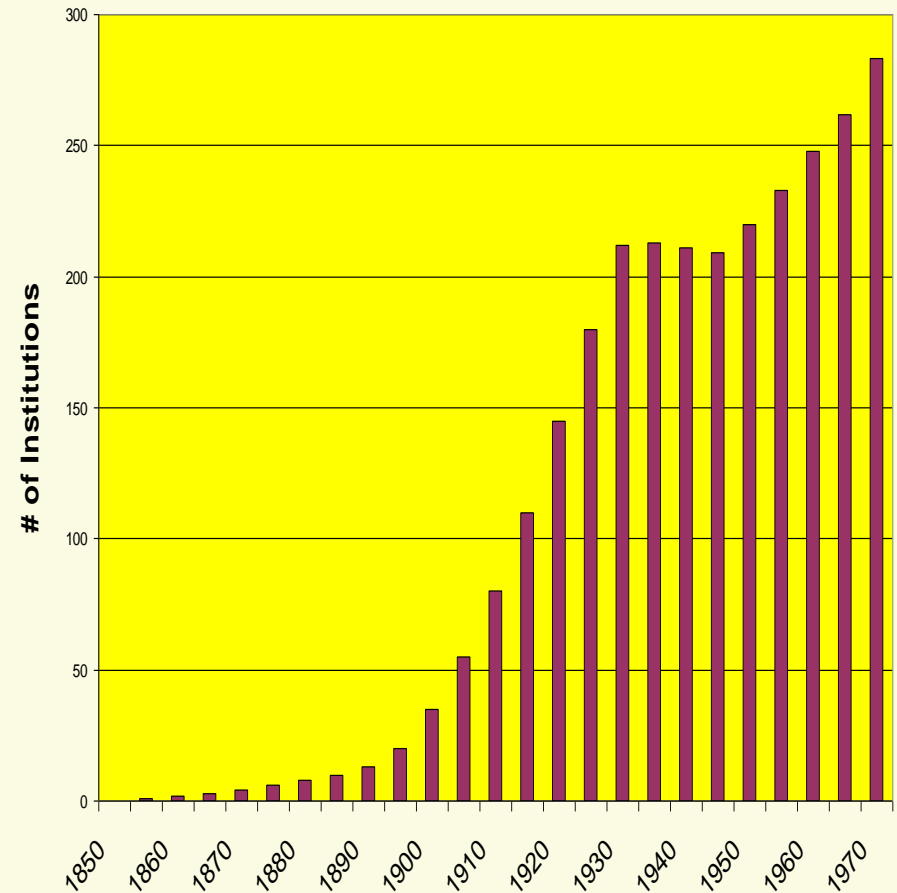
# America's Sad History in the Disability Field

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- 📄 America's great judge, Oliver Wendell Holmes, was the source of many of these ideas
- 📄 As we all know, the writings of Holmes were later used extensively by the Nazis
- 📄 At this time in U.S. history, the facilities were named things like "Pennhurst Home for the Segregation of the Feeble Minded and Epileptic"

# How Did America Respond to the Advice of its Greatest Expert?

- Quick!
- Build more!
- Make them bigger!
- Diagnose more people!
- Keep the facilities full!
- We need more staff!
- We need higher pay!
- WE STILL NEED MORE STAFF!



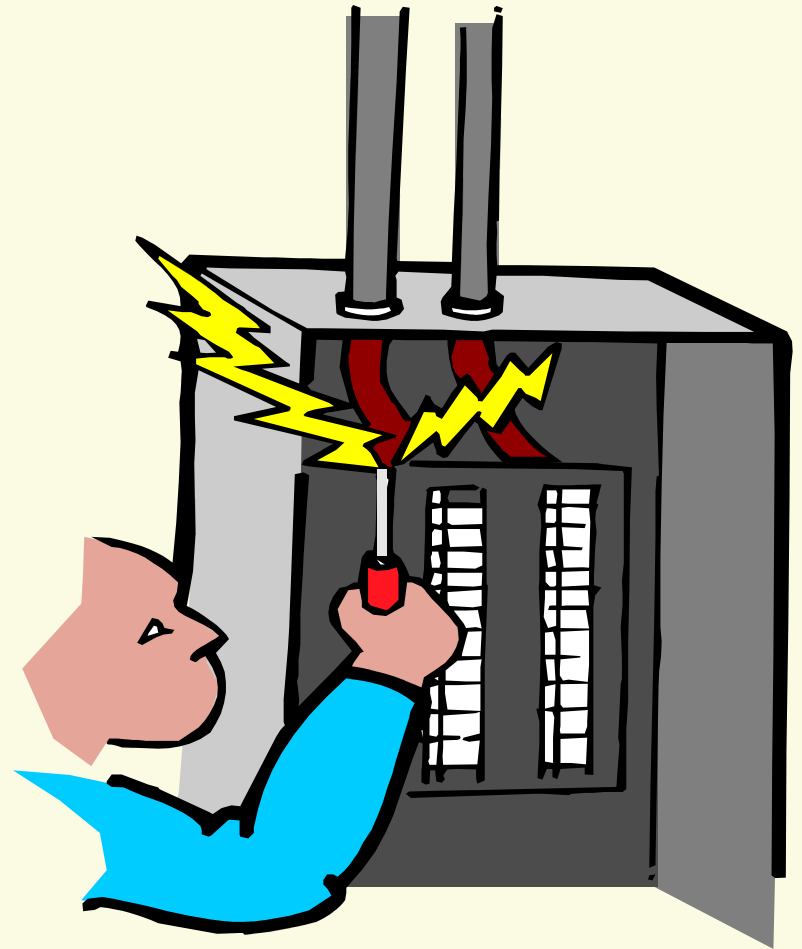
# In Idiomatic Slang, We Say, “This Is Where I Came In”

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- 📄 A personal note
- 📄 1970, just out of University
- 📄 No idea what to do with a degree in Physiological Psychology
- 📄 Got a strange job by pure chance
- 📄 Working on a national survey of people with “developmental disabilities”
- 📄 Right at the national peak of institutions

# Went to Collect Scientific Data

- At an institution named “Pennhurst State School and Hospital”
- Located near Valley Forge, the cradle of American liberty
- I was shocked



# Pennhurst: Poor Conditions

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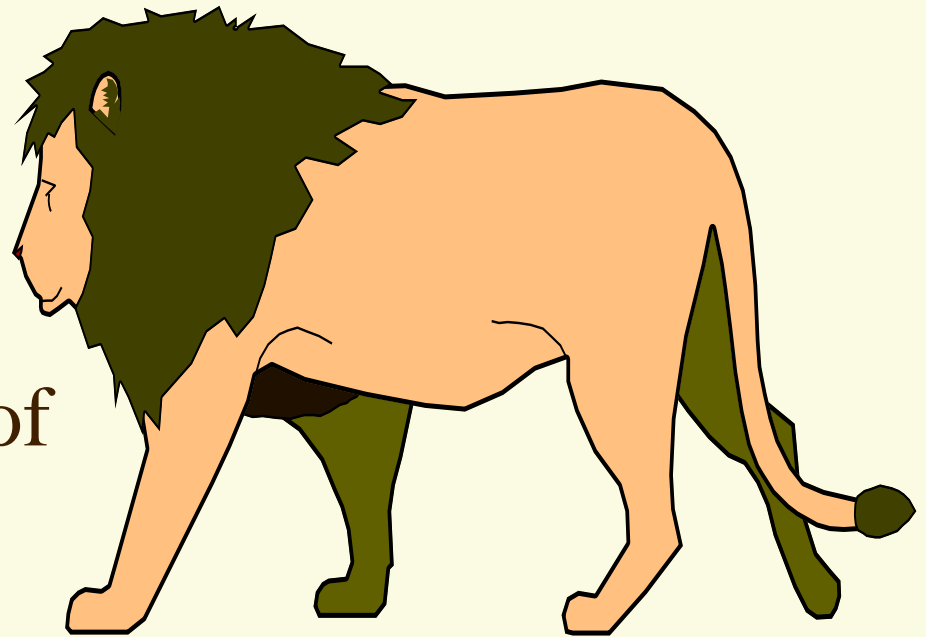
- 📄 2800 people lived there
- 📄 It was designed for 700
- 📄 People were left in cribs all day and night
- 📄 Broken bones went untreated
- 📄 “Problem” people had all teeth pulled
- 📄 “Bathing” was often a hose sprayed at a group in a room with a floor drain
- 📄 **Why treat human beings this way?**

# I Found This Out:

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📄 The average cost per person at Pennhurst was \$5.90 per day


📄 The average cost of keeping a lion at the Philadelphia zoo was \$7.15 per day




# I Believed Then That We Should Improve the Institution

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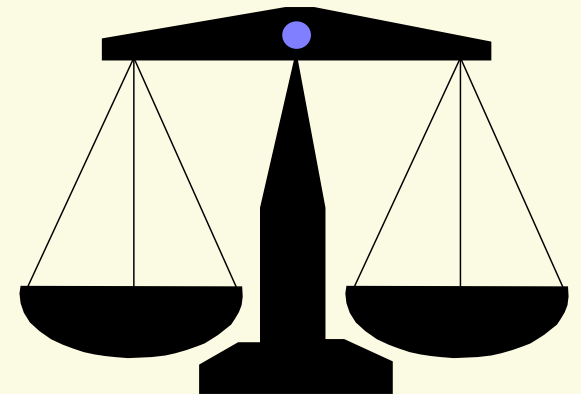
 Spent 12 years working on this

 We worked in a model institution, built in 1972, not overcrowded, and with access to huge resources in money and University faculty and students

 I was able to show scientifically that tremendous resources did result in minor skill development and small improvements in qualities of life

# But We Got A Big Surprise

- 📄 In the midst of America's efforts to create “good” institutions
- 📄 A U.S. Federal Court declared Pennhurst to be **“Unconstitutional by its very nature”**
- 📄 Because it was specifically and consciously designed to segregate
- 📄 And because the people
  - had lost skills (they
  - had been harmed)



# Judge Ordered All People Should Have a Chance to Live in Society

- ☞ I was a skeptic
- ☞ Deinstitutionalization in the mental illness field had been a disaster and a disgrace
- ☞ I thought this would be, too
- ☞ So I wanted to do research on this




# The Pennhurst Longitudinal Study

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 Began in 1979

 Largest such study ever done

 Tracked 1,154 people

 Visited every person every year

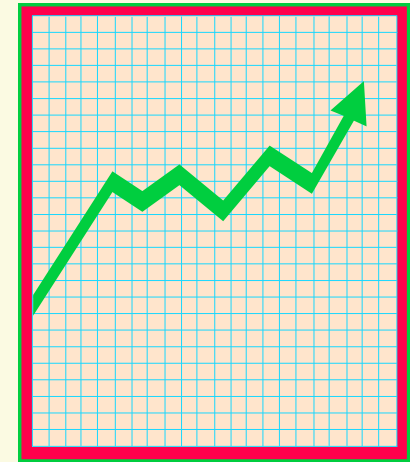
 Surveyed every family every year

 Measured qualities of life and satisfaction  
and costs

 (This process still continues in 2007)

# Purposes of Pennhurst Longitudinal Study

- Track 1,154 people
- Are these people better off?**
- In what way(s)?
- How much?
- At what cost?
- What problems and deficiencies can be detected and addressed?



# Aspects of Quality of Life

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- power to make one's own life choices (self determination)
- skill development
- emotional adjustment
- challenging behavior
- attitudes and experience of caregivers
- health
- use of medications
- earnings
- hours per week of productive activity

- relationships
- family contacts
- financial interest in the home
- satisfaction
- individual wishes, and ambitions
- home environment
- family/next friend opinions and satisfaction
- integration
- individual planning process

# What Kind of People?

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📄 Average age 39 years  
at the beginning of the  
study

📄 Had lived at Pennhurst  
an average of 24 years

📄 64% male

📄 33% had seizures

📄 13% blind

📄 4% deaf

📄 18% unable to walk

📄 50% nonverbal

📄 47% less than fully  
toilet trained

📄 40% reported to be  
violent at times

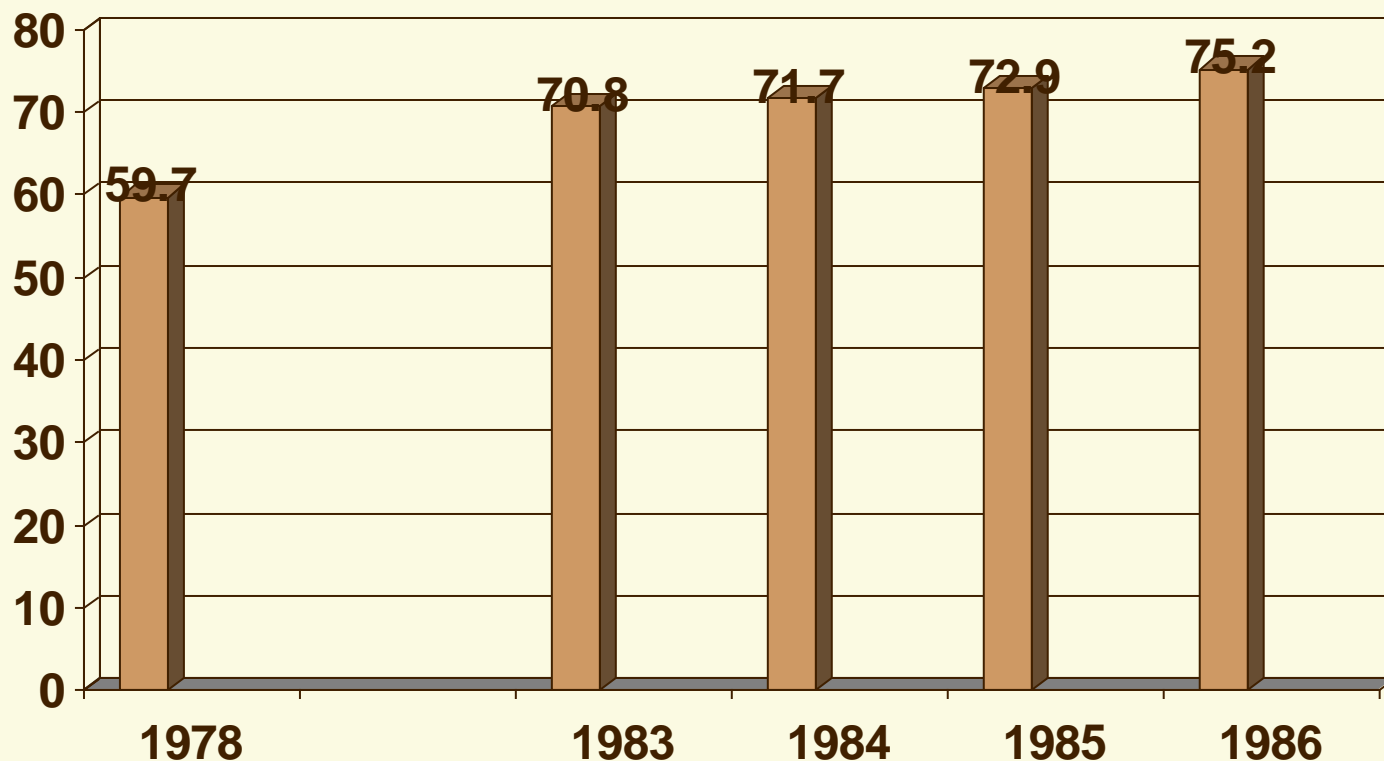
📄 **86% “severe or  
profound”**

# What Kind of Community Homes?

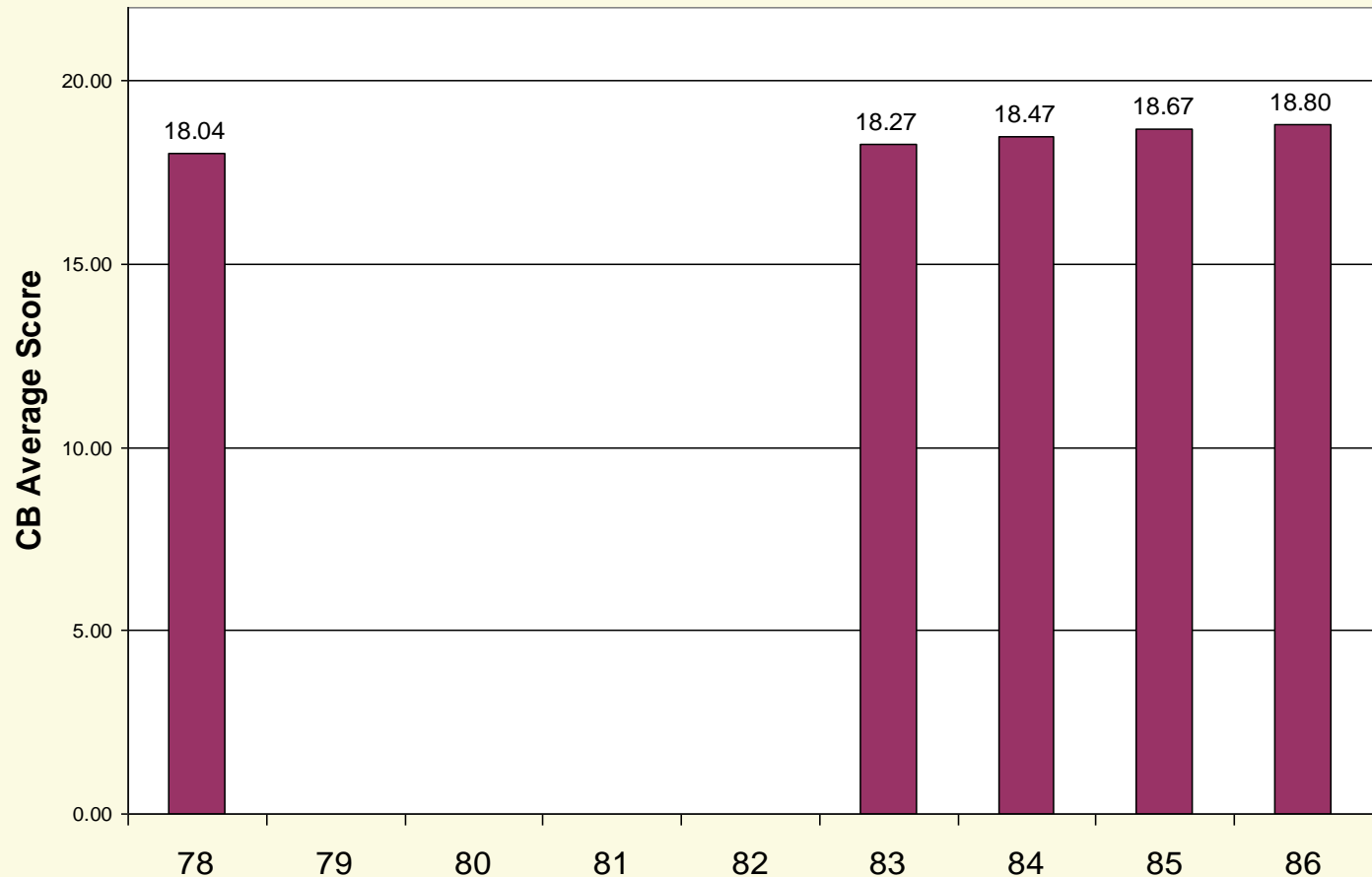
- ☞ “Community Living Arrangements
- ☞ 3 people
- ☞ Some with live-in staff
- ☞ Most with shift staff
- ☞ 24 hour staffing
- ☞ With licensing, monitoring, and case management oversight



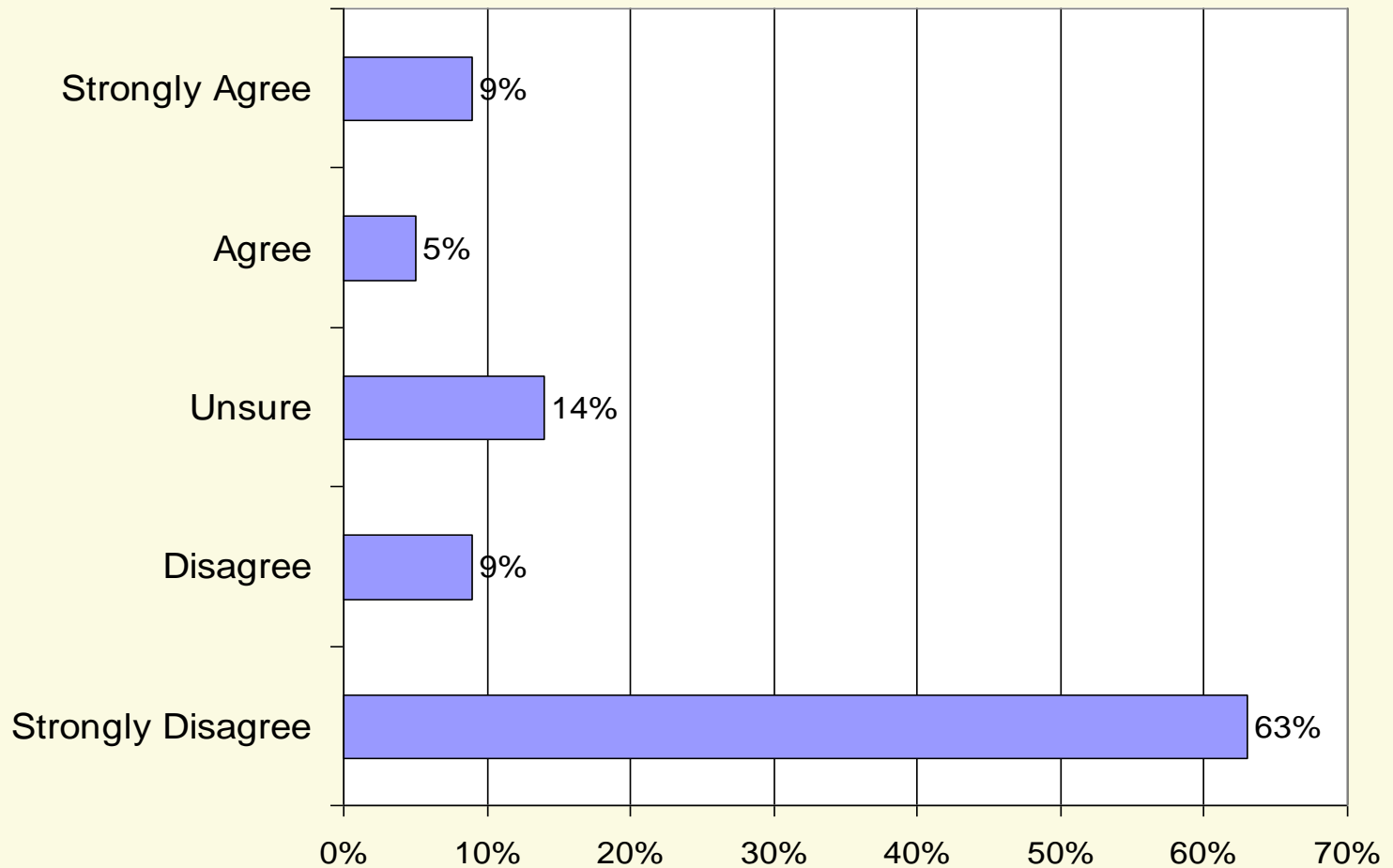
# Pennhurst Class Members: Adaptive Behavior Development



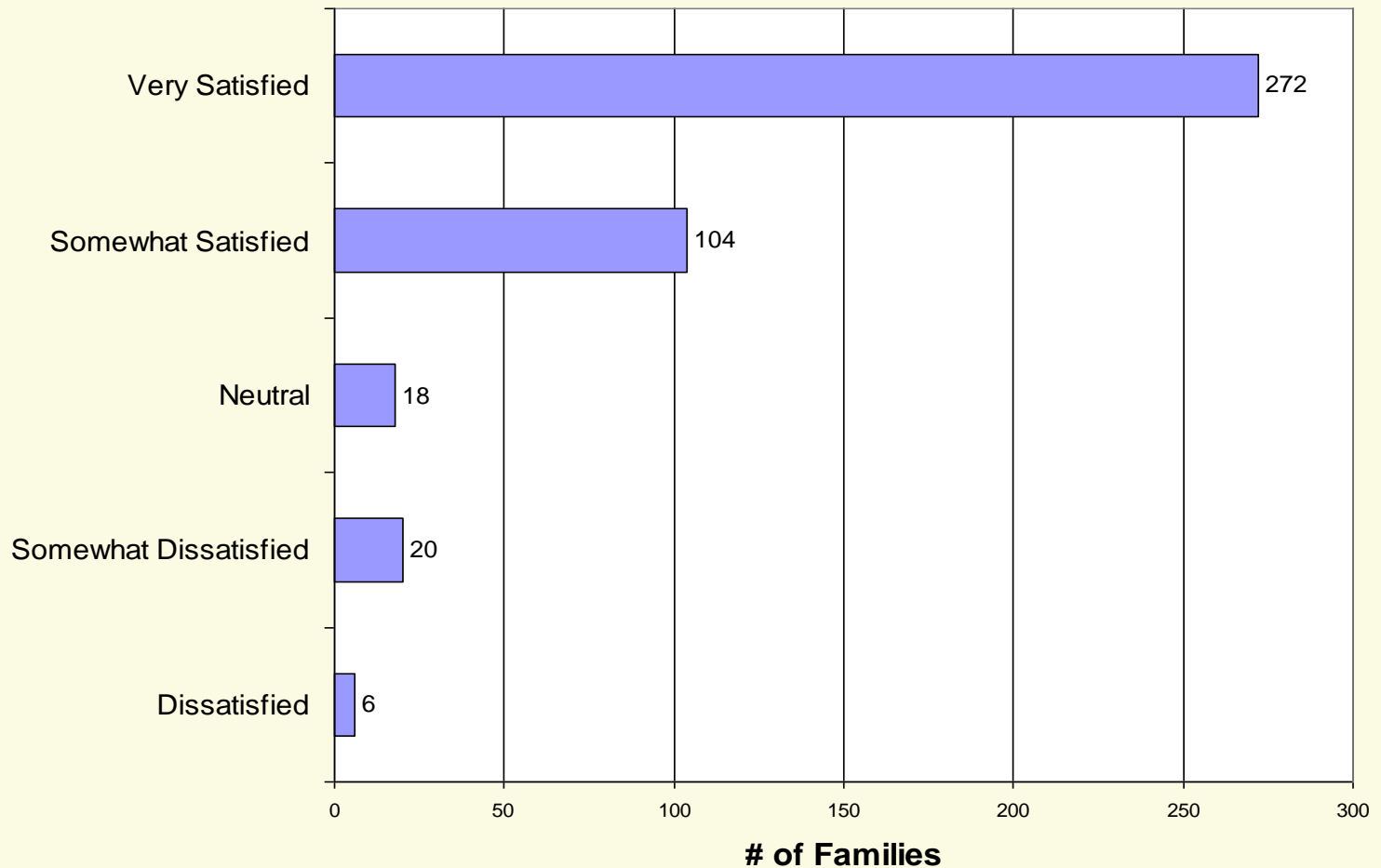
# Pennhurst Class Members: Improved Self-Control of Challenging Behavior



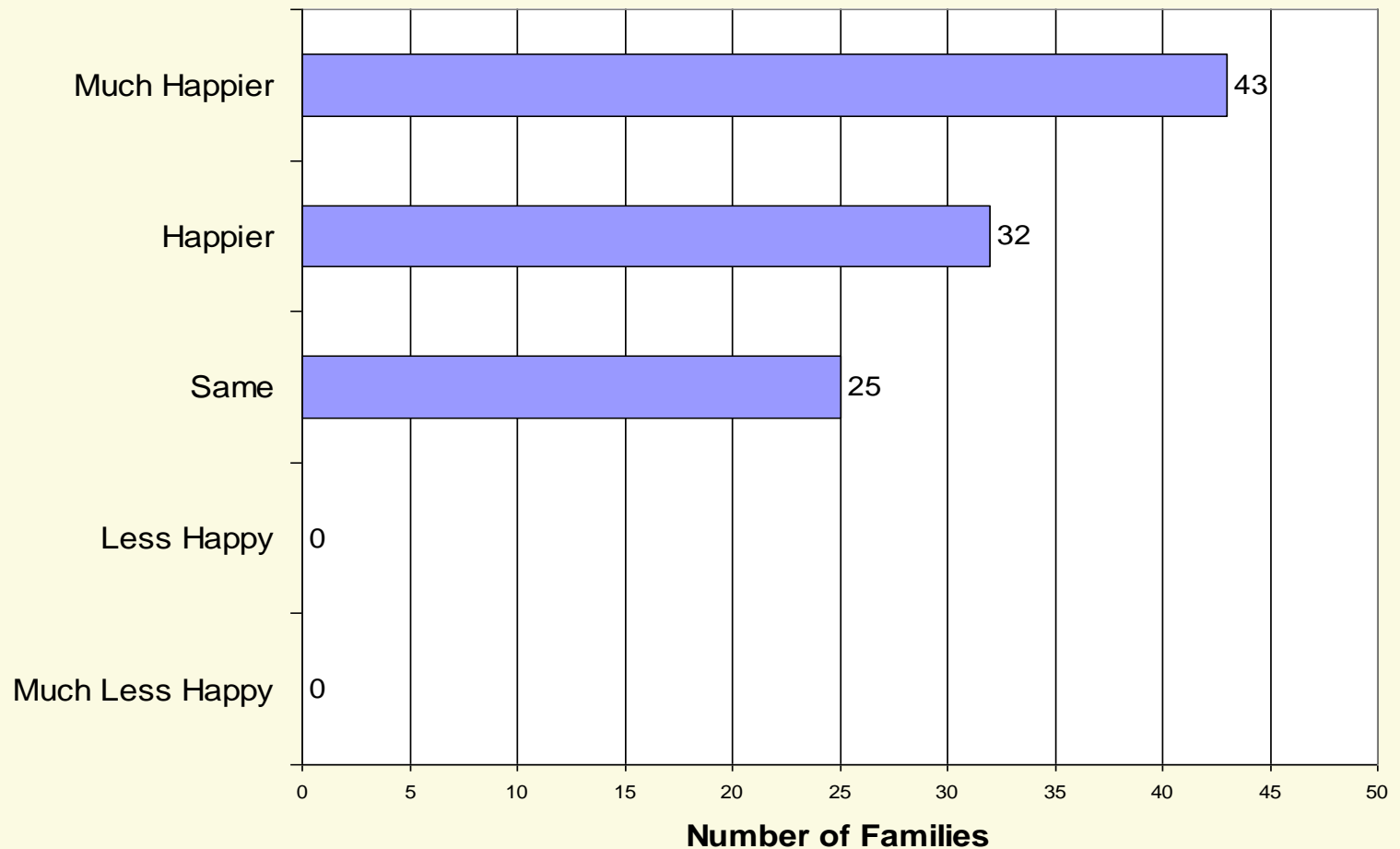
# Pennhurst: Strong Initial Family Resistance to Community Idea



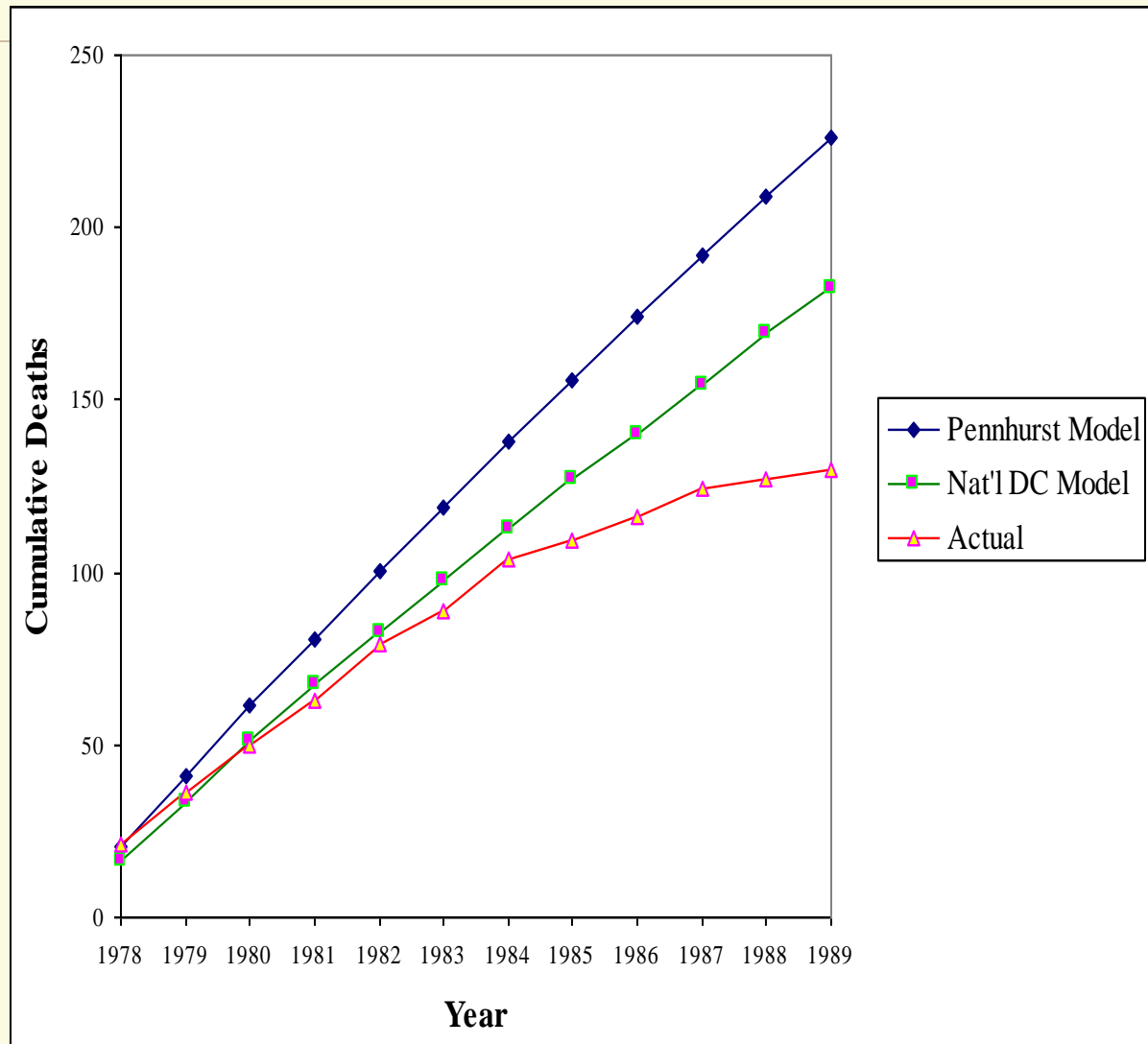
# Pennhurst: 1991 Community Family Satisfaction



# Different Question: Has Your Relative's General Happiness Changed Since Moving?"

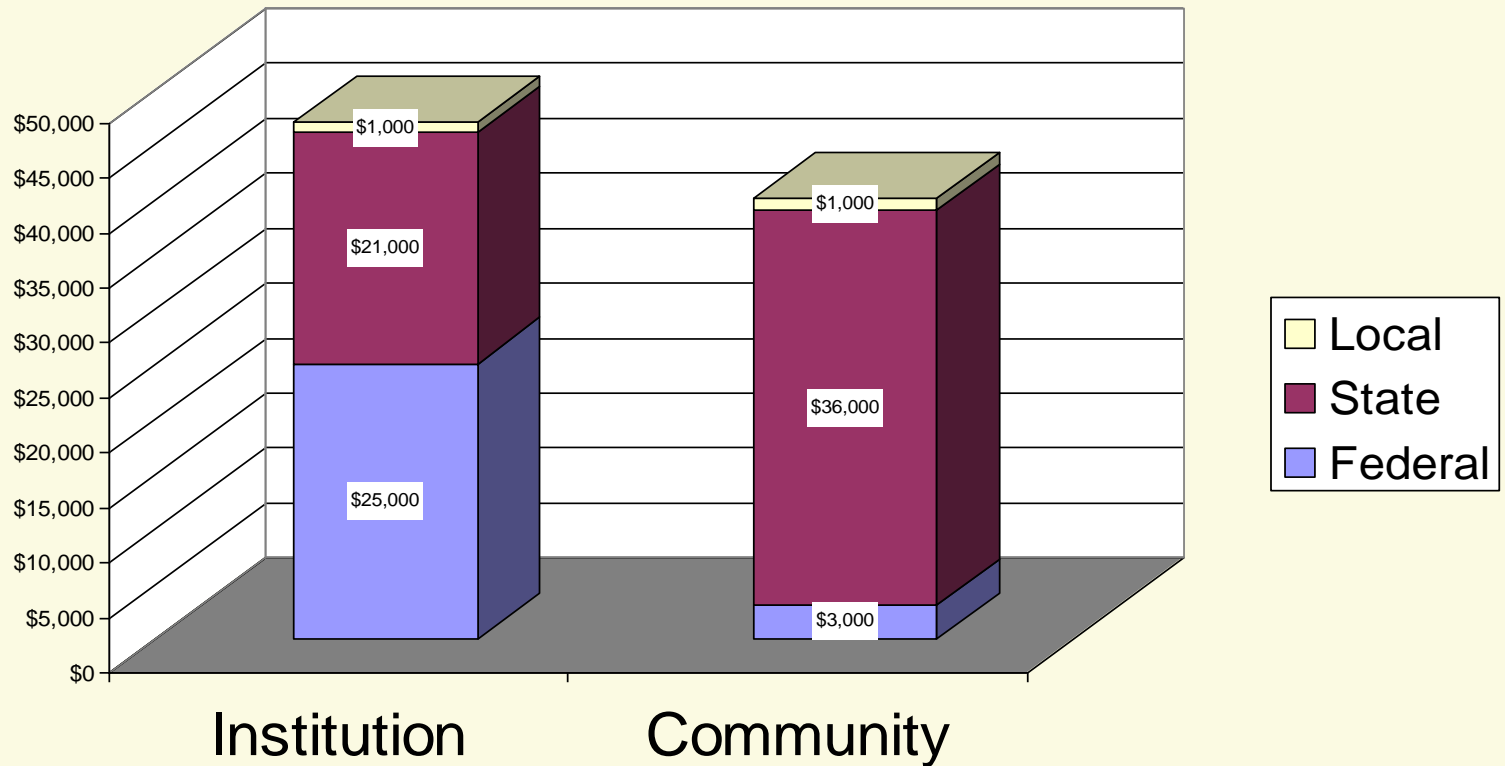


# Pennhurst Mortality



# Pennhurst Costs Study, 1982

## Pennhurst Longitudinal Study: Who Pays?



# Pennhurst Results: Were People Better Off?

Independence	Yes, 14% gain
Challenging Behavior	Yes, 8% improvement
Health	No change in general health, longevity increased
Integration	Large increases in outings and friendships
Choicemaking	Increased opportunities to make choices

# Pennhurst Results: Were People Better Off?

Consumer Satisfaction	Those who could communicate with us were much happier in every way, would never want to go back
Family Satisfaction	Families initially opposed the move, changed their minds; overwhelmingly in favor; and very surprised

# Pennhurst Results: Were People Better Off?

Qualities of Environments:	
Physical Quality	Yes, scores increased from 76 to 86 (12% increase)
Normalization	Yes, scores increased from -232 to +172
Individualization	Yes, scores increased from 58 to 65 (12% increase)

# Pennhurst Results: Were People Better Off?

Productivity	Increased day program hours, employment, earnings, household chores
Services	Increased teaching time
Services	Increased Case Manager contacts
Services	Increased therapies
Costs	Down from \$47,000 to \$40,000 (about 15%)

# The Pennhurst Longitudinal Study: 1154 People, 20 Years

<b>INDEPENDENCE</b>	Increased 14 scale points (100)
<b>SOCIAL BEHAVIOR</b>	Improved 8 scale points (100)
<b>SELF-DETERMINATION</b>	Increased Choice making
<b>PRODUCTIVITY</b>	Increased: Day program hours, Employment, Earnings, Household chores
<b>INTEGRATION</b>	Increased Outings, Friendships
<b>COMMUNITY ATTITUDES</b>	More positive: Neighbors, General Public, Media
<b>CONSUMER SATISFACTION</b>	Much happier (those able): In every area; never want to go back
<b>FAMILY SATISFACTION</b>	Radical, dramatic shift from anti to pro: Perceived improvements in <u>every</u> area
<b>QUALITIES OF ENVIRONMENTS</b>	Enhanced: Physical quality, Individualization, Normalization
<b>SERVICE DELIVERY PROCESS</b>	Increased services: More teaching/training, More therapies, Higher goal attainment, More Case Manager contact, More consumer involvement, Enhanced planning process, Increased monitoring
<b>CASE STUDIES</b>	Illustrated the outcomes
<b>COSTS</b>	Decreased by 26% (Matched comparison)

# Did the Pennhurst Results Meet the Scientific Test of Replication?

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- ☞ Yes, 1356 people in Connecticut
- ☞ Yes, 1000 people in Oklahoma
- ☞ Yes, 400 people in New Hampshire
- ☞ Yes, 1100 people in North Carolina
- ☞ Yes, 200 people in Kansas
- ☞ Yes, 400 people in Illinois
- ☞ Yes, 2400 people in California

# Now We Have Followed More Than 7,000 People

- As they moved out of institutions
- Into regular homes in communities
- Other researchers have gotten the same results
- Australia, Canada, England, New Zealand, France, Sweden, etc.

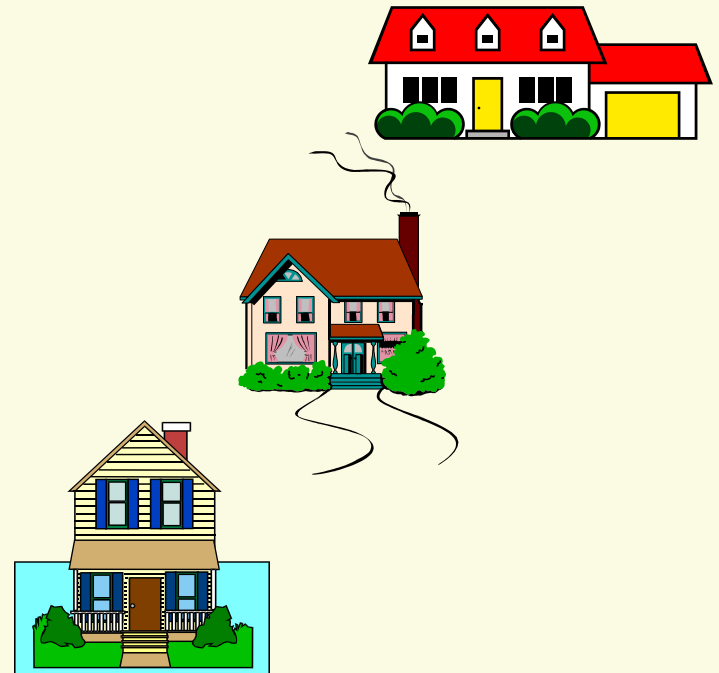


# Movement from Institution to Community

From large, segregated,  
historically state of the  
art settings



To small, integrated,  
more recent models of  
what a “home” means

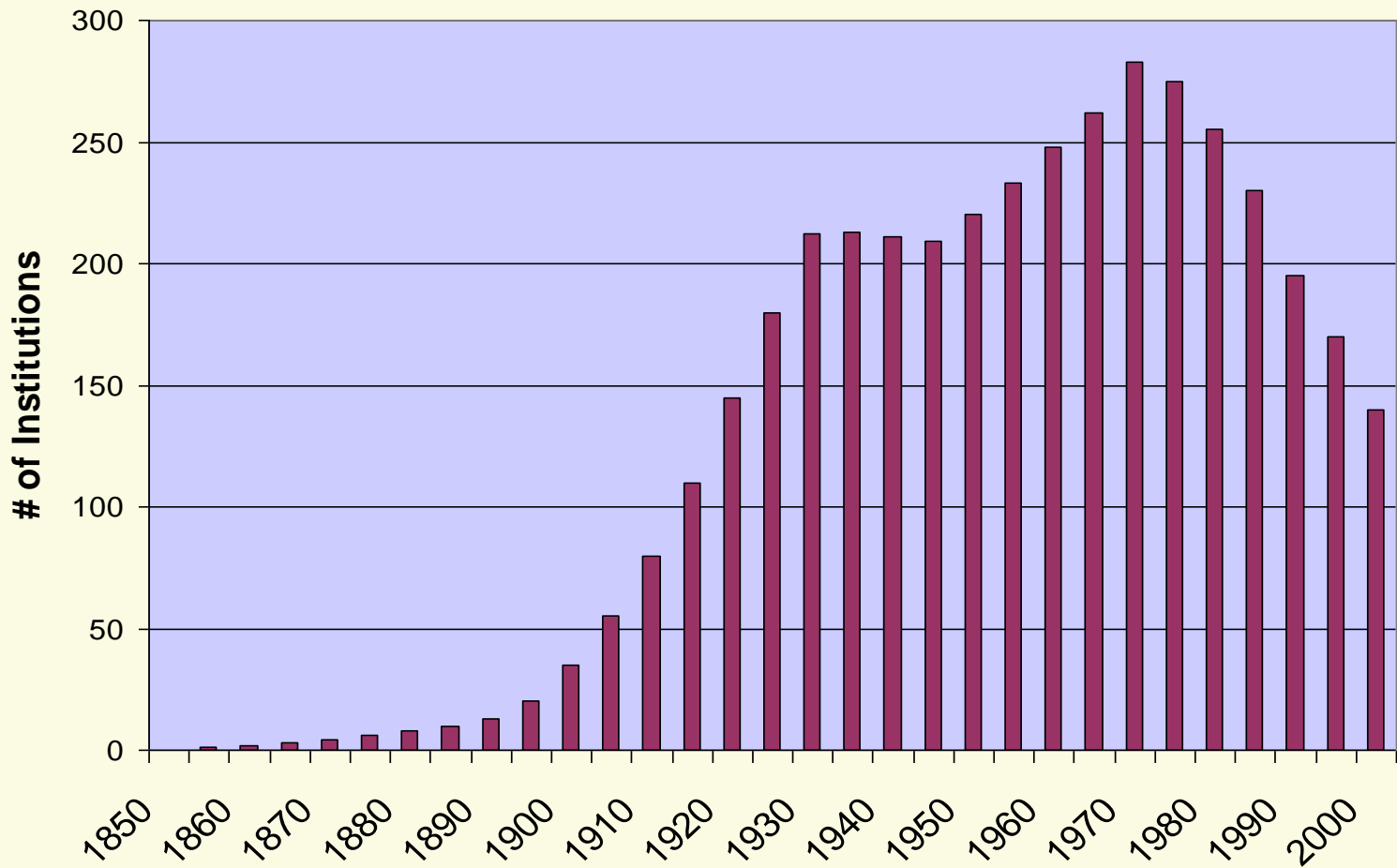


# Lessons Learned

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- 📄 Probably a mistake to create “group homes”
- 📄 They are congregate care too
- 📄 They tend to keep unnecessary restrictions on peoples’ freedom
- 📄 Probably better to move directly to supportive foster care and supported living models
- 📄 Designed around each individual

# Number of Public Institutions in the U.S., 1850-2000



# Good or Bad?

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 Probably the most successful  
“social experiment” in  
America this century

# Theory: Is Big Always Bad?


BIG=BAD?

?

small=good?

?

- ❏ No
- ❏ Nor is small always good
- ❏ But consider the **Zimbardo prisons experiment** (power, control, and abuse)
- ❏ Plus the **Milgram experiment** (authority, followers)
- ❏ And **DIS-economies of scale**
- ❏ What kind of setting is MOST prone to abuse of power and authority?
- ❏ It's the larger ones....
- ❏ And they cost the most too.....
- ❏ Where is Gentle Teaching easiest and hardest to implement?

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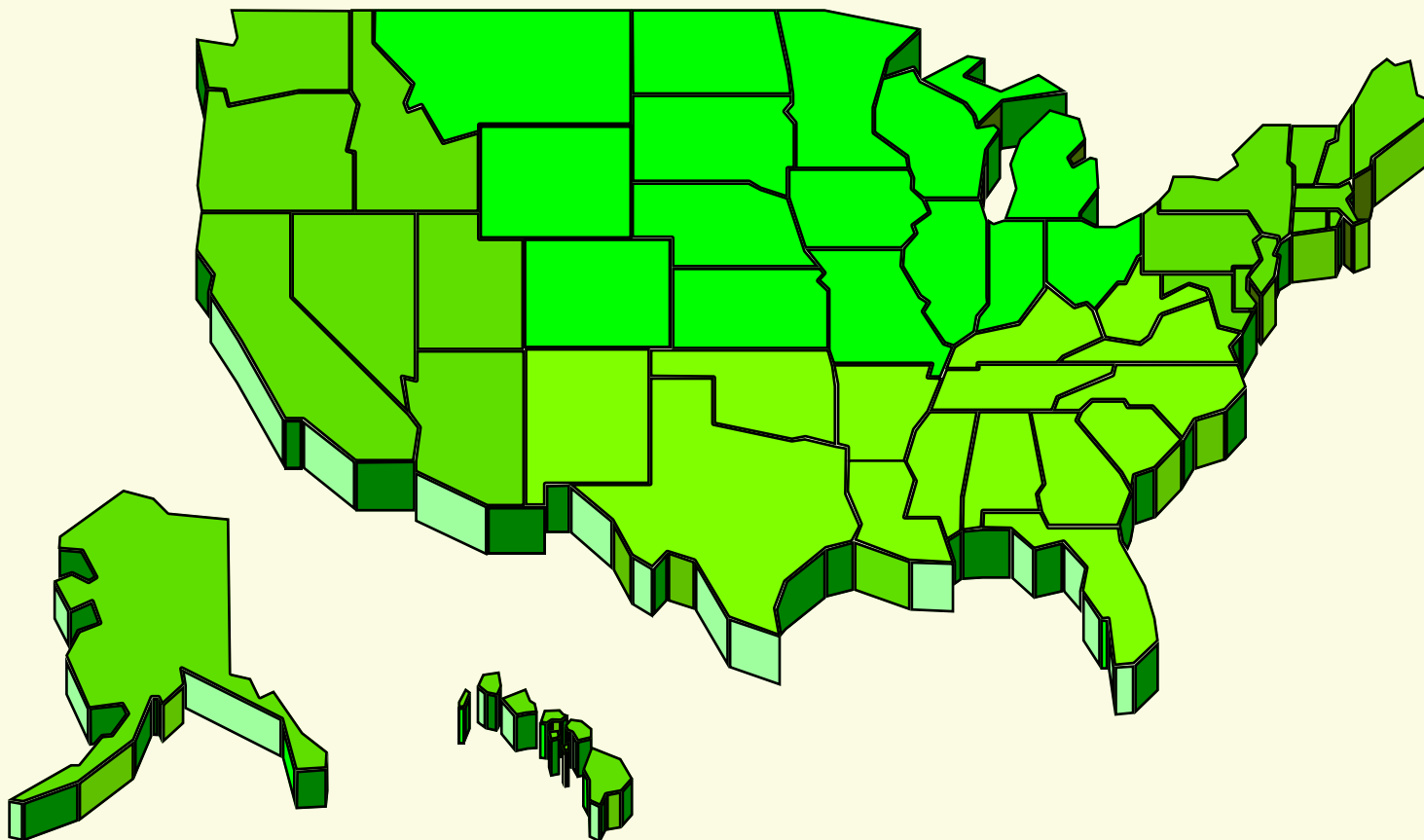
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“You can always count on  
Americans to do the right  
thing - after they've tried  
everything else.”

Winston Churchill

# The End

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The scientific, reliable measurement of individual outcomes.

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An outcome is an observable change in one of a person's many qualities of life.



**Process  
measures,  
standards,  
paper**

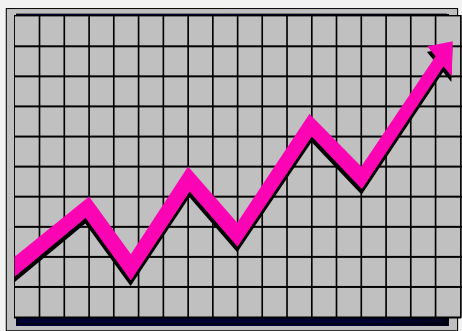
There is absolutely no substitute for measuring each person's qualities of life.

**Individual well-being (including self determination) is the ultimate unit of accountability for service systems.**

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**Collecting and utilizing individual outcome information is far less costly, and far more valuable, than most people would suspect.**

**Advances in information technology have made person-centered monitoring and quality assurance feasible.**



# The Scientific Outcomes

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- 1977 first published article: a warning
- Tracked more than 7,000 individuals
- As they moved out of institutions
- And measured qualities of life for more than 40,000 other people in all kinds of homes
- Completed studies in 12 states
- The results have been consistent

# Historical Significance

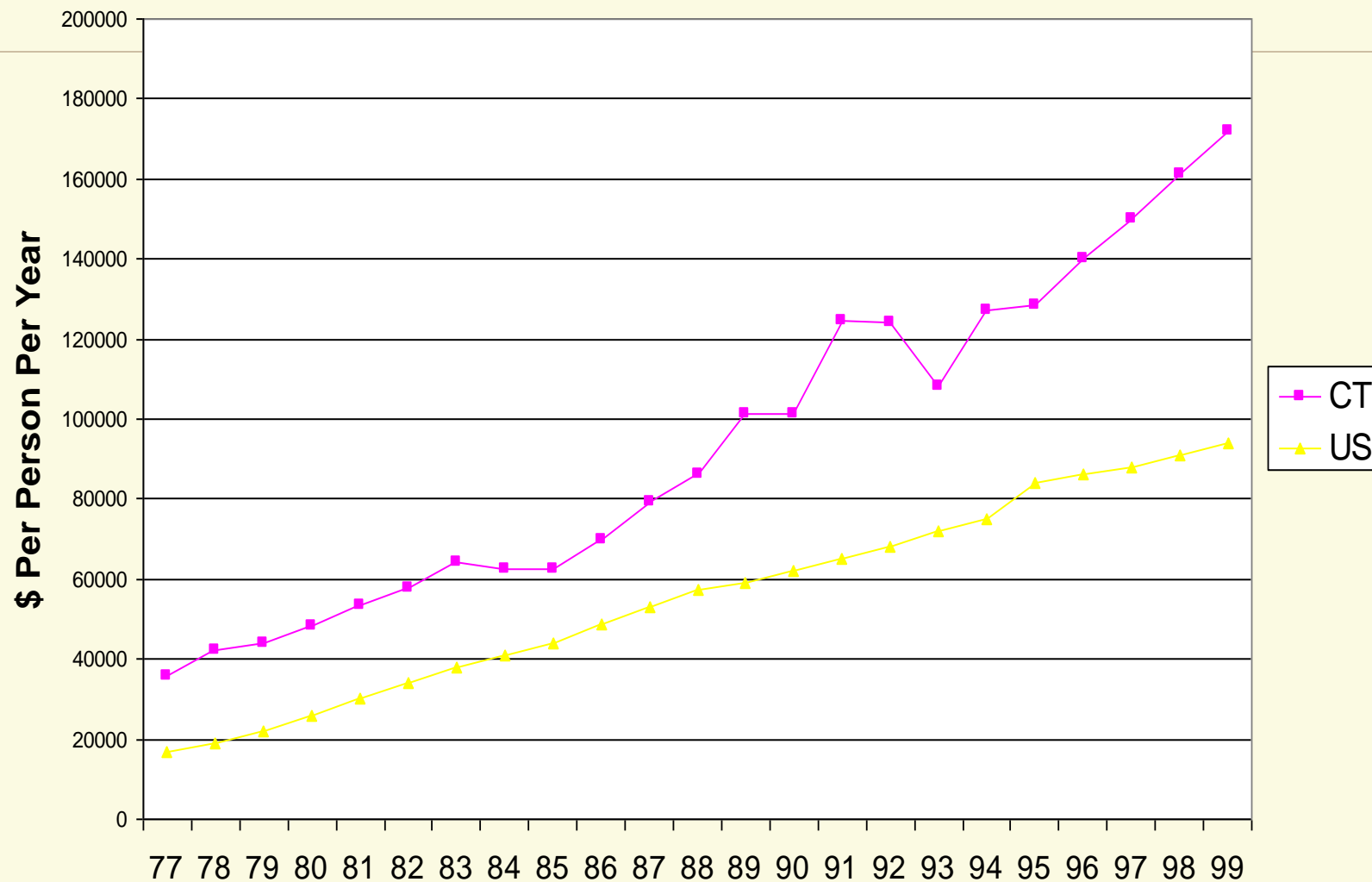
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 Over 900 people moved to community

 Connecticut joined the company of:

- PA, Pennhurst, 1100
- Michigan, Plymouth, 800
- New Hampshire, Laconia, 600
- New York, Willowbrook, 2000

## Growth of Costs of Public Institutions, CT and US



# Example: Integration, Outings

## Integrative Activities During the Past Month

Copyright © James W. Conroy, 1997

ABOUT HOW MANY TIMES did this person do each of the following in the PAST MONTH? ONLY COUNT ACTIVITIES WHEN THE PERSON WAS IN THE PRESENCE OF NON-DISABLED CITIZENS. (**Rough estimates are fine.** If the past month was not typical, ask about the average month during the past year. Write DK if "Don't Know.")

- |       |     |  |
|-------|-----|--|
| _____ | 1.  | Visit with close friends, relatives or neighbors                         |
| _____ | 2.  | Visit a grocery store  |
| _____ | 3.  | Go to a restaurant   |
| _____ | 4.  | Go to church or synagogue  |
| _____ | 5.  | Go to a shopping center, mall or other retail store to shop              |
| _____ | 6.  | Go to bars, taverns, etc.  |
| _____ | 7.  | Go to a bank   |
| _____ | 8.  | Go to a movie  |
| _____ | 9.  | Go to a park or playground   |
| _____ | 10. | Go to a theater or cultural event (including local school & club events) |
| _____ | 11. | Go to a post office  |
| _____ | 12. | Go to a library  |
| _____ | 13. | Go to a sports event   |
| _____ | 14. | Go to a health or exercise club, spa, or center                          |
| _____ | 15. | Use public transportation (May be marked "N/A")                          |
| _____ | 16. | Other kinds of "getting out" not listed above                            |

# How Modern Outcome Studies are Conducted: Data Collection (“Visits”)

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- Need access to the person, whoever knows the person best, records, home
- California 1997-98: 1,215 people, 83 minutes average
- Florida 1,500 people, 92 minutes
- Self-Determination, 120 minutes
- Once a year visits

# The Process of Visiting

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## General Instructions





This package is composed of many measures, scales, instruments, and interview items. Practically all of the information collected in this package is related to quality of life. In order to complete the package, you must have access to:

1. The person (to attempt a 5 to 15 minute direct interview)
2. The person's home (for a 5 to 10 minute tour and observation)
3. Whoever knows the individual best on a day to day basis (average 45 minutes)
4. The person's records, including medical records
5. In some cases, a health care professional (about 5-10 minutes)

With access to these five sources of information, you should in most cases be able to complete this package within the range of 60 to 90 minutes.

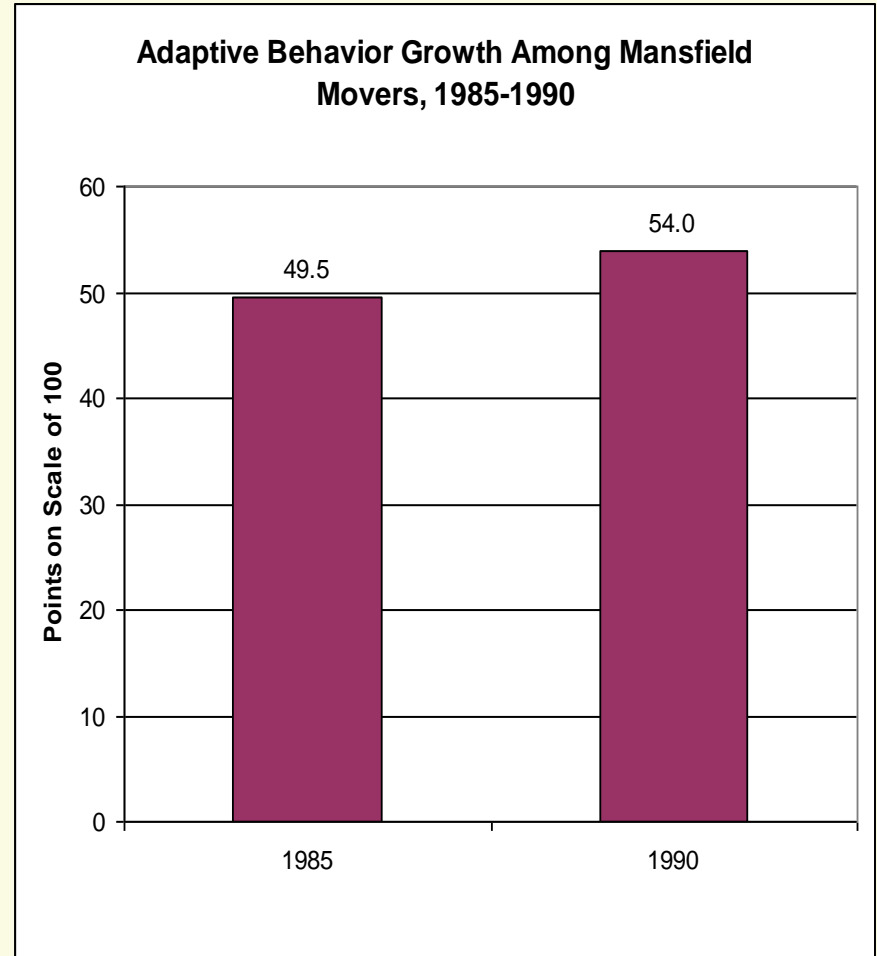
# The Mansfield Longitudinal Study: Three Research Designs

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-  Family Survey (memory and satisfaction)
-  Matched comparison
-  Pre-post
-  Also: External comparisons

# Adaptive Behavior Development

- Adaptive behavior development means growth toward more independent functioning
- Average score increased from 49.5 to 54.0 (statistically significant at  $p < .0001$ )
- People have become slightly less dependent



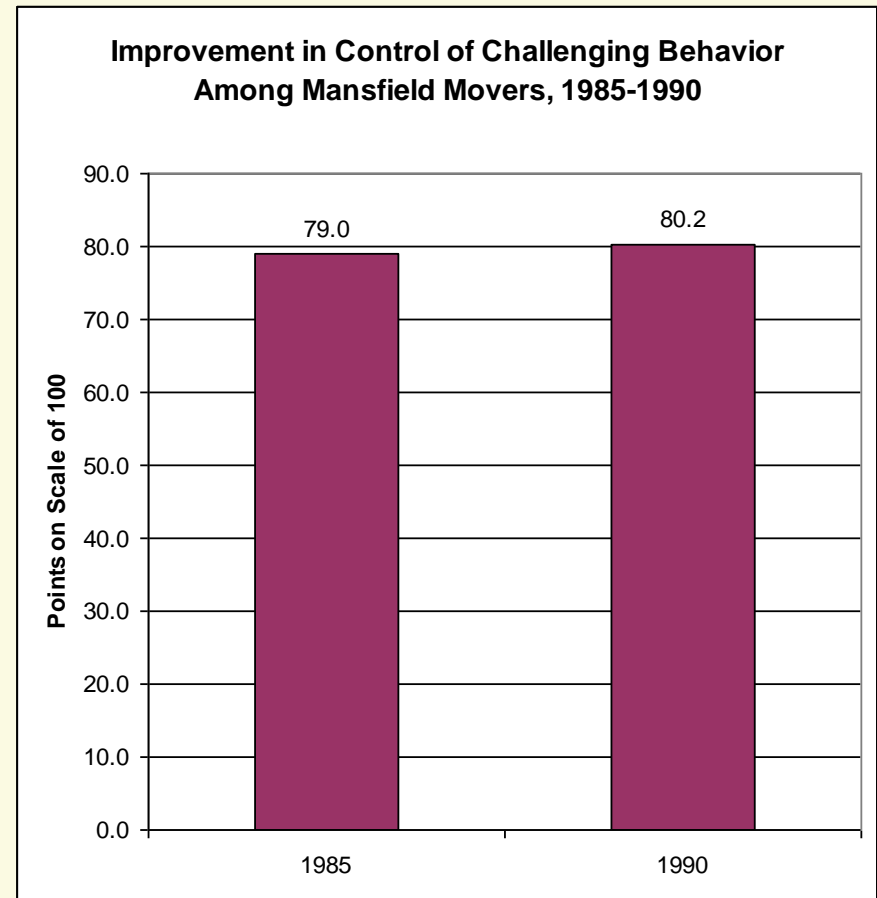
# CT Challenging Behavior

## Self-Control

Challenging behavior control means control by the individual, not by others

Average score increased from 79.0 to 80.2 (nearly but not quite statistically significant,  $p < .061$ )

People may have become slightly more able to control their behavior



# Services and Employment

Quality Dimension	Pre: DC	Post: Comm- unity	Signif.
Number of Services in Written Plan	8.2	8.4	NS
Day Program Hours	26	26	NS
Percent Involved in Supported Employment	1.4	17.8	.0001
Average Earnings Per Week	\$2.06	\$10.02	.001

# Environmental Qualities and Integration


<b>Environmental Qualities and Integration</b>	<b>Pre: DC</b>	<b>Post: Community</b>	<b>Signif.</b>
Physical Quality Scale	60.6	67.8	.0001
Individualized Practices Scale	5.3	16.5	.0001
Integrative Activities Scale	4.3	8.8	.0001

# Staff Indicators

Staff Indicators	Pre	Post	Signif.
Staff Like Job	8.6	9.1	.003
Staff Like Working With This Person	8.1	8.9	.0001
Progress Seen Toward Individual Goals, 5 Point Scale	3.7	4.3	.0001


# The Voices of the Class Members

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 We attempted to interview the person

 On every visit

 Regardless of level of disability

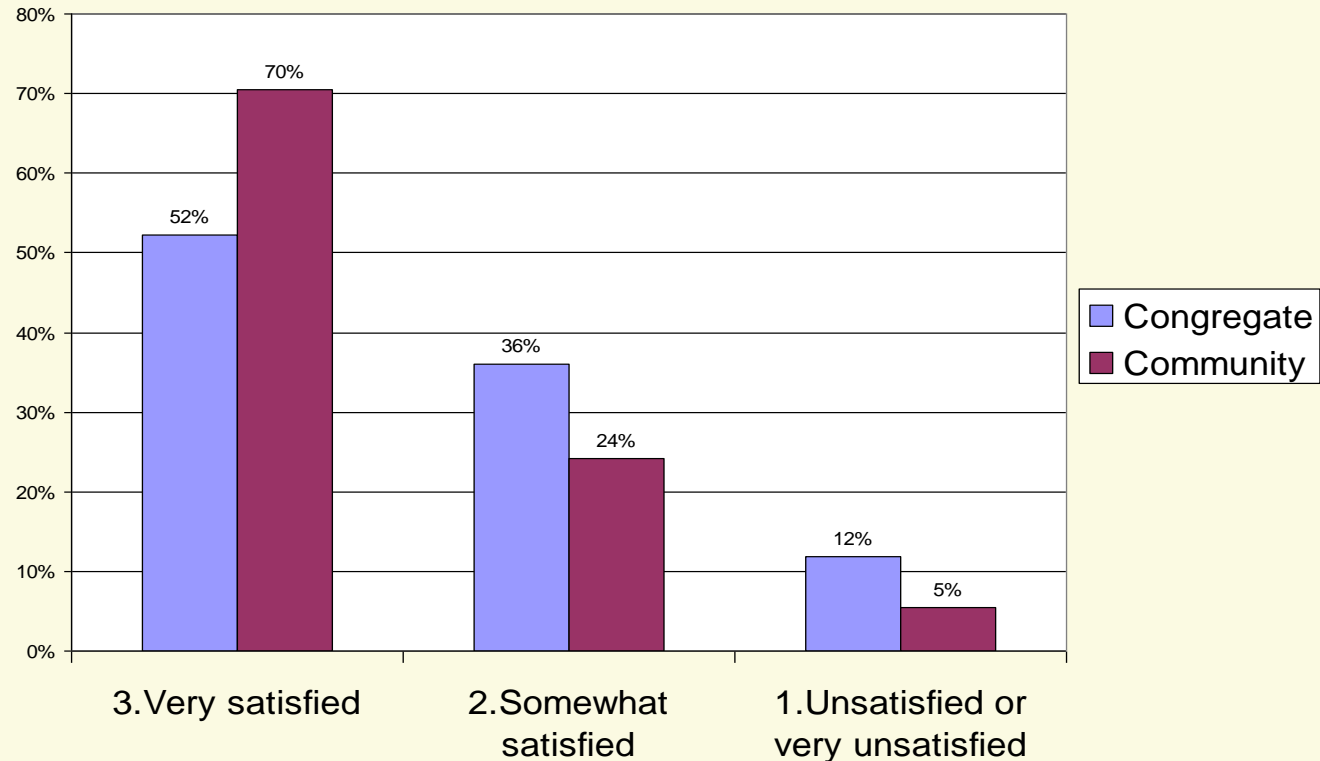
 Using any alternative means of communication available

– Language board, computer, signing, non-English, gestures

 Over 1,300 attempts; in this case, surrogate respondents were permitted

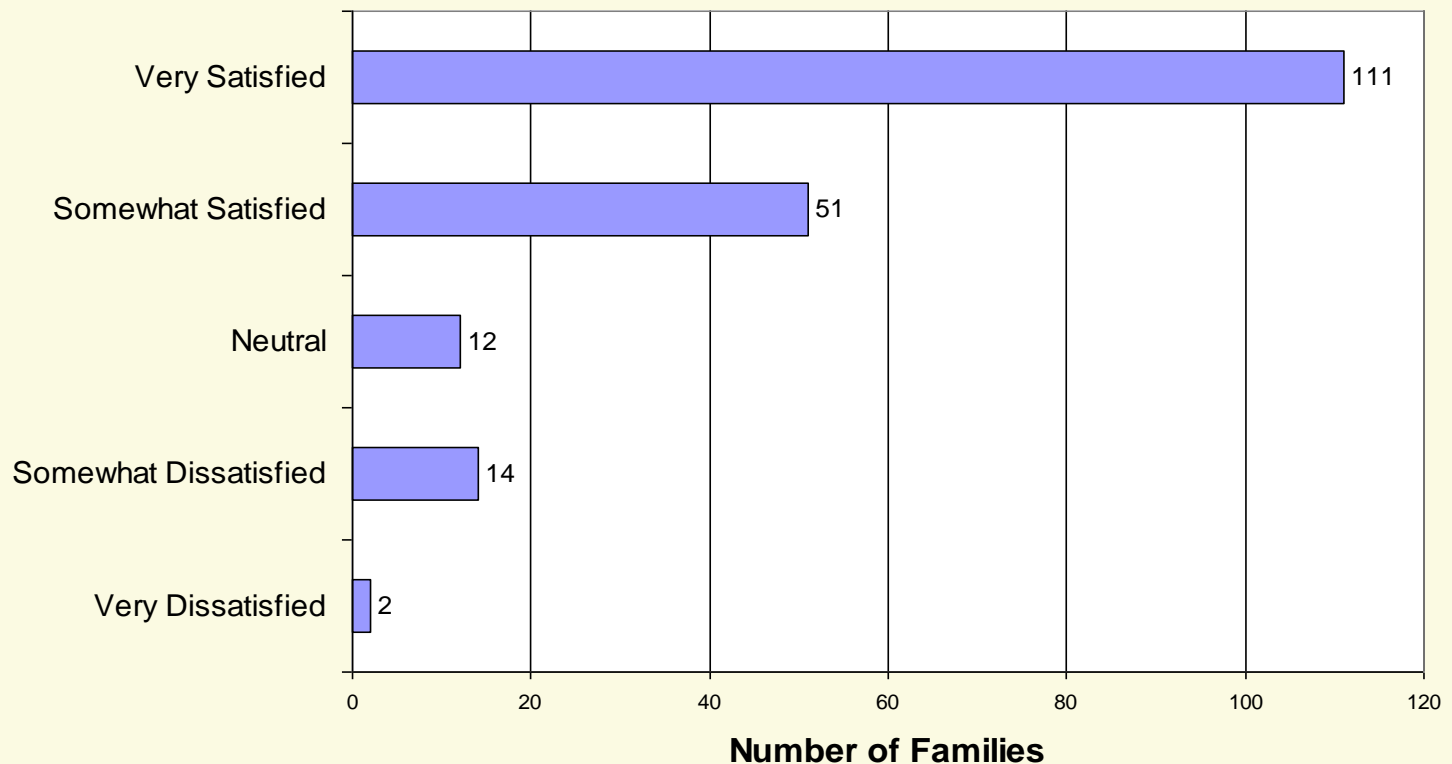
# Personal Interviews: Schalock's QOL Scale

**How Satisfied Are You With Your Current Home?  
1092 CT Class Members in 1990**



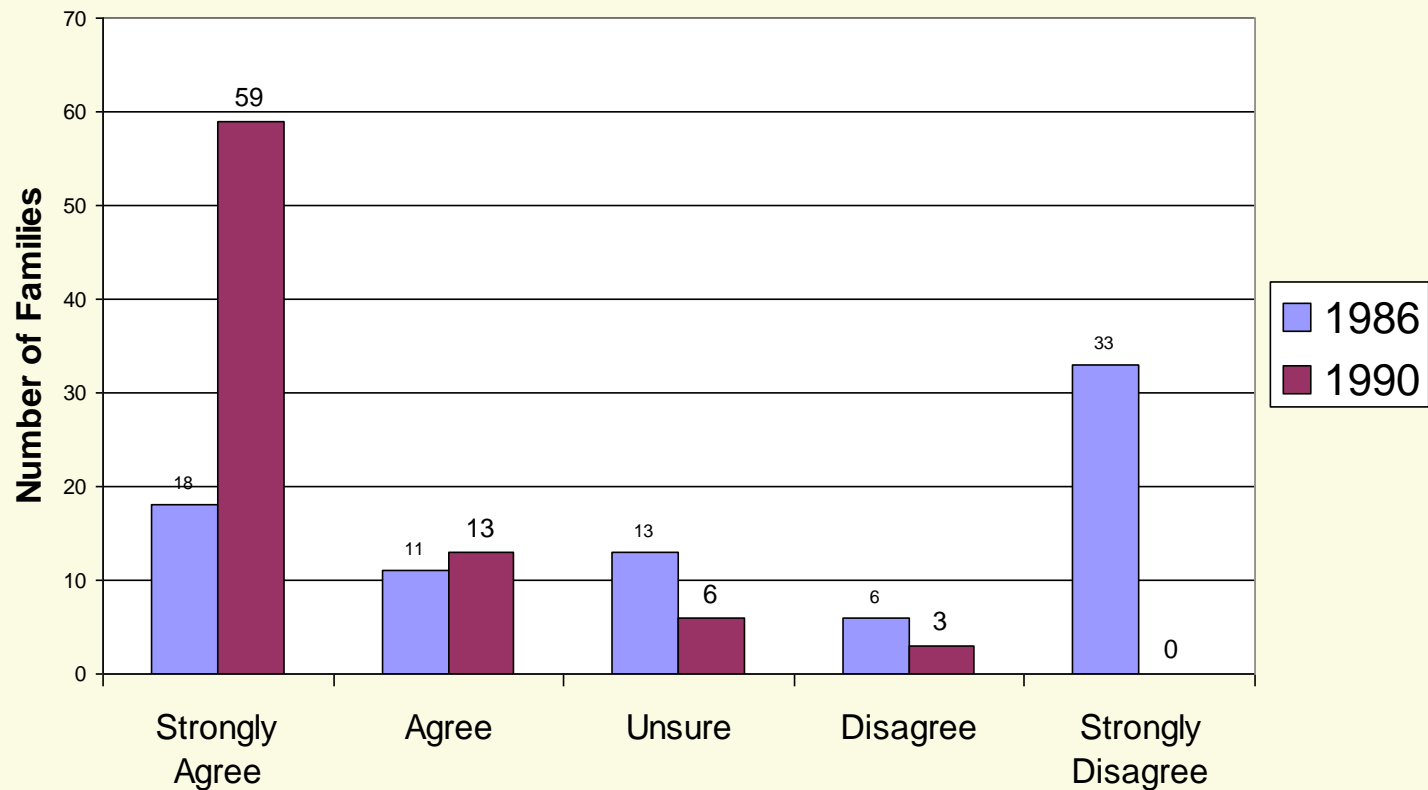
# Was Family Satisfaction High in CT's Community Programs?

**CT Family Survey 1990: How Satisfied Are You With Your Relative's Community Home?**



# Did CT Family Opinions About Community Living Change?

## Mansfield Longitudinal Study: Changes in Family Attitudes Re: Community Placement



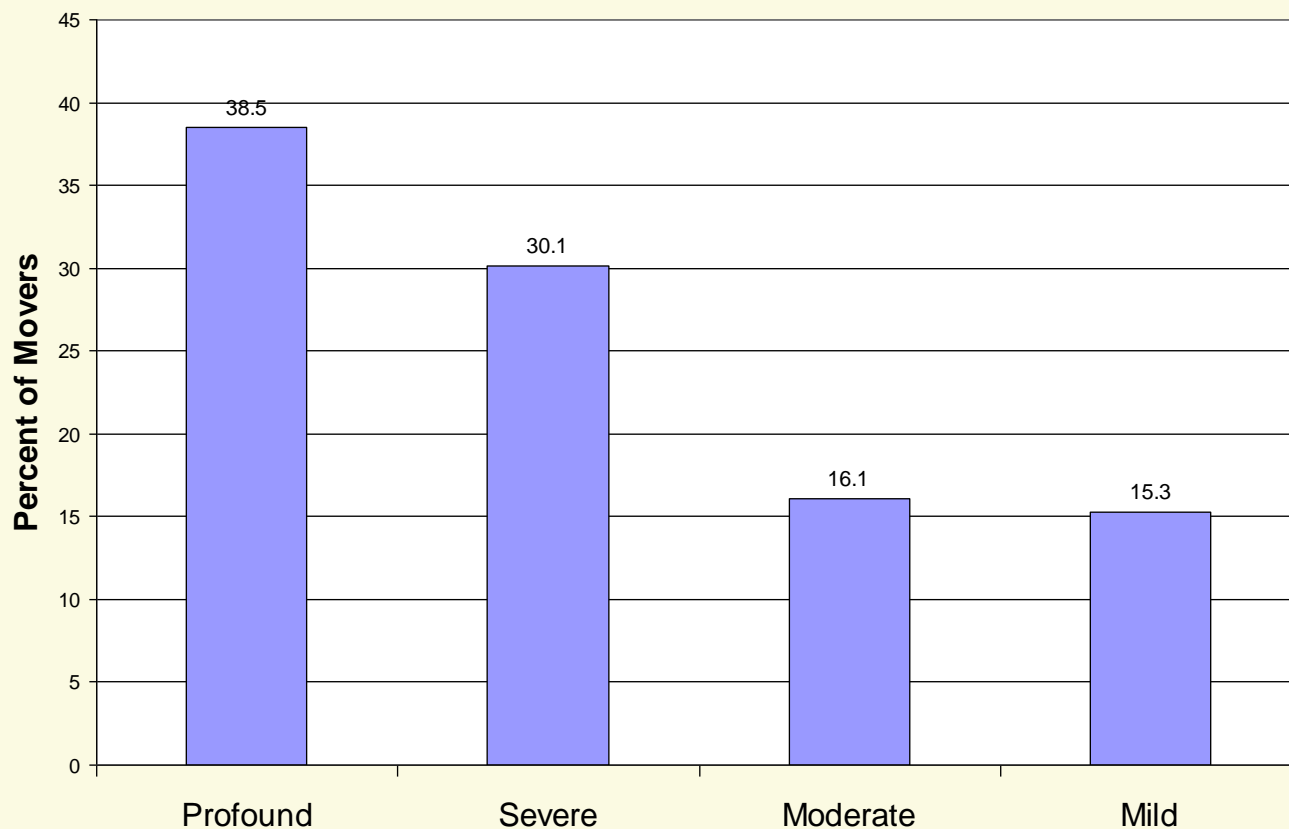
# The Patterns of Family Feelings That Have Emerged in Multiple Studies

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- Initial strong resistance to notion of community living (Sprent, et al 1987)
  - Lack of concrete knowledge and experience of such options
  - Sometimes lack of availability of such options
  - Likely cognitive dissonance, difficult to change opinion maintained for decades
- Later strong acceptance of community
  - Larson & Lakin meta-analysis, 1990
  - Confirmed again in CA, 1998
    - “Would you go back?” Overwhelming “No.”

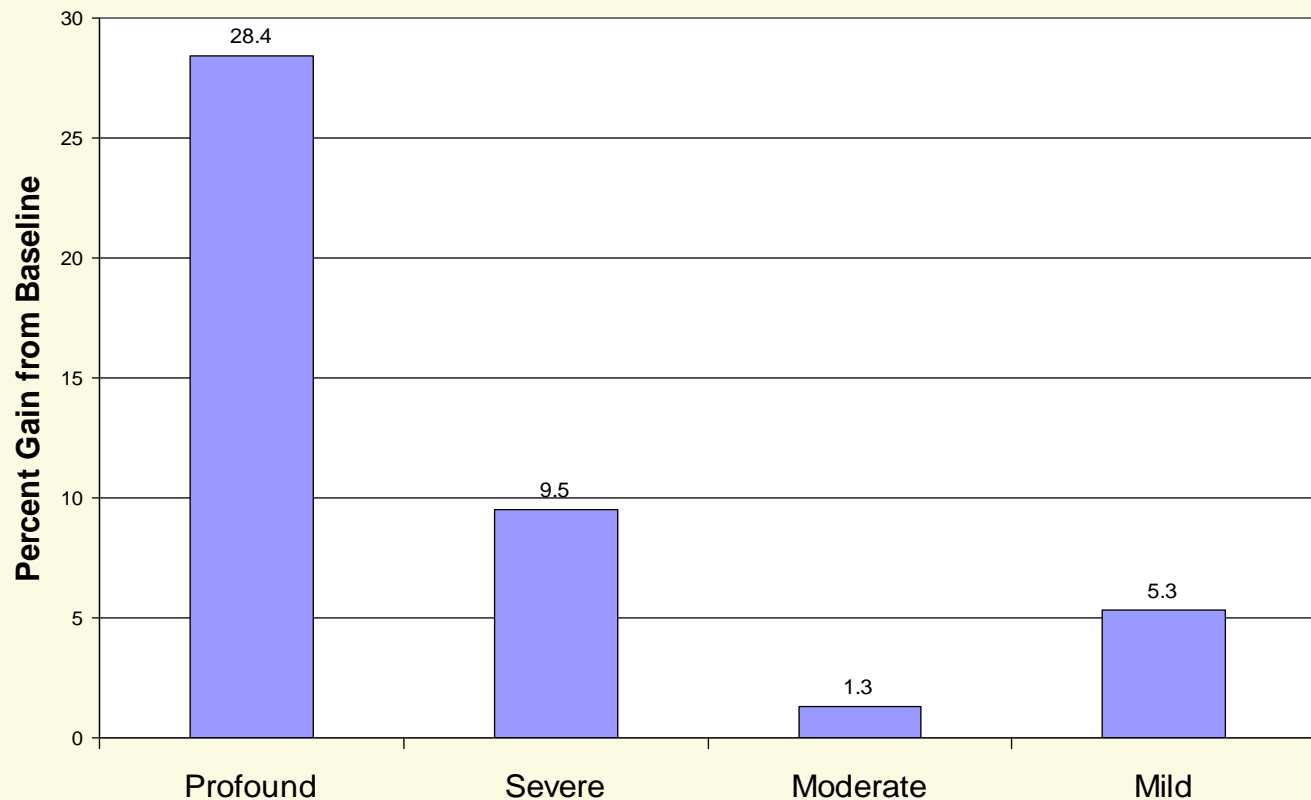
# The Mansfield Movers 1985 to 1990: Major Disabilities

**Level of Retardation Labels of People Who Moved from  
Institution to Community in CT, 1985-1991**



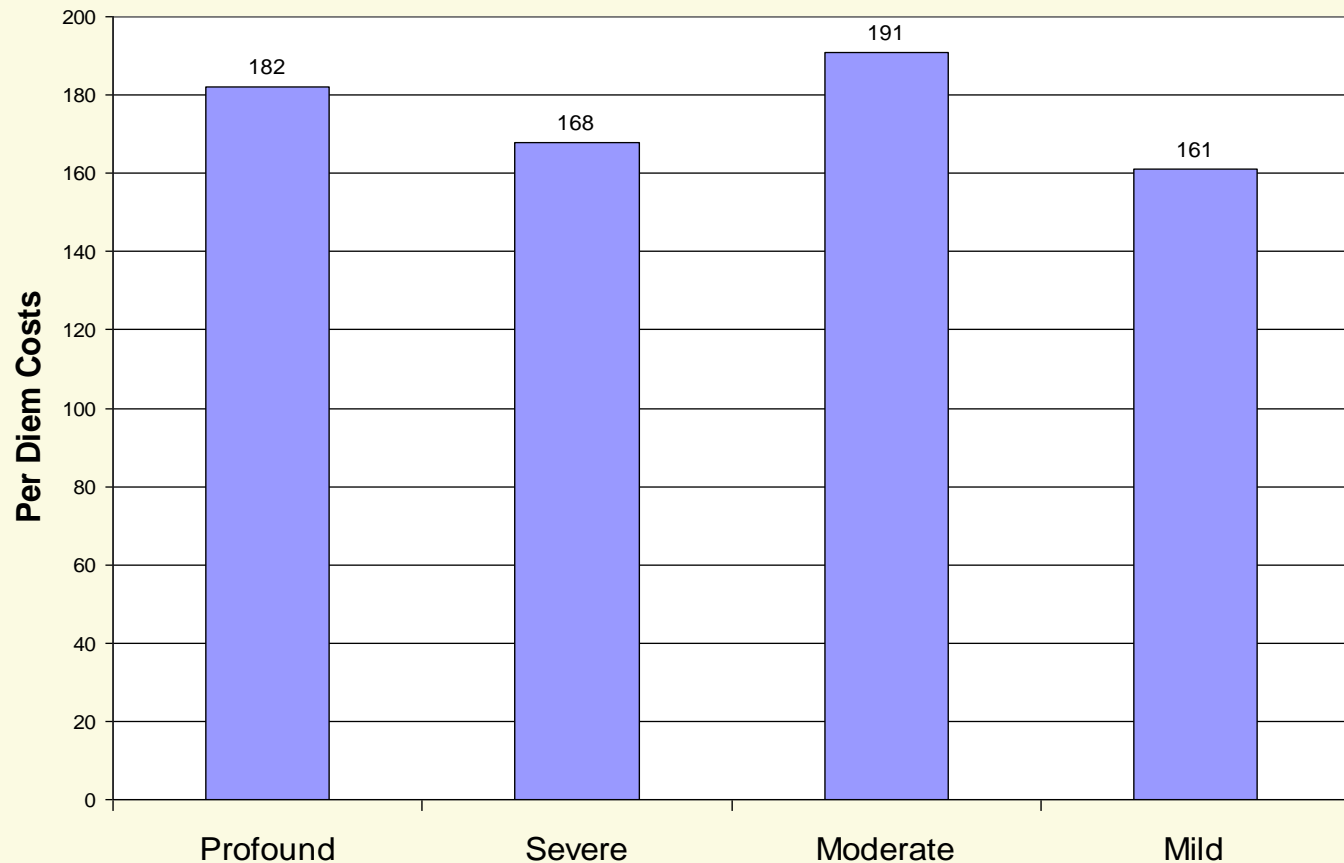
# What Kind of People Made the Largest Proportional Gains?

**Connecticut Movers, 1985-1991:  
Percentage Gain in Adaptive Behavior**



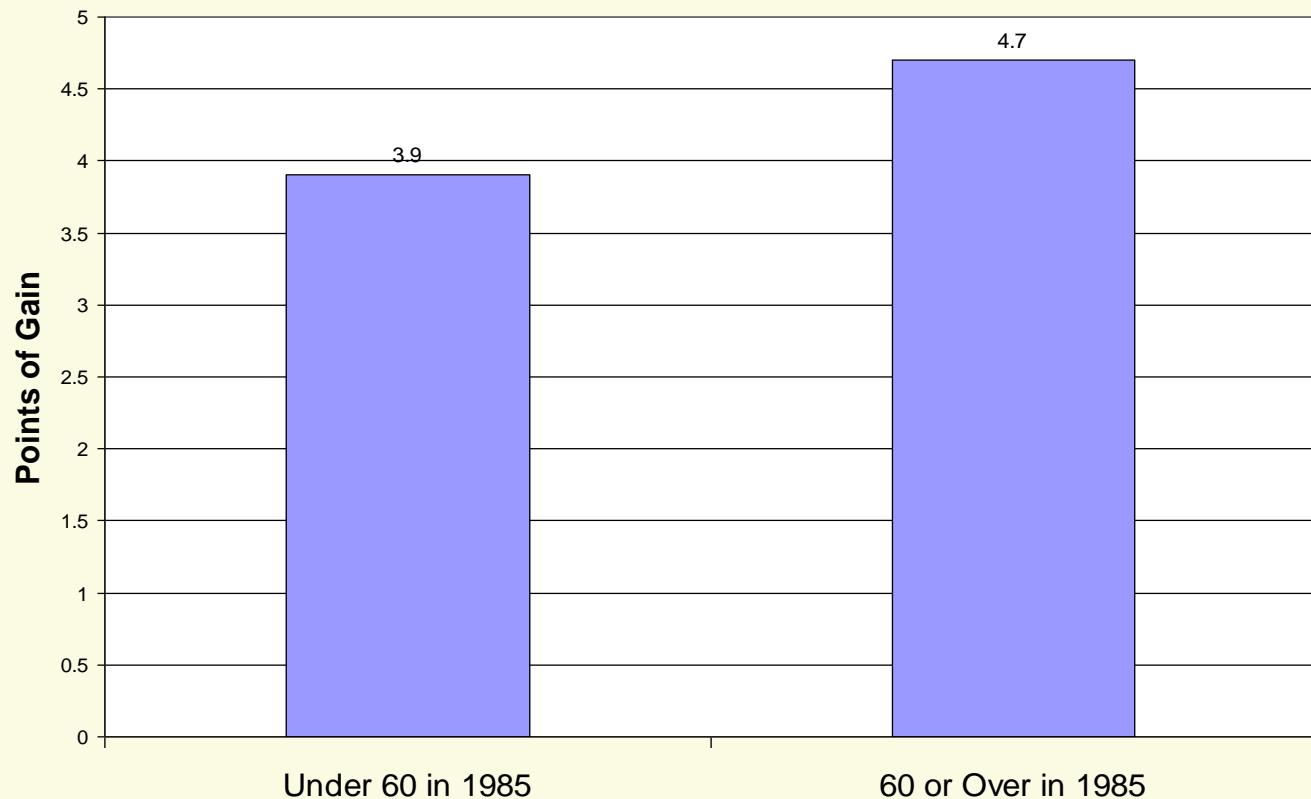
# Did People with More Severe Disabilities Really Cost Much More in the Community?

**Total Costs by Level of Retardation**



# Is It True That Older People Can't Benefit From Moving to Community Homes?


**Movers Who Were Under 60 and Over 60 in 1985:  
Adaptive Behavior Gains from 1985 to 1990**



**INDIVIDUAL OUTCOMES**  
**ASSOCIATED WITH DEINSTITUTIONALIZATION**  
**According to the Longitudinal Research Design**  
**Connecticut's Mansfield Class Members, 1985-1991**

<b>Outcome Measure</b>	<b>Longitudinal Design</b>
<b>Adaptive Behavior Improvement</b>	<b>Very Pos.</b>
<b>Challenging Behavior Improvement</b>	<b>Pos.</b>
<b>Intensity of Medical Needs</b>	<b>Neg.</b>
<b>Reduced Daily Medications</b>	<b>Neg.</b>
<b>Increased Earnings</b>	<b>Pos.</b>
<b>Day Program Productivity</b>	<b>Very Pos.</b>
<b>Subjective Quality Ratings</b>	<b>Very Pos.</b>
<b>Individualized Treatment</b>	<b>Very Pos.</b>
<b>Physical Quality of Residence</b>	<b>Pos.</b>
<b>Social Presence (Integration)</b>	<b>Very Pos.</b>
<b>Frequency of Case Manager Visits</b>	<b>Pos.</b>
<b>Family Visits to Person</b>	<b>Pos.</b>
<b>Person Visits with Family</b>	<b>Pos.</b>

Source: The Center for Outcome Analysis, Connecticut Applied Research Project, 1991

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Do these results correspond to  
results obtained in other studies,  
other states?

# The Hissom Outcomes Study: 1000 People, 8 Years

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Quality Dimension	Outcome
Adaptive Behavior	V. Pos.
Choice-Making	V. Pos.
Challenging Behavior	V. Pos.
Productivity	V. Pos.
Integration	V. Pos.
Developmental Services	V. Pos.
Family Contacts	V. Pos.
Medications	Pos.
Health Care	No Change
Satisfaction	V. Pos.
<b>Overall Conclusion</b>	<b>V. Pos.</b>

## **Results of the 5-Year Coffelt Quality Tracking Project**

### **1,215 People, 1993 to 1998**

<b>CAPABILITIES (Adaptive Behavior)</b>	Increased self-care abilities
<b>SOCIAL BEHAVIOR</b>	Increased socially appropriate behavior (decreased in challenging behavior)
<b>SELF-DETERMINATION</b>	Increased choice making
<b>SERVICES</b>	Increased number of services in written plan, significantly higher goal attainment
<b>PRODUCTIVITY</b>	Increased day program hours, decreased earnings and number of people employed.
<b>INTEGRATION</b>	Average number of outings per week doubled
<b>STAFF ATTITUDES</b>	Increased 1 scale point on a 10 point scale
<b>CONSUMER SATISFACTION</b>	Perceived significant increases in <b>all</b> measures of qualities of life
<b>FAMILY SATISFACTION</b>	Perceived significant increases in <b>all</b> measures of relative's qualities of life
<b>QUALITIES OF ENVIRONMENTS</b>	Enhanced: Physical quality and Individualization
<b>LIVING COSTS</b>	Decreased by 45%

## Outcome Summary for Winfield Movers

<b>Quality Dimension</b>	<b>Outcome</b>	<b>Direction</b>
Adaptive Behavior Scale	Significant 1.7 point gain (5% up)	<b>V. Positive</b>
Orientation Toward Productive Activities Scale	Large gain 1.7 to 11.5 points	<b>V. Positive</b>
Challenging Behavior	Modest 2.7 point gain (3% improvement)	<b>Positive</b>
# of Services in Individual Plan	Up from 5.2 to 8.2	<b>Positive</b>
Hours of Day Program Services	Up from 4 to 18 hours per week	<b>V. Positive</b>
Total Hours of Day & Res Services	Unchanged	<b>Neutral</b>
Normalization	Large increase	
Integration	Large increase from 3 to 31 outings per montha	<b>V. Positive</b>
Choicemaking	Up 50% from 27 to 40	<b>V. Positive</b>
Qualities of Life Ratings	Up from 68 to 78 (Now to Now)	<b>V. Positive</b>
Qualities of Life Perceptions of Changes	Up in every area but one (dental)	<b>V. Positive</b>
Staff Job Satisfaction	Up by 1.2 points out of 10	<b>V. Positive</b>
Staff Like Working With This Person	Up by 1.4 points out of 10	<b>V. Positive</b>
Staff Get Sufficient Support	Up 1 point (3.7 to 4.7, still low)	<b>Positive</b>
Staff Pay Rate	Down \$4000	<b>Mixed</b>
Health Rating	Up from 3.5 to 3.8 out of 4	<b>Positive</b>
Health by Days Ill Past 28	Down from 3.2 to 0.8 days/28	<b>V. Positive</b>
Medications, General	Down from 5.7 to 4.9	<b>Positive</b>
Medications, Psychotropic	Down from 18 people to 6	<b>V. Positive</b>
Doctor Visits Per Year	Down from 22 to 6	<b>Unclear</b>
Dental Visits Per Year	Down from 2.3 to 0.5	<b>Negative</b>
Family Contacts	Up from 7 to 18 contacts per year	<b>V. Positive</b>
Individualized Practices Scale	Up from 47 to 72 points	<b>V. Positive</b>
Physical Quality Scale	Up from 76 to 86 points	<b>Positive</b>
Subjective Impressions of Visitors	Up on 4 out of 5 dimensions	<b>Positive</b>
Total Public Costs	Down about 15%	<b>Positive</b>
	From \$109,000 to \$91,000	

# Adaptive Behavior Gains in Deinstitutionalization Studies

State	Number of Years	Time-1 Average Adaptive Behavior Score	Time-2 Average Adaptive Behavior Score	Gain on 100 Point Scales
Pennsylvania	14 years	39.8	50.2	10.4
New Hampshire	8 years	53.0	62.3	9.3
Louisiana	7 years	56.2	64.2	8.0
Oklahoma	6 years	41.3	47.4	6.2
<b>Connecticut</b>	<b>5 years</b>	<b>49.5</b>	<b>54.0</b>	<b>4.5</b>
California	3 years	44.7	46.7	2.0
North Carolina	2 years	52.7	54.8	2.2
Kansas	1 year	33.1	34.8	1.7
Indiana	.5 year	46.4	48.8	2.4

# Challenging Behavior Changes in Deinstitutionalization Studies

State	# of Years	Time-1 Average Challenging Behavior Score	Time-2 Average Challenging Behavior Score	Gain on 100 Point Scales
Pennsylvania	14 years	77.7	87.3	9.6
New Hampshire	8 years	79.6	78.6	-1.0
Louisiana	7 years	80.9	84.1	3.2
Oklahoma	6 years	89.7	93.5	3.8
<b>Connecticut</b>	<b>5 years</b>	<b>79.0</b>	<b>80.2</b>	<b>1.2</b>
California	3 years	68.1	76.4	8.3
North Carolina	2 years	87.7	89.4	1.7
Kansas	1 year	78.6	81.3	2.7
Indiana	.5 year	72.1	69.9	-2.2

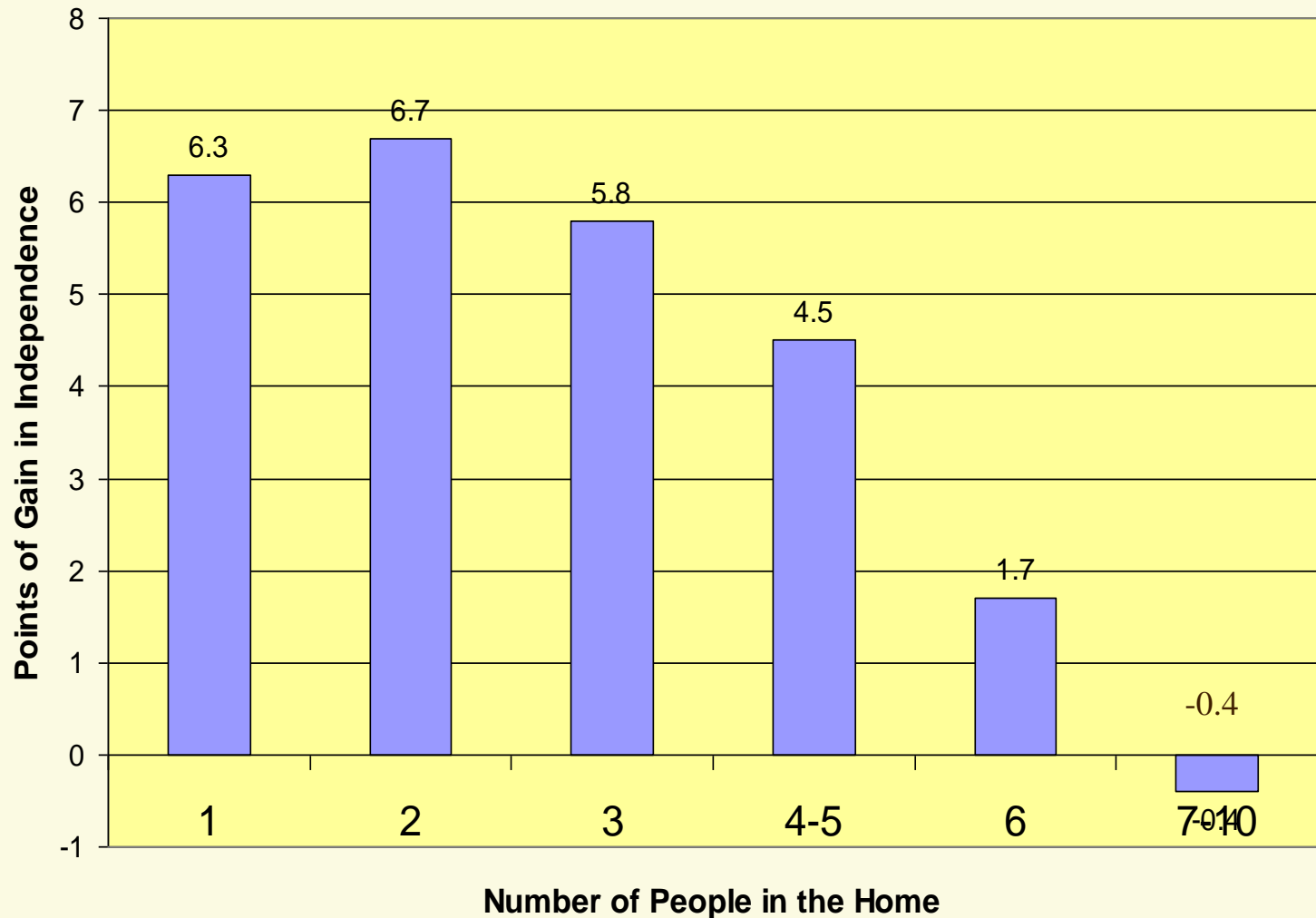
# Integration Increases in Deinstitutionalization Studies

State	# of Years	Time-1 Integrative Activities Score	Time-2 Integrative Activities Score	Change
Pennsylvania	14 years		9.2	
New Hampshire	8 years		10.0	
Louisiana	7 years			
Oklahoma	6 years	2.7	7.1	4.4
Connecticut	5 years	4.3	8.8	4.5
California	3 years	3.4	7.6	4.2
North Carolina	2 years	1.8	6.2	4.4
Kansas	1 year	0.8	7.7	7.0
Indiana	.5 year	2.7	7.4	4.7

# Summary of Studies Performed

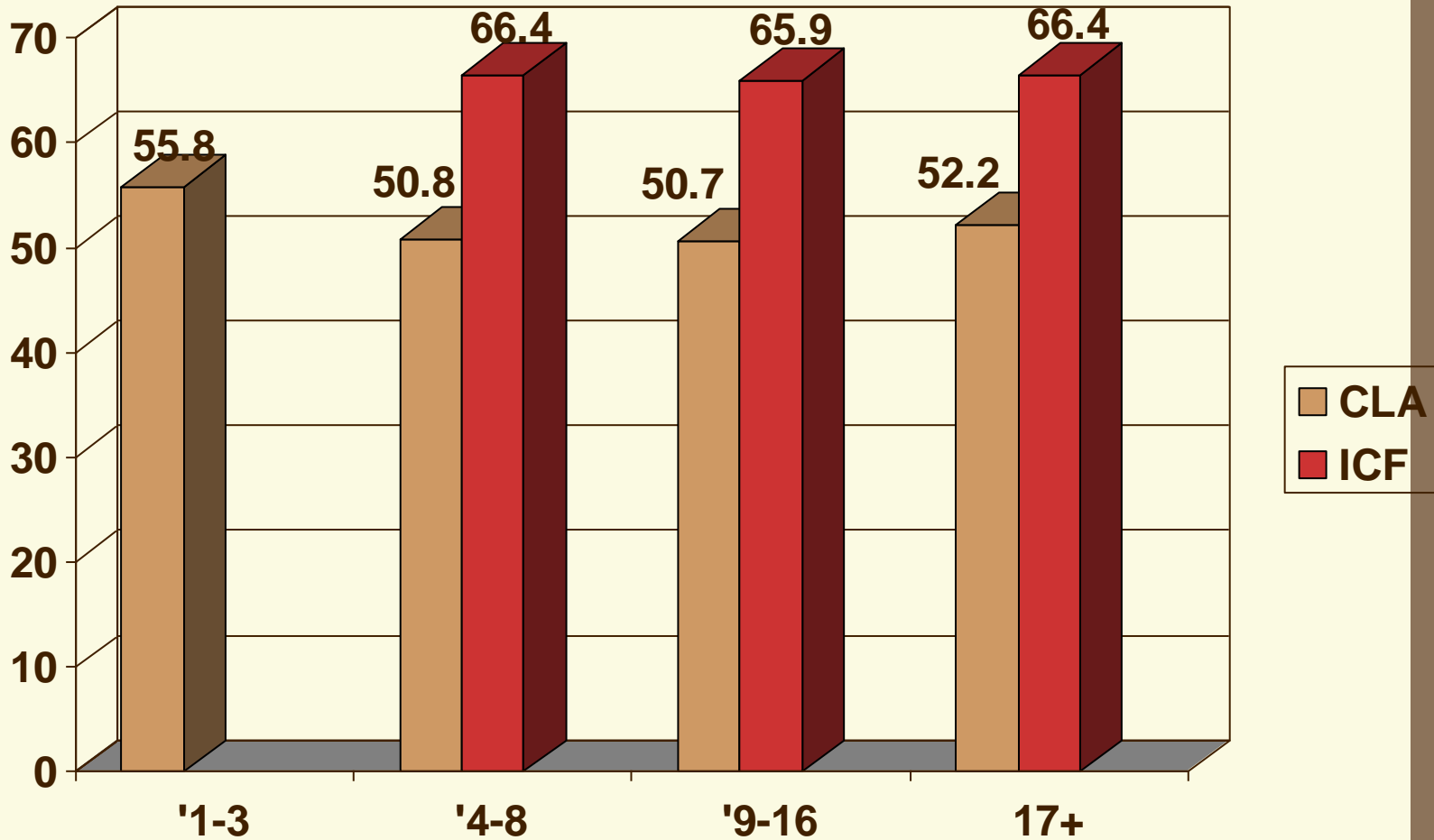
	<b>Court-Ordered?</b>	<b>Number of People</b>	<b>Number of Years</b>	<b>Community Model</b>	<b>Average Age</b>	<b>% Severe/Profound</b>	<b>% Nonambulatory</b>	<b>Years</b>
PA	Yes	1100	14	3 person	43	86%	18%	78-92
NH	Yes	600	3	4 to 6	39	66%	21%	79-86
LA	Yes	268	5	Varied	25	68%	17%	80-86
OK	Yes	380	9	Supp Liv	25	86%	27%	90-99
CT	Yes	590	5	Varied	44	86%	23%	85-90
CA	Yes	1200	4	4 to 6	37	68%	28%	94-99
NC	Yes	900	4	4 to 6	46	26%	12%	92-99
KS	No	88	2	2 by 4	43	100%	58%	97-99
IN	No	200	1	Supp Liv	39	67%	23%	98-99
NJ	No	57	2	4 to 6	36	7%	13%	89-93
		5383						
STS	No	730		Varied	55	78%	29%	

# Progress in Independent Functioning by Size of Home: 2200 People in Oklahoma, US 1990-1996 (100 point scale)




# Average Annual Cost By Size

## PA CLAs and ICFs, 1995




# And Also This:

- 
- [It is] best ... bringing up the child among ordinary children, and subjecting him to ordinary social and family influences
- People run counter to this principle for the sake of **economy**, and of some other good end, which they suppose cannot be had in any other way
  - as when they congregate the insane in hospitals, vicious children in reformatories, criminals in prisons, paupers in almshouses, orphans in asylums, blind children and mute children in boarding schools

## And More:

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 Hence I begin to consider such establishments as evils which must be borne with, for the time, in order to obviate greater evils.

## And Finally (in 1866!):

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- ☞ I would take heed, however, against multiplying them unnecessarily.
- ☞ I would keep them as **small** as I could.
- ☞ I would take the most stringent measurements for guarding against those undesirable effect
- ☞ and for **dispensing with as many of them as may be possible.**

# Example: Power Measure

## Decision Control Inventory 1: For People in Residential Settings

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Ask the respondent to select a number from 0 to 10 to show who actually makes decisions in each area. If decisions are made entirely by PAID PERSONNEL (the respondent, other program staff, Case Manager, agency officials, doctors, etc.), enter "0" for that area. If decisions are made entirely by the PERSON AND/OR UNPAID FAMILY, FRIENDS, ADVOCATES, etc., enter "10." If decisions are equally shared, enter "5." BE SURE TO WRITE N/A if the item really doesn't apply.

0-----1-----2-----3-----4-----5-----6-----7-----8-----9-----10  
**PAID** **PERSON AND/OR UNPAID FRIENDS**  
**STAFF** **OR RELATIVES OR ADVOCATES**

### FOOD

- \_\_\_\_\_ 1 What foods to buy for the home when shopping
- \_\_\_\_\_ 2 What to have for breakfast
- \_\_\_\_\_ 3 What to have for dinner
- \_\_\_\_\_ 4 Choosing restaurants when eating out

### CLOTHES AND GROOMING

- \_\_\_\_\_ 5 What clothes to buy in store
- \_\_\_\_\_ 6 What clothes to wear on weekdays
- \_\_\_\_\_ 7 What clothes to wear on weekends
- \_\_\_\_\_ 8 Time and frequency of bathing or showering

### SLEEP AND WAKING

- \_\_\_\_\_ 9 When to go to bed on weekdays
- \_\_\_\_\_ 10 When to go to bed on weekends
- \_\_\_\_\_ 11 When to get up on weekends
- \_\_\_\_\_ 12 Taking naps in evenings and on weekends

# Values

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 People

 Families

 Professionals

 Legislators

# People

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 Having friends

 Having money

 Being able to go places

 Having control

# Families


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 Health

 Health care

 Safety

 Permanence

 Freedom from abuse

# Professionals

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 Integration

 Independence

 Employment

 Sexuality

 Self-determination

# Legislators

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 Never mind all that

 What does it cost?

# The Original Concept

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## **Self Determination:**

- If people gain control,
- Their lives will improve,
- And costs will decrease.

# Harlow – Univ Wisconsin – 1960s

## “Total Social Deprivation”

 A

 B

 C



# Avoiding Mistakes

- ❏ In the U.S. and U.K.
- ❏ We already made most of the dumb mistakes
- ❏ I hope I can help
- ❏ Avoid the worst

