Health and Health Care During America's Deinstitutionalization and Disability Rights Movements

Reflections on a Half Century of Progress

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Three Themes Today

- Community – People are better off
  - Deinstitutionalization has enhanced outcomes – quality of life, health, and longevity
- Mortality scare in community debunked
  - The past 18 years of "scare" about higher mortality in the community is the result of a simple counting error
- Future: Relationships & quality of life
  - Real life quality means relationships & participation
  - Without which health & safety are hollow
  - The real goal of health care for people is to be able to "have a good life" (or "to get my life back")

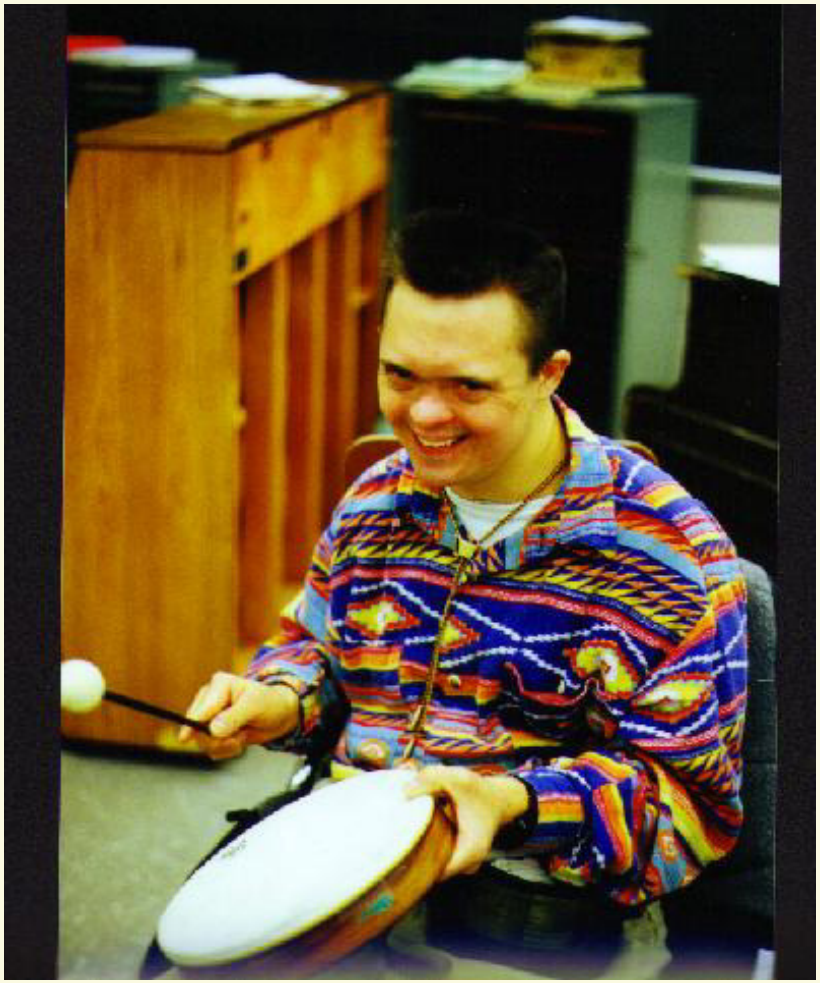
First, A Bit of History

- History is important
- Those who ignore history are doomed to...

Major in something else….

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



Why Did Parents Do This?

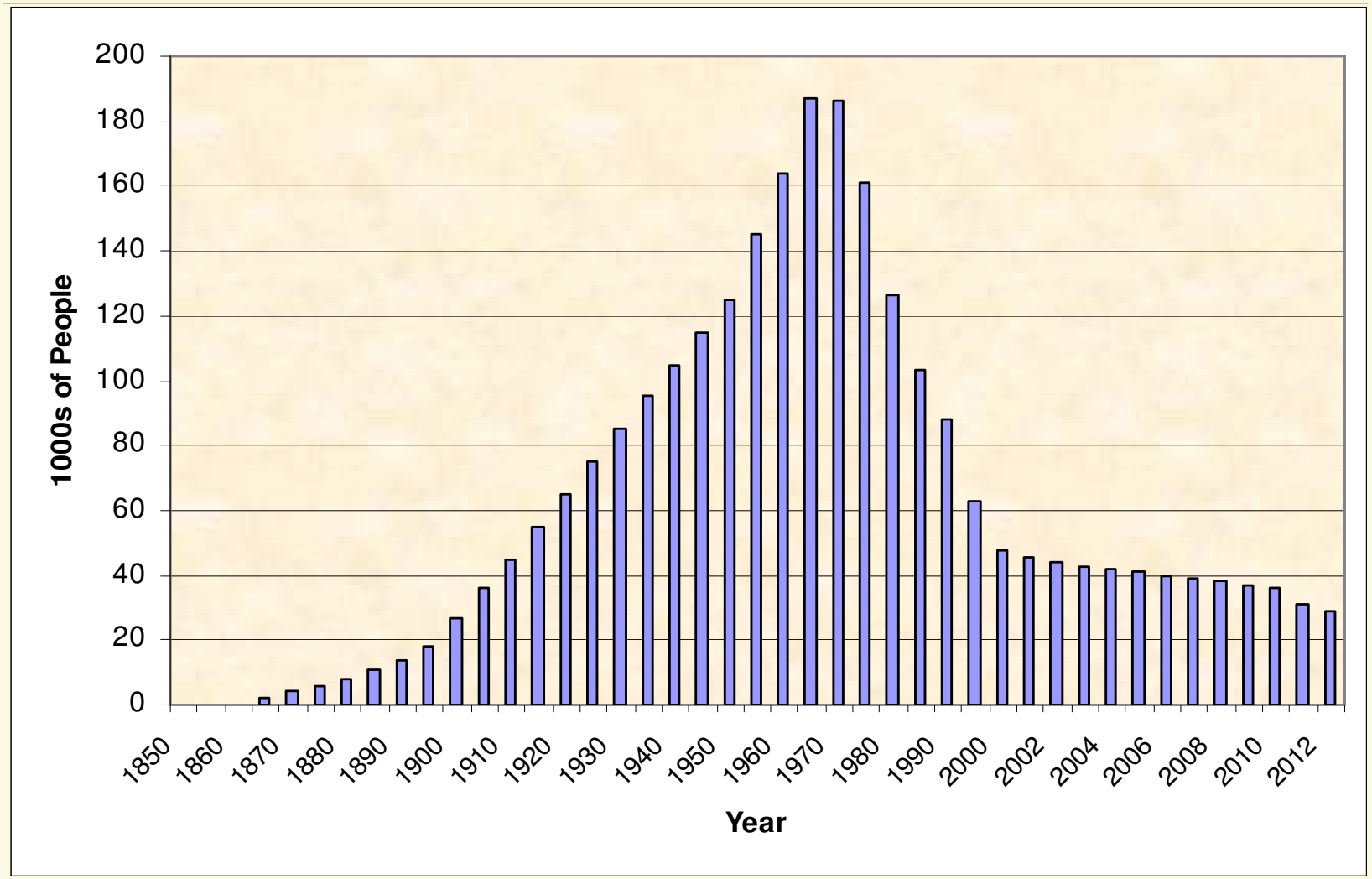
- Because professionals told them to
- Primarily doctors
- Doctors had authority
- Knew “what’s best”
- With the best intentions

Movement from Institution to Community

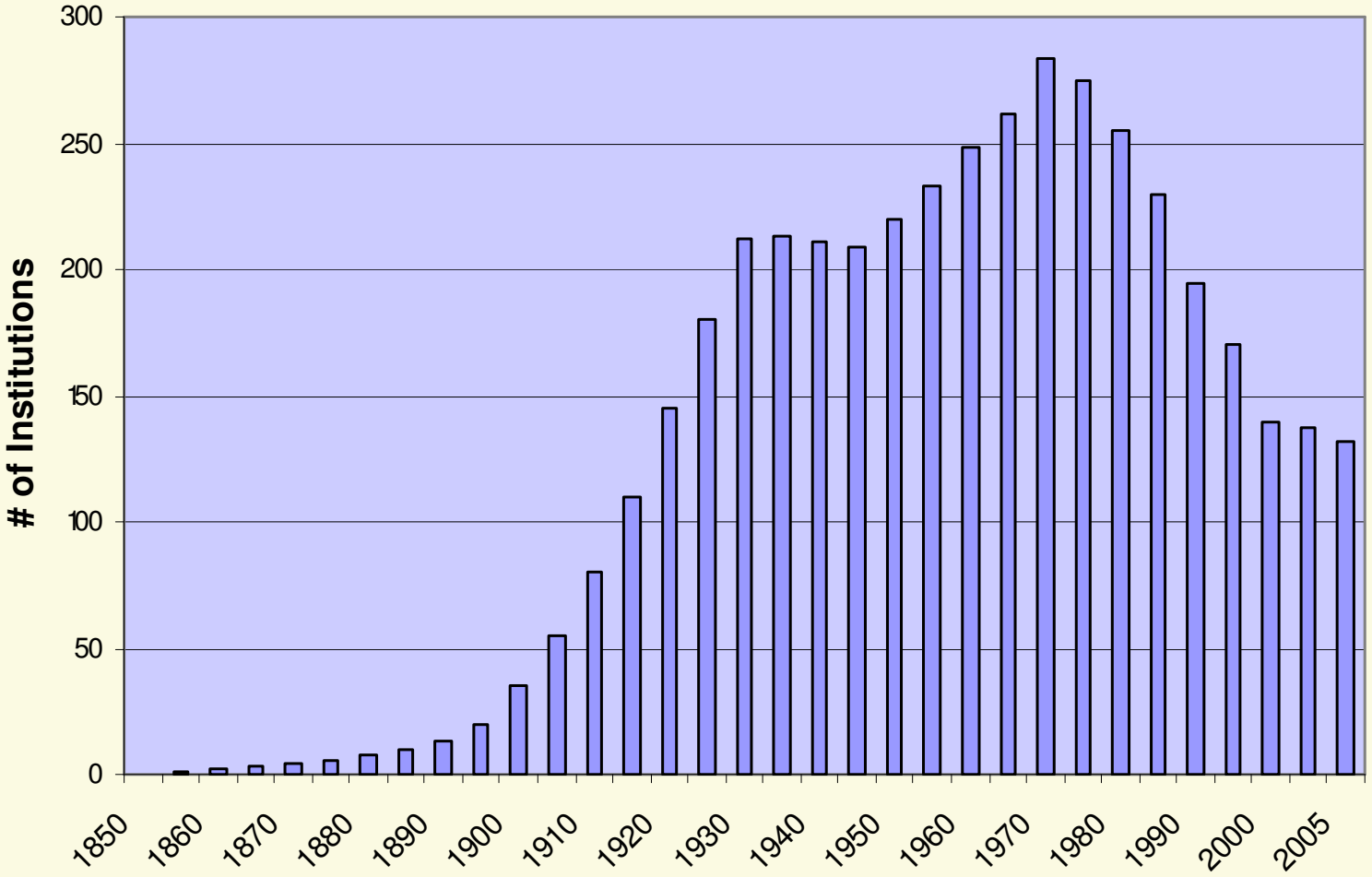
From large, segregated, historically state of the art settings

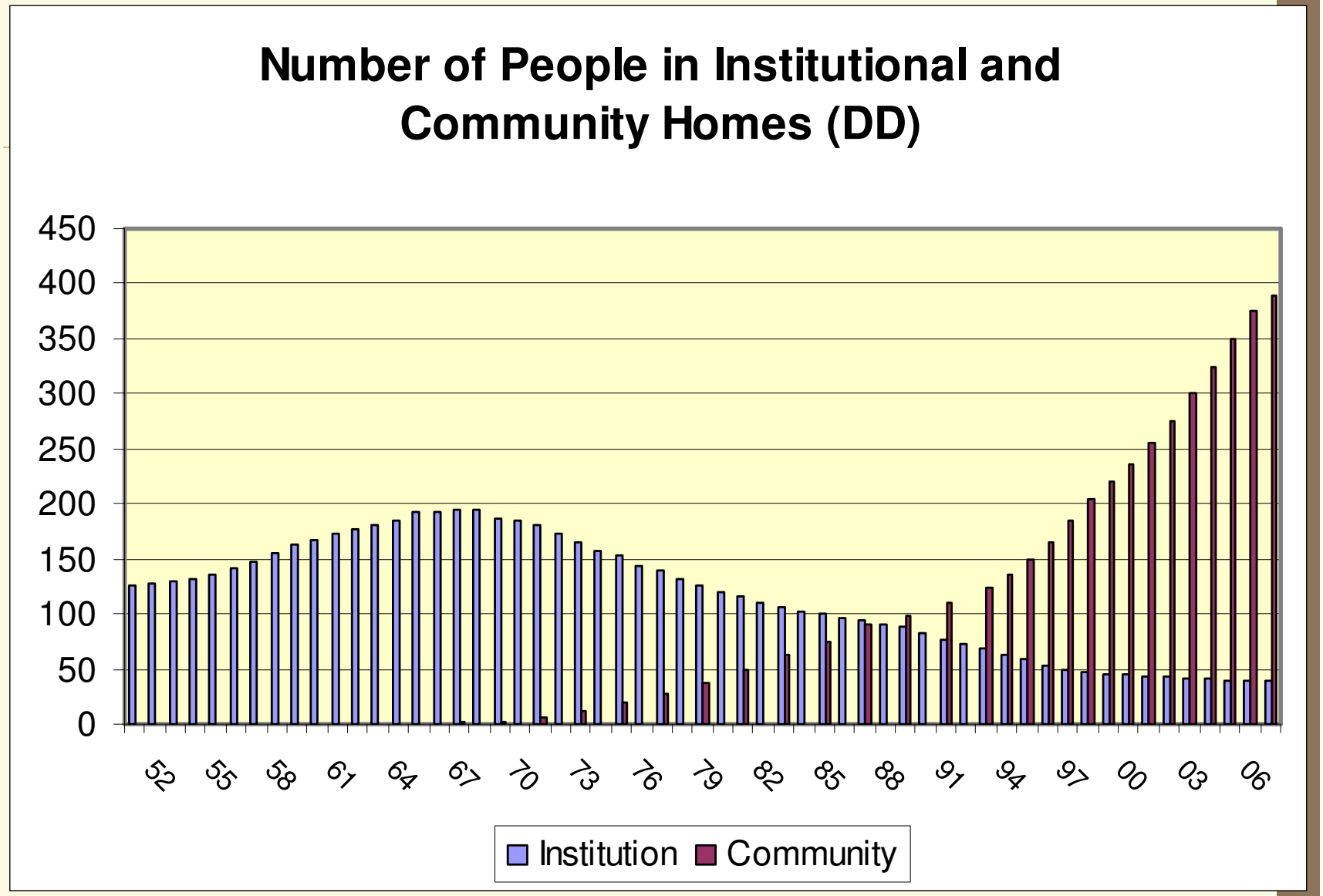
To small, integrated, more recent models of what a “home” means

150 Years of Institutionalization



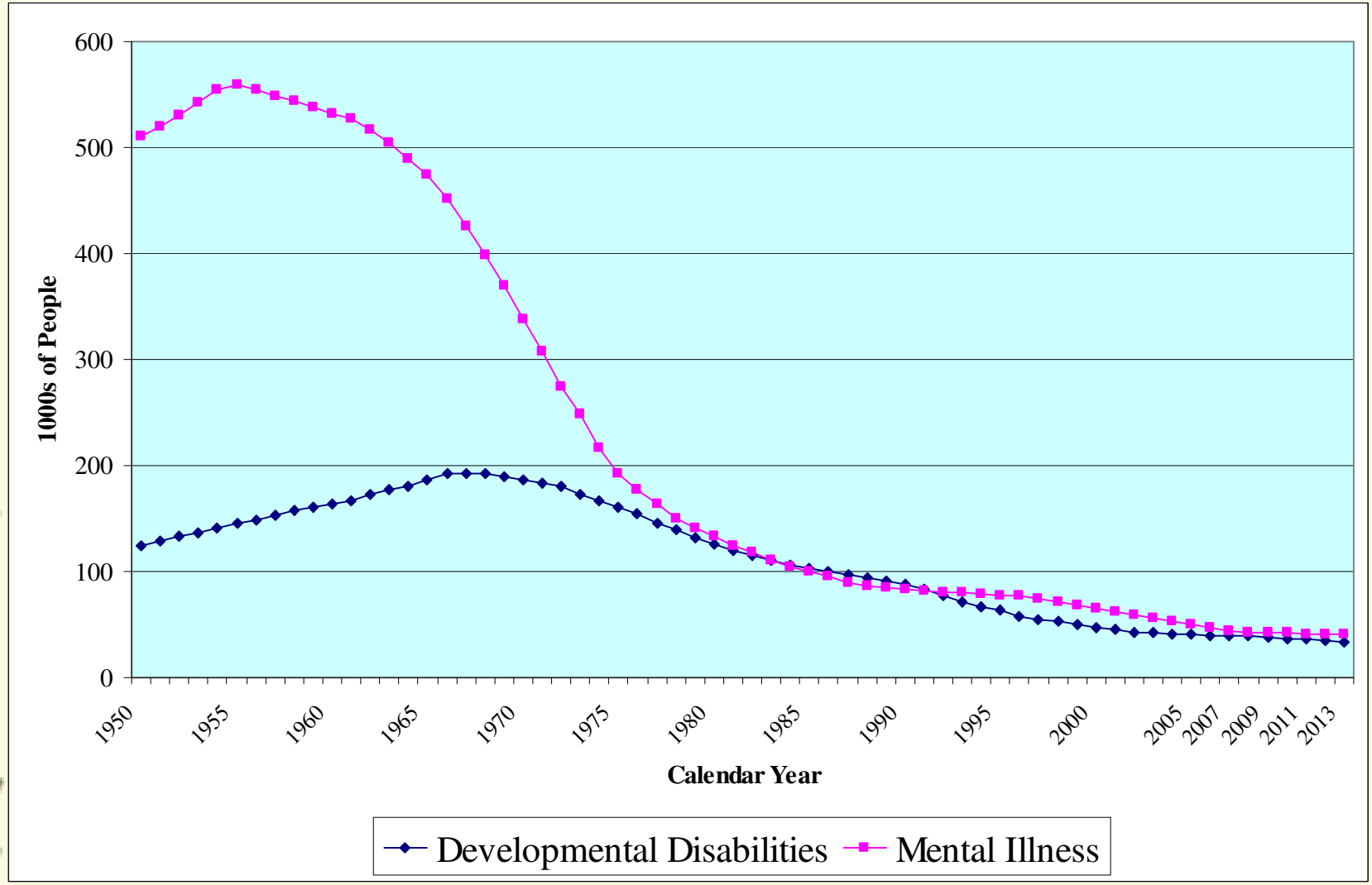
Number of Public Institutions




Number of People in Institutional and Community Homes (DD)
450
400
350
300
250
200
150
100
50
0
52
55
58
61
64
67
70
73
76
79
82
85
88
91
94
97
00
03
06
Institution
Community

U.S. Deinstitutionalization –

Developmental Disabilities Versus Mental Illness



Source of The Institutional Model

- 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

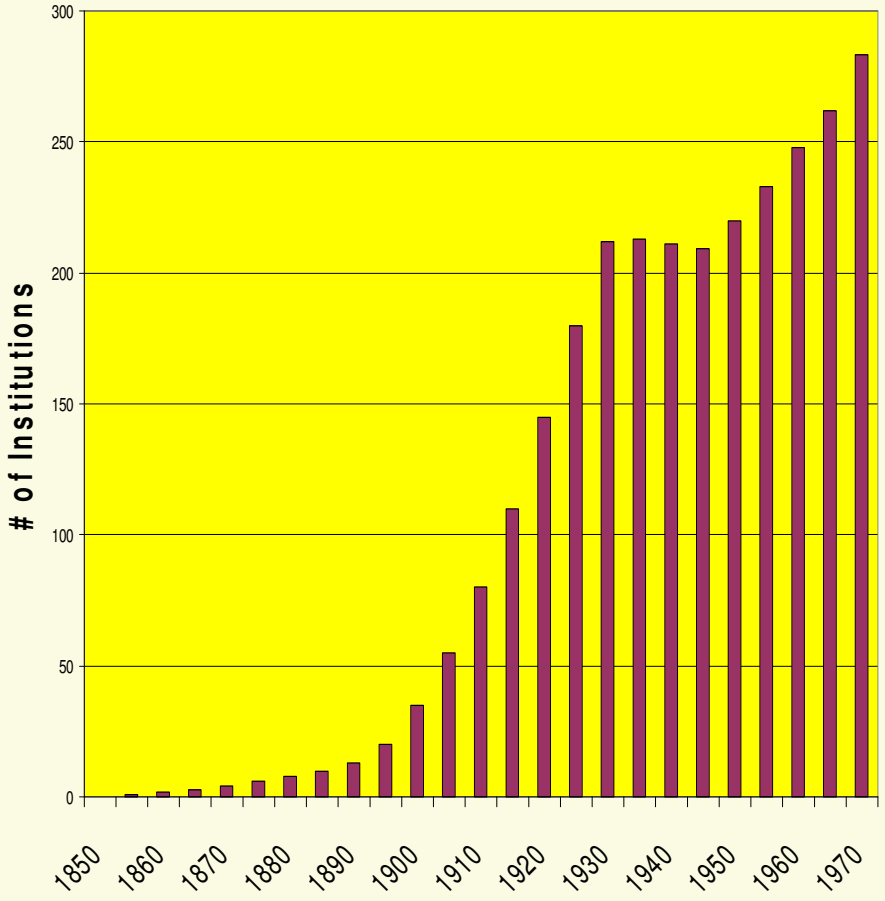
- First publicly funded facilities ---
- 1848 Fernald Center, Massachusetts
- 1849 Dorothea Dix Center, North Carolina
- 1849 California Prison Ship, San Francisco Bay – 30 inmates – Stockton 1851
- All meant to do good

By 1866, Samuel Gridley Howe Was Saying This:

- **"… 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.**

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!



The Dark Side of Good Intentions

- We adopted and spread the "**Eugenics**" period of American history, 1880 to about 1920
- **Social Darwinism** was the key concept
- America decided "These people are inferior"
- They cannot be permitted to breed
- They should be isolated from society
- Thereby we could improve the human race
- Thinking later adopted by Germany's Nazi party - using Oliver Wendell Holmes' writings

“This Is Where I Came In”

- 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 stunned
- Saddened
- Disappointed in my country
- This – during Vietnam, civil rights, and women's liberation movements?

Pennhurst: Poor Conditions

- 2800 people lived there
- Horribly overcrowded
- 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

Skewed Values in the US

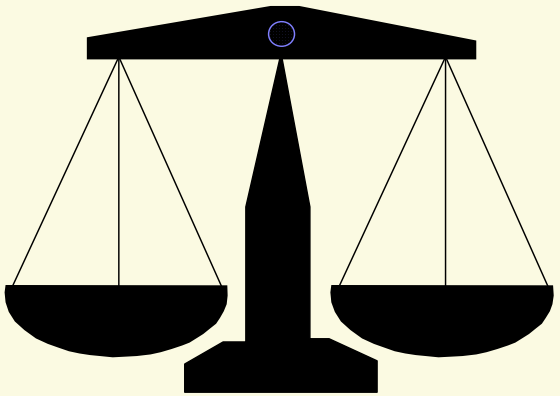
- 1969: The average cost per person at Pennhurst was $5.90 per day
- The average cost of keeping a leopard at the Philadelphia zoo was $7.15 per day
- Was this the Economy of Scale thinking at work?

I Believed Then That We Should Improve the Institution

- 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

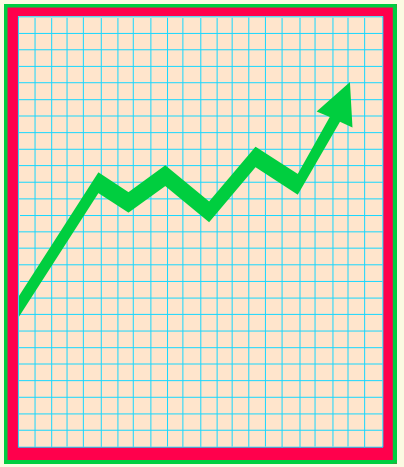
- I was a skeptic
- Deinstitutionalization in the mental illness field had been a disaster and a disgrace
- I thought this would be, too
- So I wanted to do research on this

The Pennhurst Longitudinal Study

- 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

- 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?

- 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 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%)

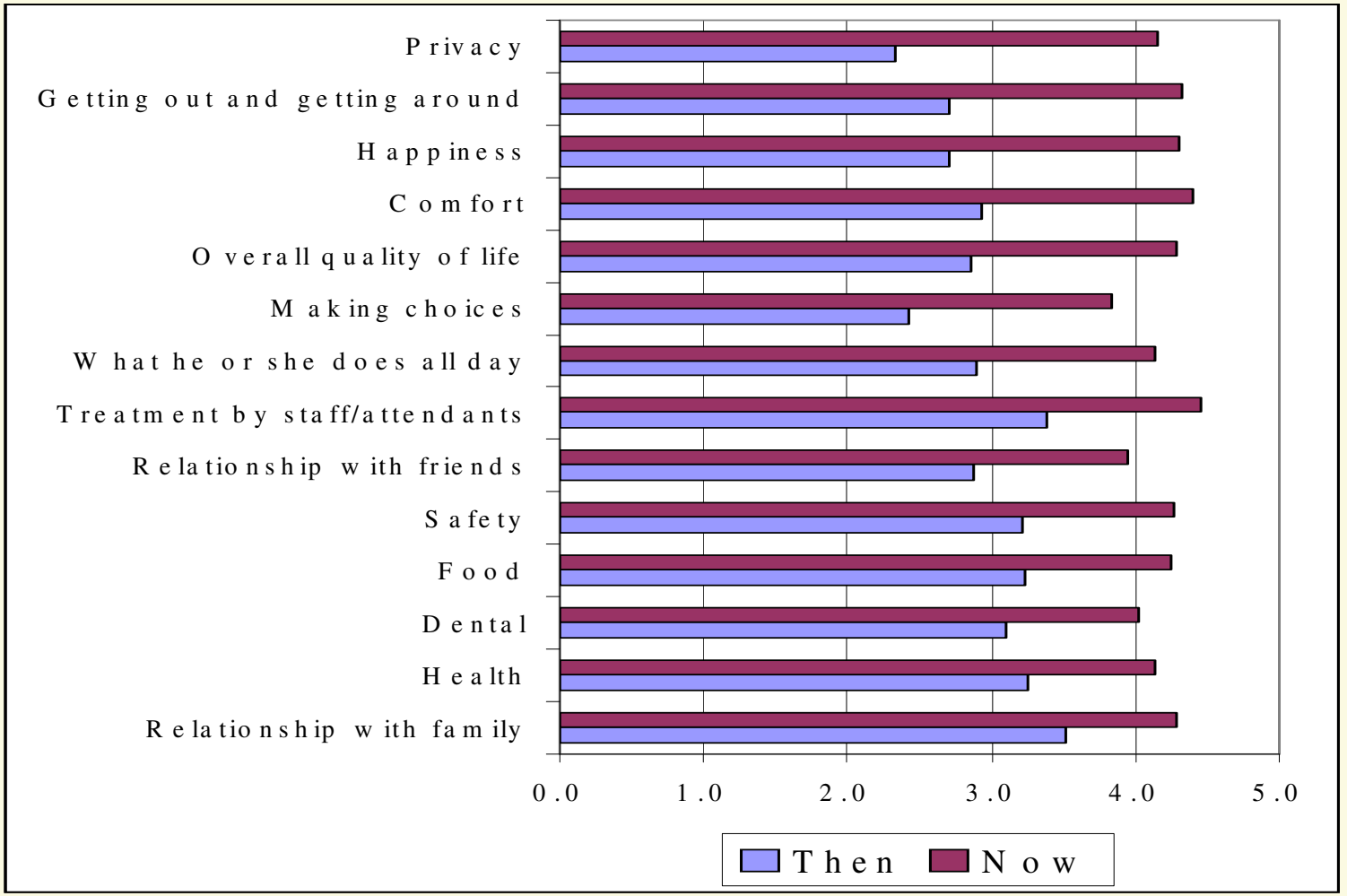
The Pennhurst Longitudinal Study: 1154 People, 20 Years

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

Did the Pennhurst Results Meet the Scientific Test of Replication?

- 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

California Coffelt Study, 2001: Family Perceptions – "Much Better Off" in Every Way – Including Health and Dental Care!



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.

The Mortality Issue

Death Rates: Institution Versus Community

- In 1996, a few researchers published a paper
- It claimed that death rates were higher in California's community homes than in the institutions
- Using a lot of complex math, they said death rate in community was 72% higher than in the institutions
- (Also 72% higher in FAMILY homes than in the institutions -- !!! No one noticed this finding. More about that later.)

The First Study

- Strauss, D., & Kastner, T. (1996). Comparative Mortality of People with Mental Retardation in Institutions and the Community. *American Journal on Mental Retardation, 101, 1,* 26-40.

Impact – Courts & Media

- This paper led to later papers
- Altogether 7 published studies (Citations)
- This body of work became a “death scare”
- Tactic used in every deinstitutionalization case
- Voice of the Retarded hired and paid:
  - Lawyers (Bill Sherman, Tom York)
  - Researchers (Ted Kastner, Kevin Walsh)
- They made sure the death scare was entered into every court record
- And they sought wide media attention
- Most recently raised in a joint legislative session on closures in New Jersey (by shouting advocates)

The Entire Foundation of the Strauss Studies: DC Mortality

- All Strauss & Kastner studies are founded on their estimate of the Developmental Center (DC) mortality rate
- Original 1996 study, Strauss & Kastner reported:
  - **16.0 per 1,000 per year**
- California state agency (DDS) actually counted each death, by name and date, and reported
  - **18.2 per thousand per year**
- (There are more details & clues about errors)

Which Figure Was Right?

- Lakin, K.C. (1999).
  - Observations on the California Mortality Studies. *Mental Retardation, 36,* 395-400.
- The difference between Strauss and the state agency's department of institution (DDS) was about 149 people.
- Can we believe that both DDS reported **MORE** deaths than actually occurred in the institutions?
  - When have bureaucrats every reported MORE bad news than they have to?
- The Strauss & Kastner count was WRONG.

What Was the Cause?

- Strauss & Kastner obtained all mortality data from the California Department of Health Services
  - These Vital Statistics tapes contained all deaths in the state, including locations
- A standard practice at California institutions::
- **People who were dying were moved to local community hospitals for specialized intensive care**
- When they died in these community hospitals, Strauss & Kastner counted them as “community deaths”
- They were **not counted** as institutional DC deaths
- That’s how Strauss & Kastner undercounted DC deaths

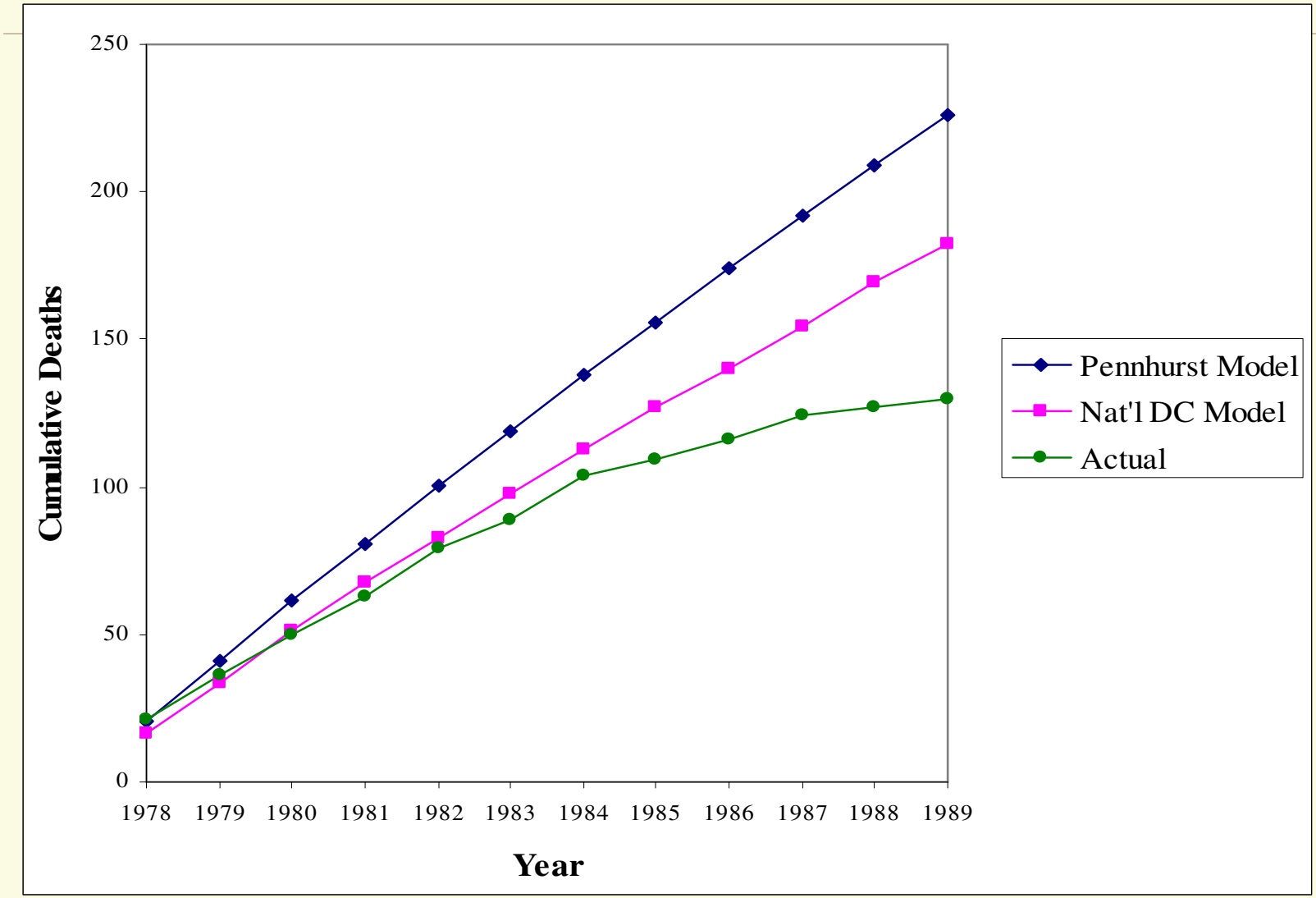
The Foundation of the Work was Fatally Flawed

- A gross underestimate of DC mortality
- Made all subsequent multiple regression models and comparisons invalid
- The true situation is likely to be the opposite of Strauss & Kastner's conclusions

Replication?

- Strauss & Kastner continued to claim that they had not undercounted
- And that they had plenty of publications
- But – It's actually replication that's the criterion of good science
- Cold fusion was published – but not **replicated** by other scientists
- No one has replicated Strauss & Kastner
- Strauss was repudiated by his own colleagues at his university
- Most recently contradicted by a controlled research design:
  - Paul Lerman, Dawn Hall Apgar, and Tameeka Jordan. Deinstitutionalization and Mortality: Findings of a Controlled Research Design in New Jersey. **Mental Retardation: Vol. 41, No. 4**, pp. 225-236.

The Real Facts: Pennhurst Mortality



Phases of Disability History

- Medical Model 1850-1970
- Professional Model 1970-1990
- Self-Advocacy, rights, and self-determination 1990-present
- All about control and power – Who's in charge of my life?
- One of our central dilemmas has been Medicaid
- Accepting tons of money through the old Medical Model is a very mixed blessing

“Health & Safety”

- Primary goal of Medicaid, HCBS, Waivers
- But –
- What promotes health most efficiently?
- Relationships – intimacy – someone is “there for me”
- More powerful predictor of health than whether or not you smoke – or your weight – or your blood pressure!

"Connectedness," Health, and Survival

- "TWINS STUDIES" -- For similar groups of people
- 100 men with congestive heart disease
- 50 of them had 3 or more contacts with close or intimate or trusted friends per week
- The other 50 had fewer than 3 contacts
- The difference in survival rate after 5 years was:
- **7 times higher for the "connected" men**

Ornish, Dean. (1999). ***Love & Survival : 8 Pathways to Intimacy and Health.*** **New York: Harper & Collins.**

The Roseto "Mystery"

- Malcolm Gladwell's *Outliers* book
- Pennsylvania town of Roseto
- All immigrants from village of Roseto Valfortore in Italy
- Became its own "tiny self-sufficient world"
- Dr. Stewart Wolf discovered incredibly low rate of heart disease over 50 years – half the average for the U.S.
- Smoked, drank, ate lots, worked way too hard
- Decades of study – not genes, habits, weight, or diet
- Only the social fabric of overwhelming interconnectedness has explained the data
- All of the Roseta houses contained three generations of the family. Rosetans took care of their own.
- Heart attacks practically absent in men over 65.

A Call to Rethink and Recommit

- We should not be fostering medical “dominance”
- The purpose of health care is to allow people to enjoy life
- Real life quality is about friends, engagement, freedom
- Just as the Direct Support Worker profession is adopting the “servant leadership” model
- We are here to serve, not to dictate
- We are here to liberate, respect rights, and encourage inclusion in the mainstream
- We are lucky to be part of such a noble movement

Thoughts About the Future

- The Affordable Care Act
- Great changes coming
- Some will bring reductions in "medical model" of support
- Example: NY ADAPT occupied NYSNA office in March over 100 hrs
- About nurse delegation of some care to non-nurses
- Essential for full use of Community First Choice rule
- We must – and will – end Medicaid's "Institutional Bias"

What Is the #1 Thing That Would Improve Health Care Quality?

- My opinion:
- A simple checklist approach
- In a very decentralized community support system, people can't be seen by docs & nurses every week or month
- Call it a scale, instrument, tool, or checklist
- Give a way for Direct Support Workers to "know what to look for"
- Make sure it's applied regularly
- The signs of health deterioration are 90% simple and easy to detect
- This would, in my opinion, extend lives and avoid health crises more than any other action

- ***The Checklist Manifesto: How to Get Things Right***
  - Atul Gawande, Holt & Company, 2009

Good or Bad?

- Probably the most successful "social experiment" in America this century

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

Winston Churchill

Thank You

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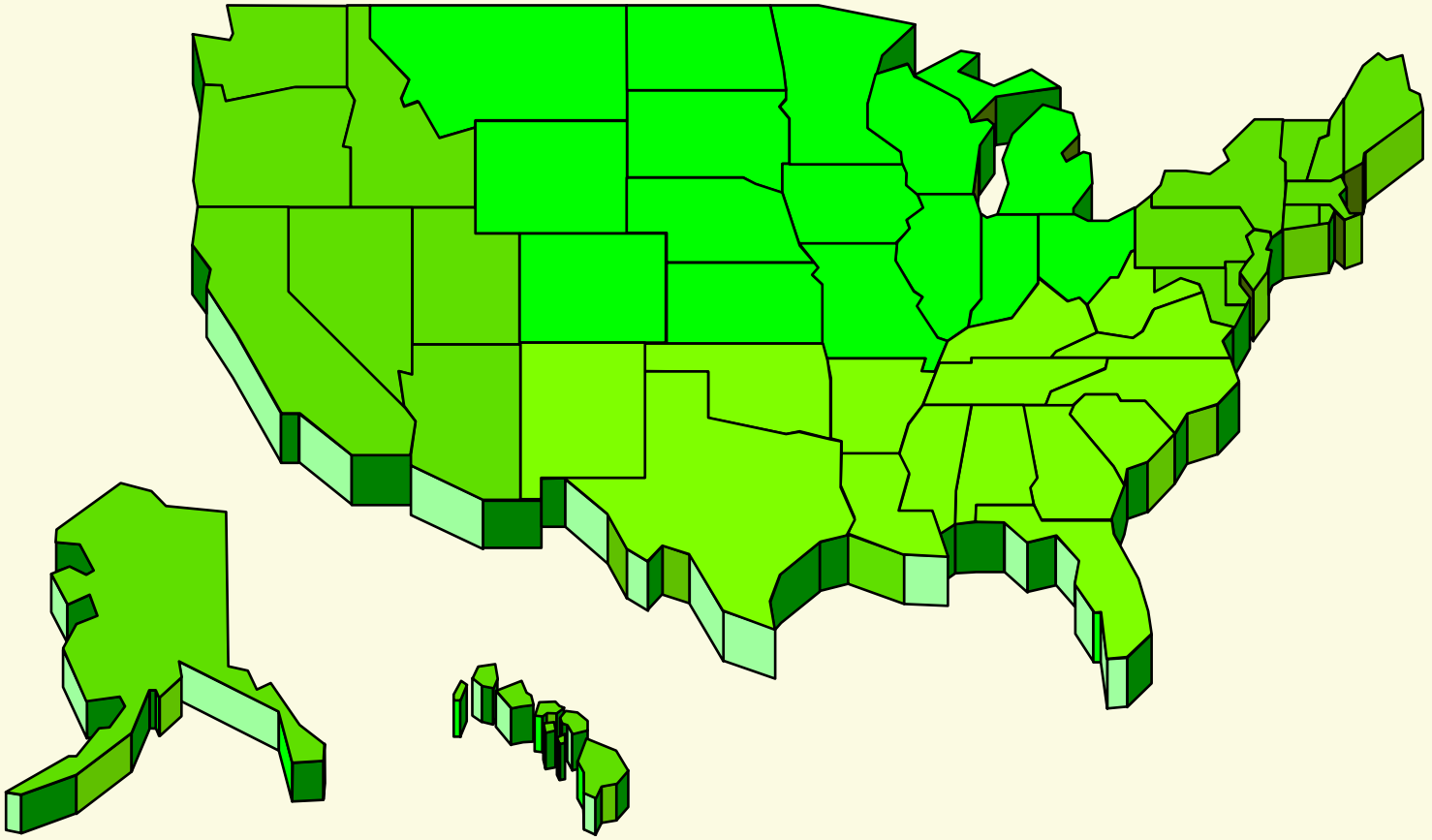

Values

- People
- Families
- Professionals
- Legislators

People

- Having friends
- Having money
- Being able to go places
- Having control

Families

- Health
- Health care
- Safety
- Permanence
- Freedom from abuse

Professionals

- Integration
- Independence
- Employment
- Sexuality
- Self-determination

Legislators

- Never mind all that
- What does it cost?