

These “New” Self-Determination and Self-Direction Models: Are They Fiscally Conservative?

IACC November 8, 2010

*James W. Conroy, Ph.D.
Center for Outcome Analysis*

www.eoutcome.org

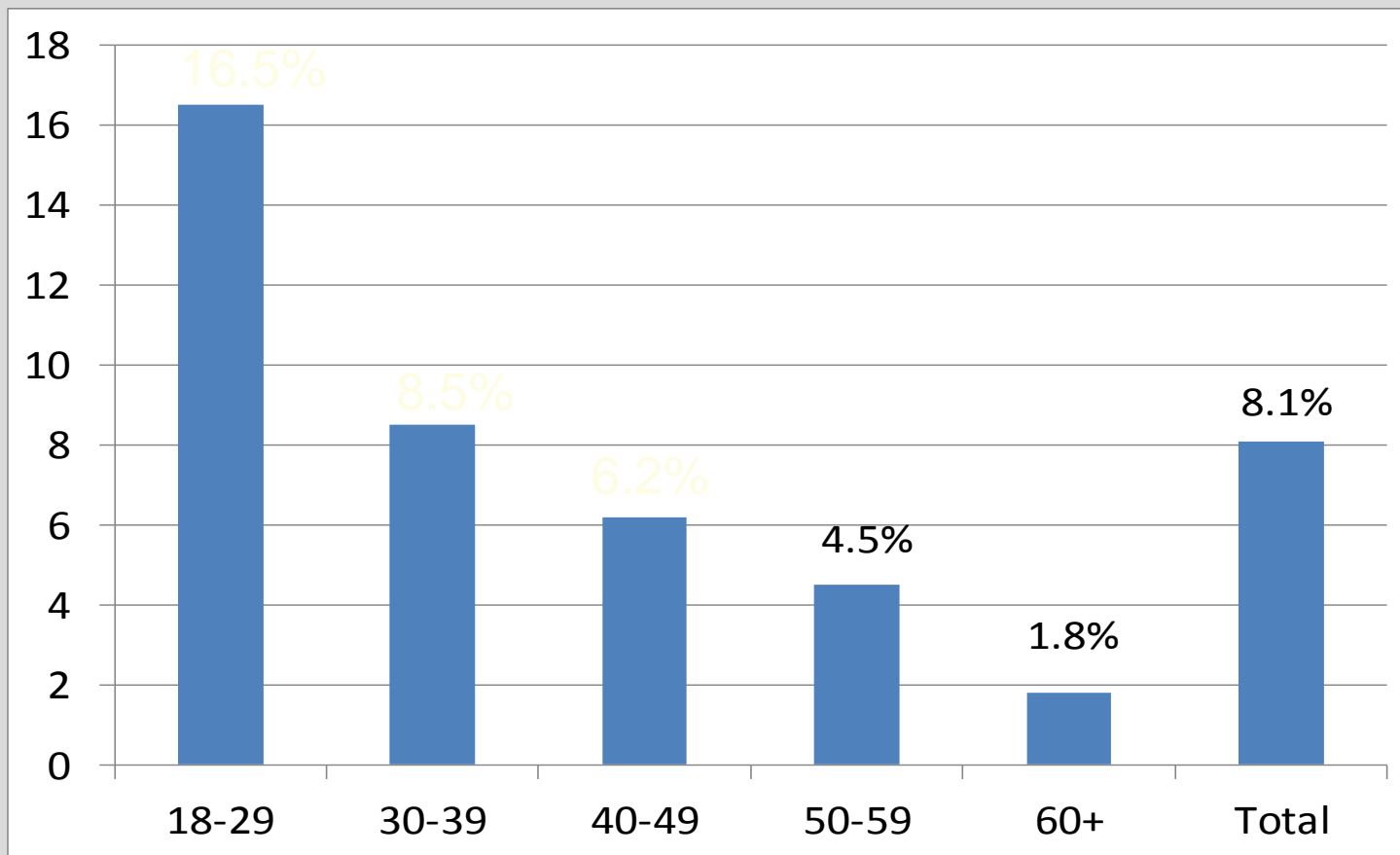
Purpose Today

- Historic trends review: ending large segregation
- Provide two points of reference
 - State government
 - Program evaluation
- Examples of self-determination
- Scientific outcomes - the short version
- Fiscal Implications from good studies
- Get some definitional clarity about power and control in our models of support
- Optimism and Caution

Developmental Disabilities

- Act of 1970
- Mental Retardation [sic], epilepsy, cerebral palsy, and related conditions
- Autism was added later
- Until then, and still afterward, conditions and labels were lumped together
- Large scale congregate care settings were the norm
- Changes began in 1970s with
 - Media scandals, legal actions, and philosophy of public policy including civil rights movements

Percentage of Persons in State ID/DD Services Systems with Autism Diagnoses by Age



Age Group

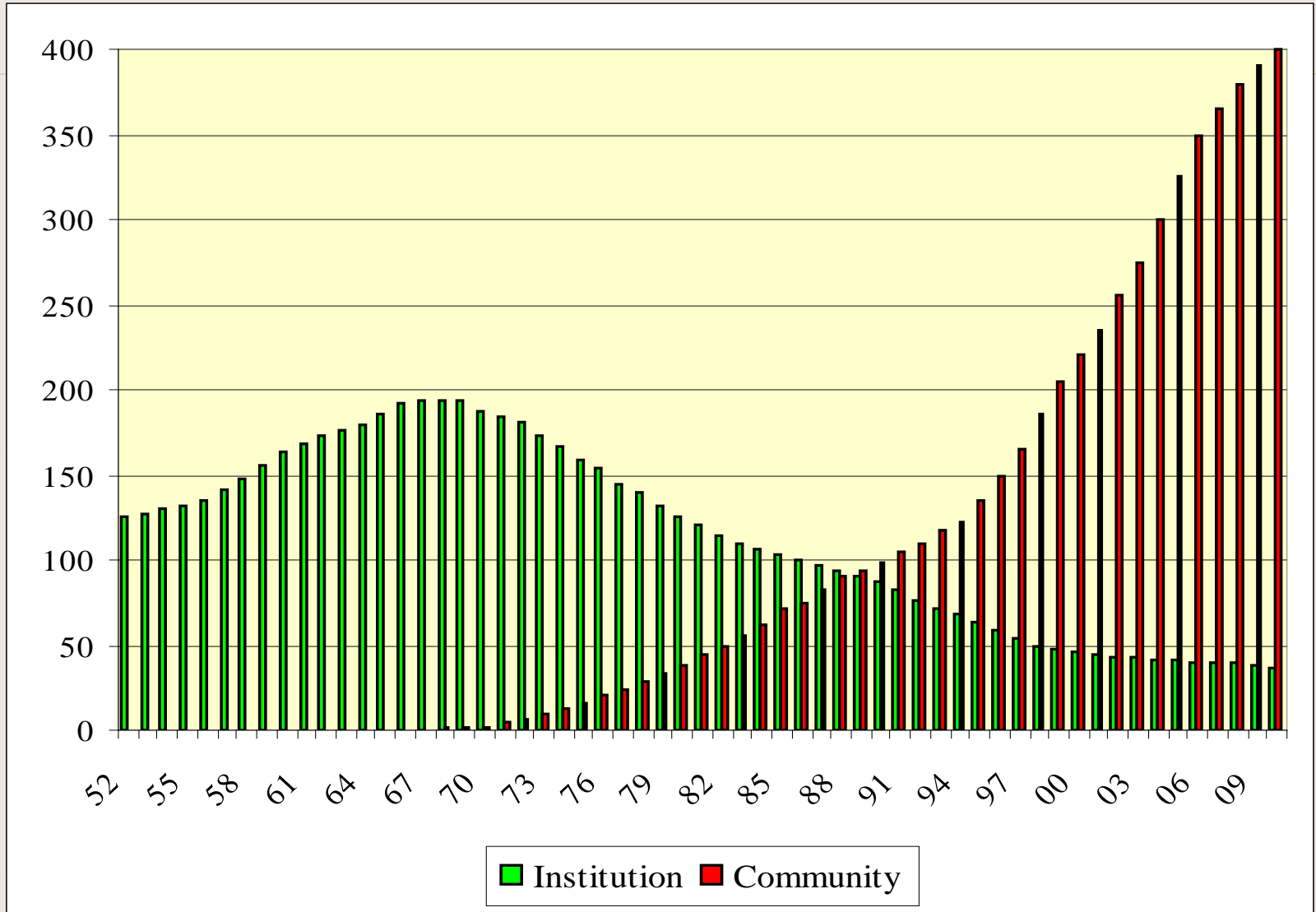
N=12,382

No. w/Autism Dx= 1,002

Conroy, IACC, 11/8/10

Source: NASDDDS & University of Minnesota, 2010

Institutional Decline, Community Rise



Our History

- Medical model
- Labeling, segregation, isolation, large scale
- 1970s community movement
 - “Normalization” zeitgeist, lawsuits, downsizing of DCs
- 1980s person centered thinking & planning
- 1990s the rise of “new” approaches
 - Early support 1992 from RWJF
 - Self-Determination, Individual Choices, and Cash & Counseling
- New century – CMS begins to turn toward self-determination, individual budgets, fiscal intermediaries, independent support coordination
- This change is continuing today
- What does it mean for public policy in autism?

The Original Concept

- **Self Determination:**
- If people gain control,
- Their lives will improve,
- And costs will decrease
 - (or not increase)

Sean – The Accident

- Just graduated from high school
- Terrible car accident, fell into a coma
- Sean's state did not have any nursing homes for head injury
- Professionals sent Sean to another state's nursing home



Sean Lived in a Nursing Home

- For several years
- 100 miles from his parents
- He didn't get much individual attention
- And he didn't improve
- His care was costing \$120,000 per year
- No one was happy



Sean's Parents Asked:

- Isn't there another way?
- How much is all this costing government?
- \$120,000? Really?
- If we had control of that money, we would do things very differently.



Sean's Parents Said:

- We would adapt a house for him
- We would hire his high school friends to work as his attendants
- We would hire nurses part time to oversee his care
- And we would have him close to us



Local Government Thought This Just Might Make Sense

- Courageous local leaders went to state and federal officials
- Explained the situation
- Asked permission to experiment with putting family in charge of how the money was spent
- Courageous state and federal officials agreed to “look the other way” while regulations were being “bent”

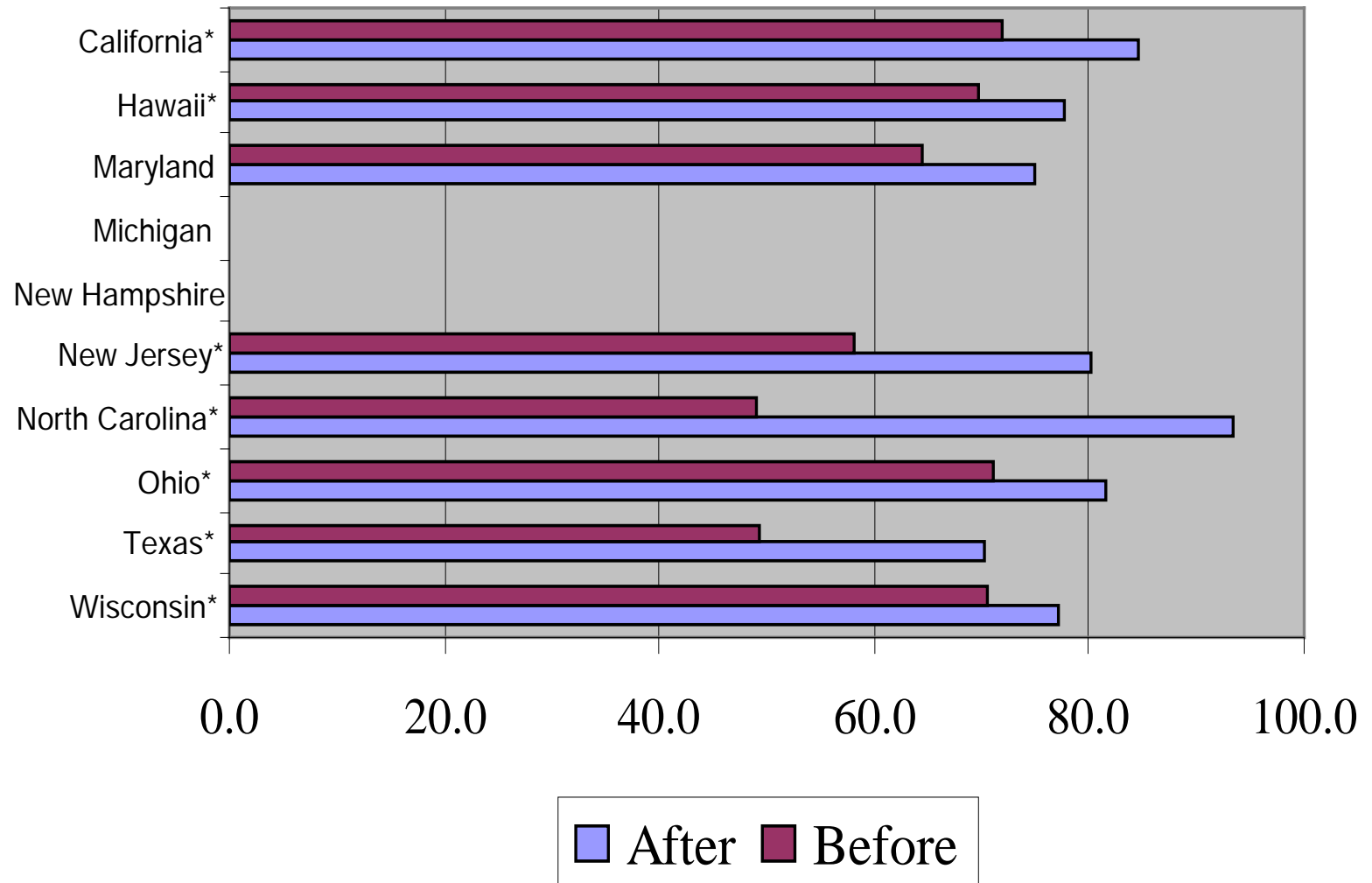
Sean Came Home

- Government dollars were used to buy a house
- And to make it accessible
- And to put in special bathroom and a lift
- Friends were hired as attendants
- They took Sean into town on outings
- Family visited frequently, reading to Sean, talking in his presence, and touching him

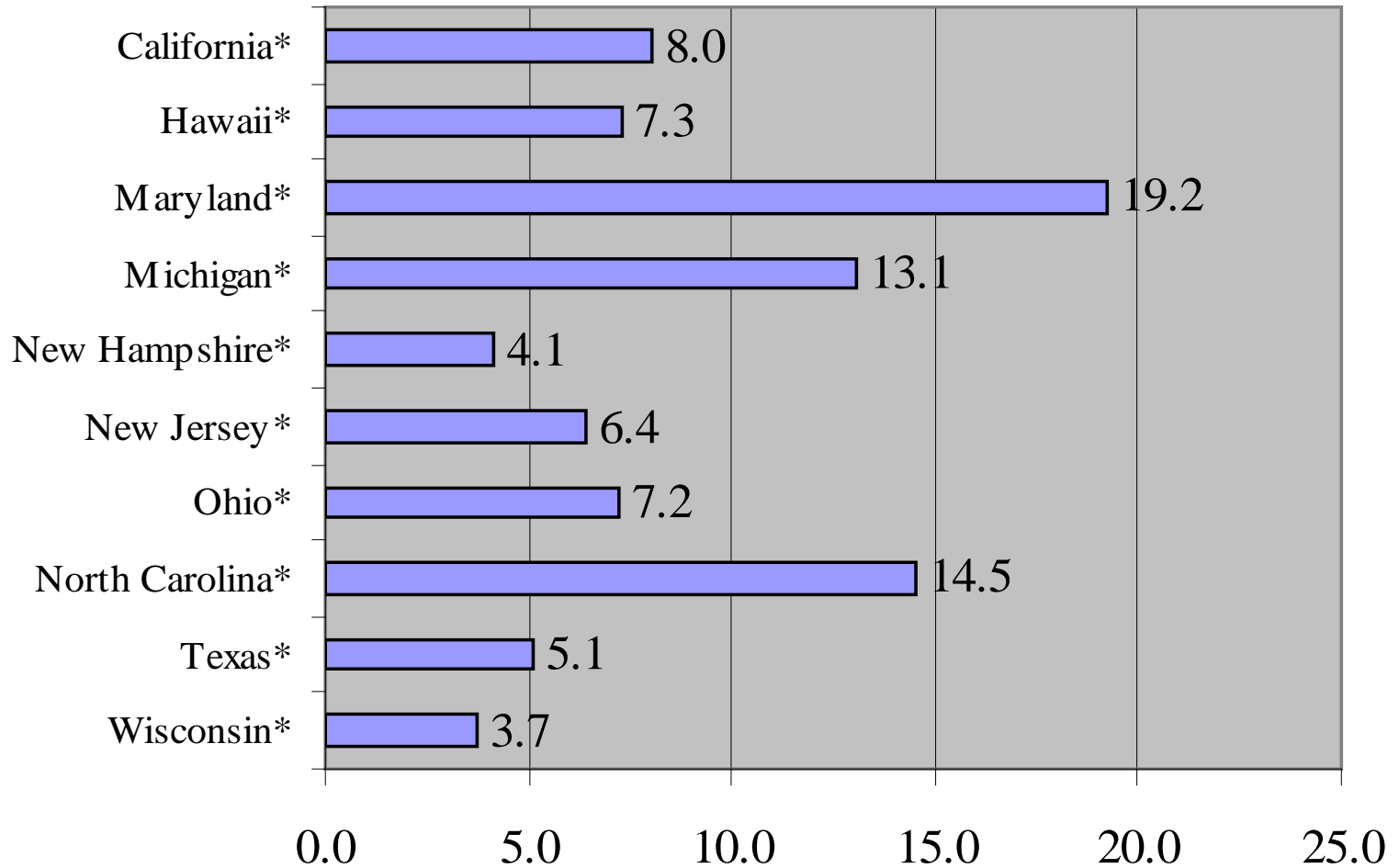
Is There Any Good Science Available About This?

- Robert Wood Johnson Foundation
 - Original pilot project in New Hampshire
 - National Self-Determination Initiative
 - 1997-2002, 23 states
 - Quantitative data from 10 states accumulated
- Cash & Counseling demonstrations
 - 3 states at first
 - Random assignment – control group designs
 - Mathematica evaluating – data still pouring in

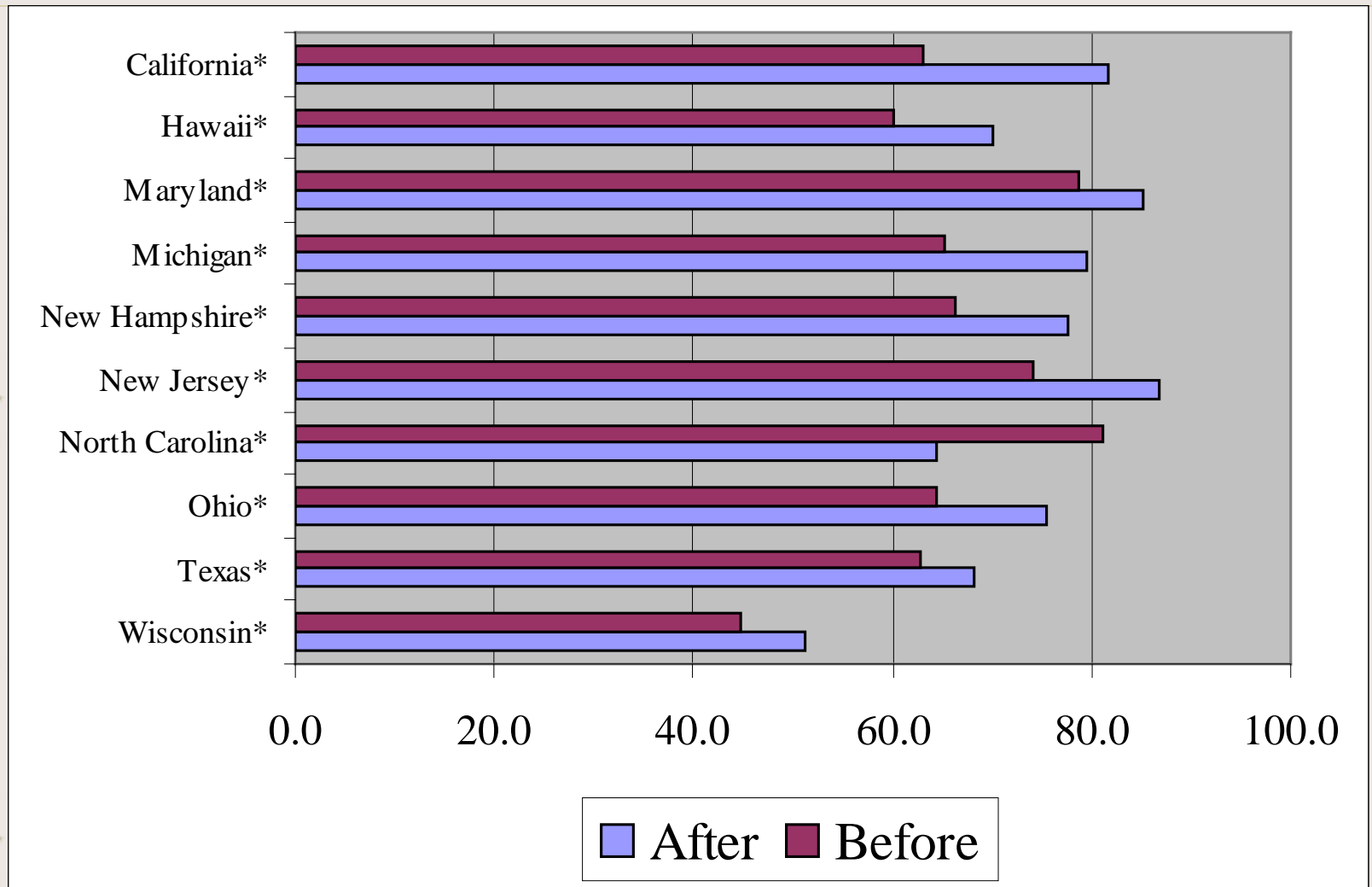
Did Planning Become More Person-Centered?



How Much Power Shift?



Improvement in Perceived Quality of Life in 14 Out of 14 Areas – in Every State!



Money

- The third part of the theory was that costs would stay the same
- Or go down
- When people and their allies got control of resources
- Did that happen?



Five Solid Cost Studies

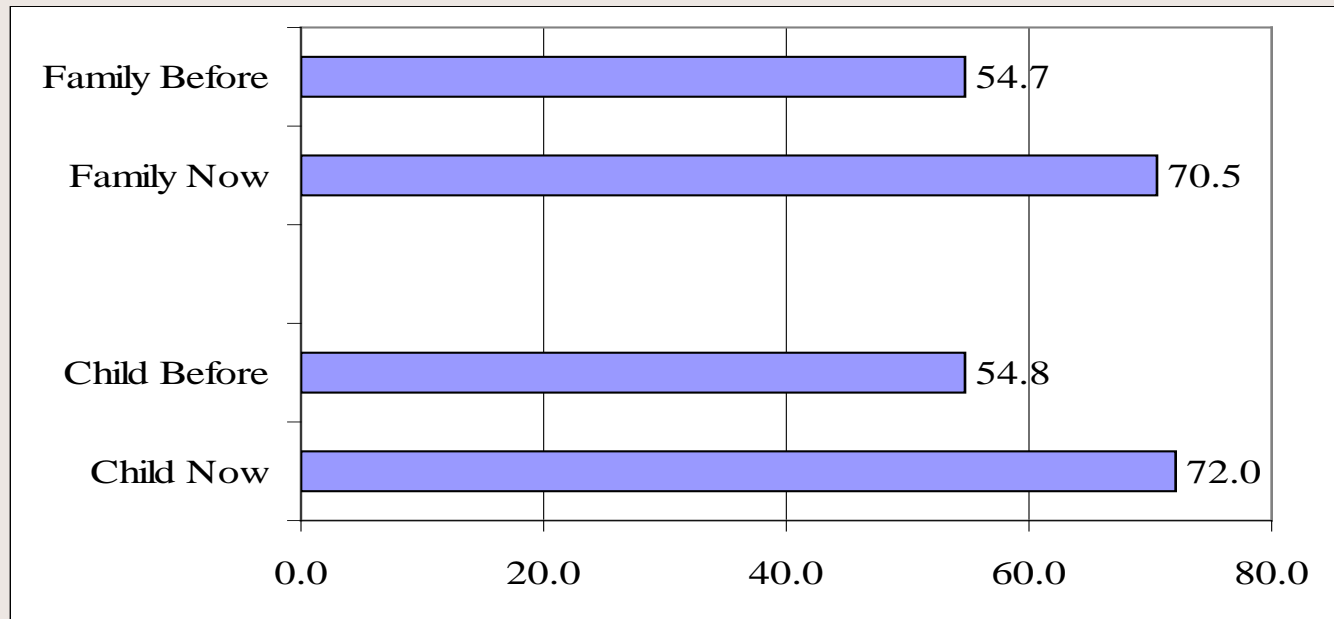
- NH
 - Down 12% to 15%, depending on estimates
- MI
 - Down 6% to 9%, depending on estimates
- NJ
 - The same as Waiver traditional models (much less than ICFs/MR or Special Needs Group Home)
- CA
 - All the participants' costs went up over 3 years
 - But a lot less than comparable non-participants
- ALLEGAN, MI
 - Superior cost-outcome ratios during time of fiscal contraction

Cost Increases in CA, 2000-2002

	Start	End	Percent Change
Participants	\$976	\$1,581	62%
Comparison	\$632	\$1,378	118%

Replication in Autism Supports: Youth Advocate Programs in PA

- Two years of outcomes tracking
 - Family and Youth Overall Quality of Life Scale:
 - Before and Now, During YAP Involvement



- Conroy, J., Brown, M., & Mitman, T. (2006, February). *Who Are the Young People Involved in the Youth Advocate Program in Pennsylvania, and How Are They Doing?* Brief Report #1 of the Youth Advocate Programs Outcomes Project. Havertown, PA: Center for Outcome Analysis.

The Strength of the Evidence

- Hard data from samples of participants
- In TEN states
- Over 800 people tracked for up to 3 years
- Remarkably consistent in positive direction
- Variable in size of the effects
- Partly because of recruitment of different kinds of people

Terminology

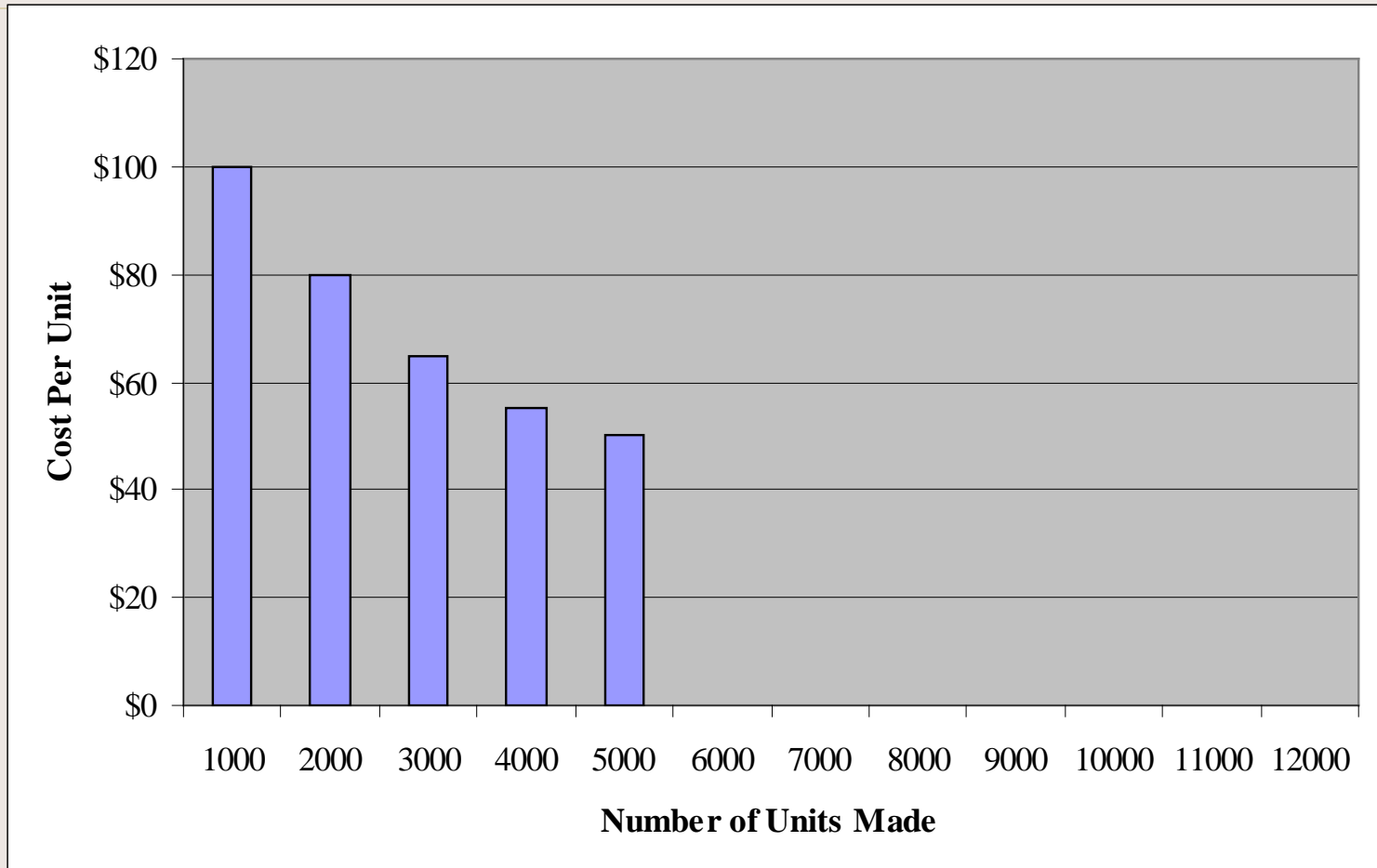
- Self-Determination (most advanced)
 - Self-direction
 - Consumer control
 - Support coordination
 - Family supports
 - Advance directives
 - Cash & Counseling
- All united by one simple concept
- People and allies tend to spend public funds conservatively, in a targeted manner, buying what is needed for a life that makes sense to each individual's situation

Optimism Tempered With Caution

- Beware of “selling” cost savings
- We’ve fallen into that trap before
- Deinstitutionalization – CA best example
 - Community homes better than institutions
 - But nowhere near as good as they might have been
 - Compare to OK or IN outcomes
 - Most community homes cost 75% of inst
 - CA tried to get by with 50%
 - “Six-Pack” group homes
- Lesson: Same dollars, better lives and better outcomes
- Cousin Buddy

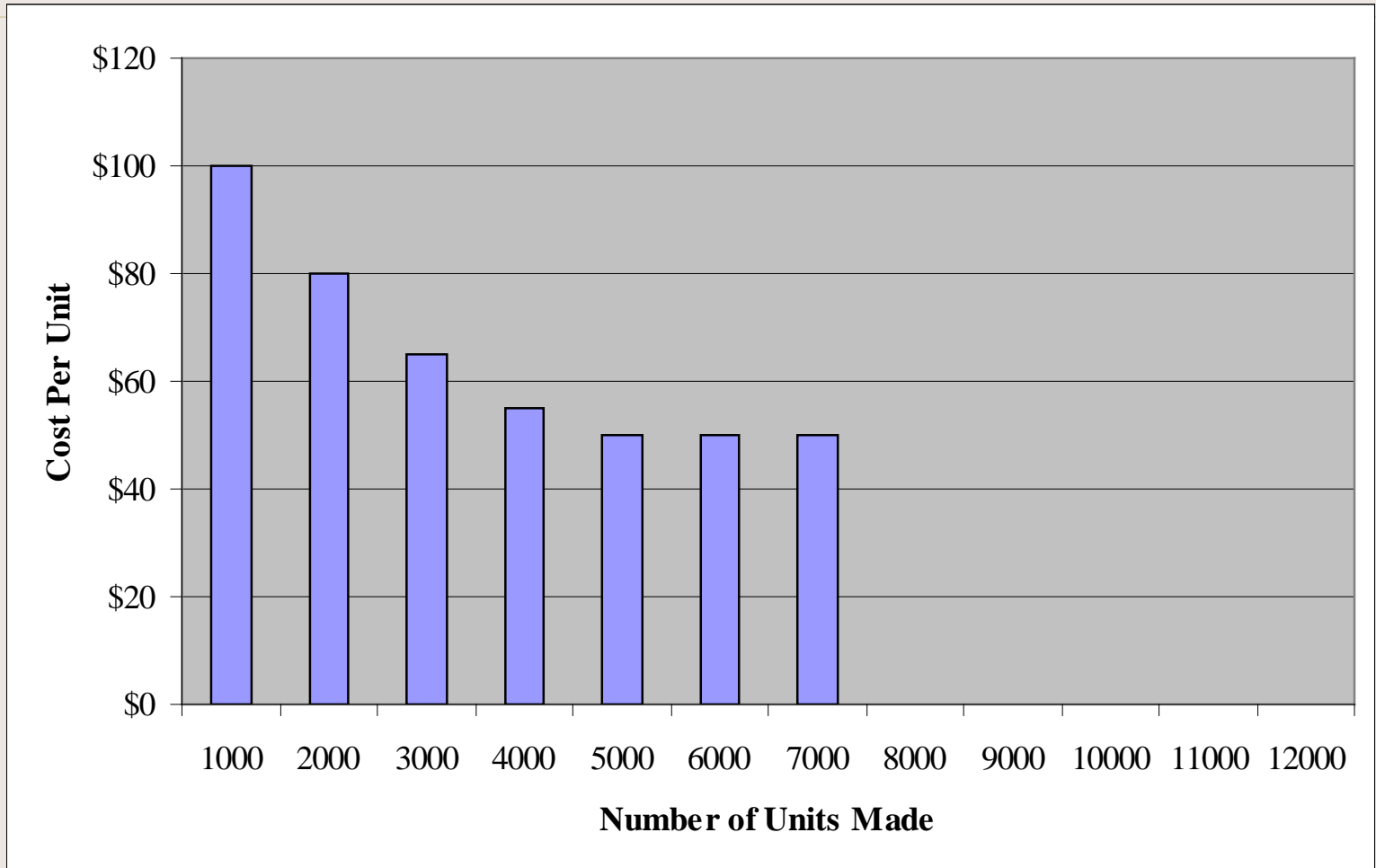
Economy of Scale 1:

Larger Organization, Lower Cost Per Unit



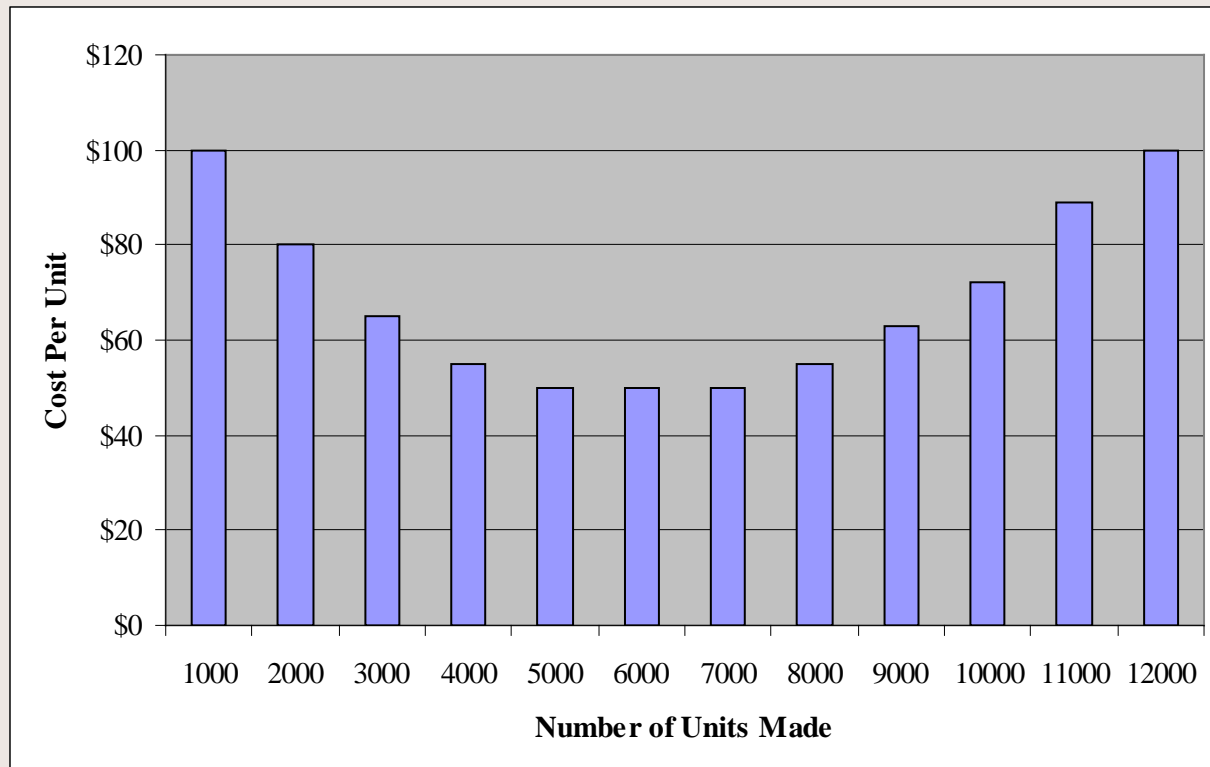
Conroy, IACC, 11/8/10

Economy of Scale 2: Diminishing Returns



Conroy, IACC, 11/8/10

Economy of Scale 3: Diseconomy of Scale



Conroy, IACC, 11/8/10