Self-Determination Impacts on Qualities of Life in the U.S.: A Brief Progress Report

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The Original Concept

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

Money and Quality

- **From a financial analyst Dad in NY:**
  - **My son was in a 6 bed ICF.**
  - **It cost $100,000 a year.**

  - **I pulled him out**
  - **because my son didn’t have**
  - **a $100,000 life.**

Where's the Proof!!!???

- Robert Wood Johnson Foundation
- We did our first outcome study in NH
- Funded a national impact assessment
- (Outcomes)
- 1998-2002
- Excellent "Before and After" data from seven states
- We also did studies in three non-RWJF states (CA, NJ, NC)
- We obtained solid data now from TEN states

A Brief History

- 1993 Original Proposal to RWJF
- 1995 Statewide in New Hampshire
- 1996 RWJF Decision to go National
- 1997 Grants to 19 States
- 1998 10 More Planning Grants
- 1998 National Evaluation Begins
- 1998 10 More States Join With State Funds
- 1999 Michigan shows positive results
- 2000 Michigan, Ohio, Wisconsin, Hawaii
- 2002 New Jersey strong results
- 2003 California strong results

Numbers: National Evaluation

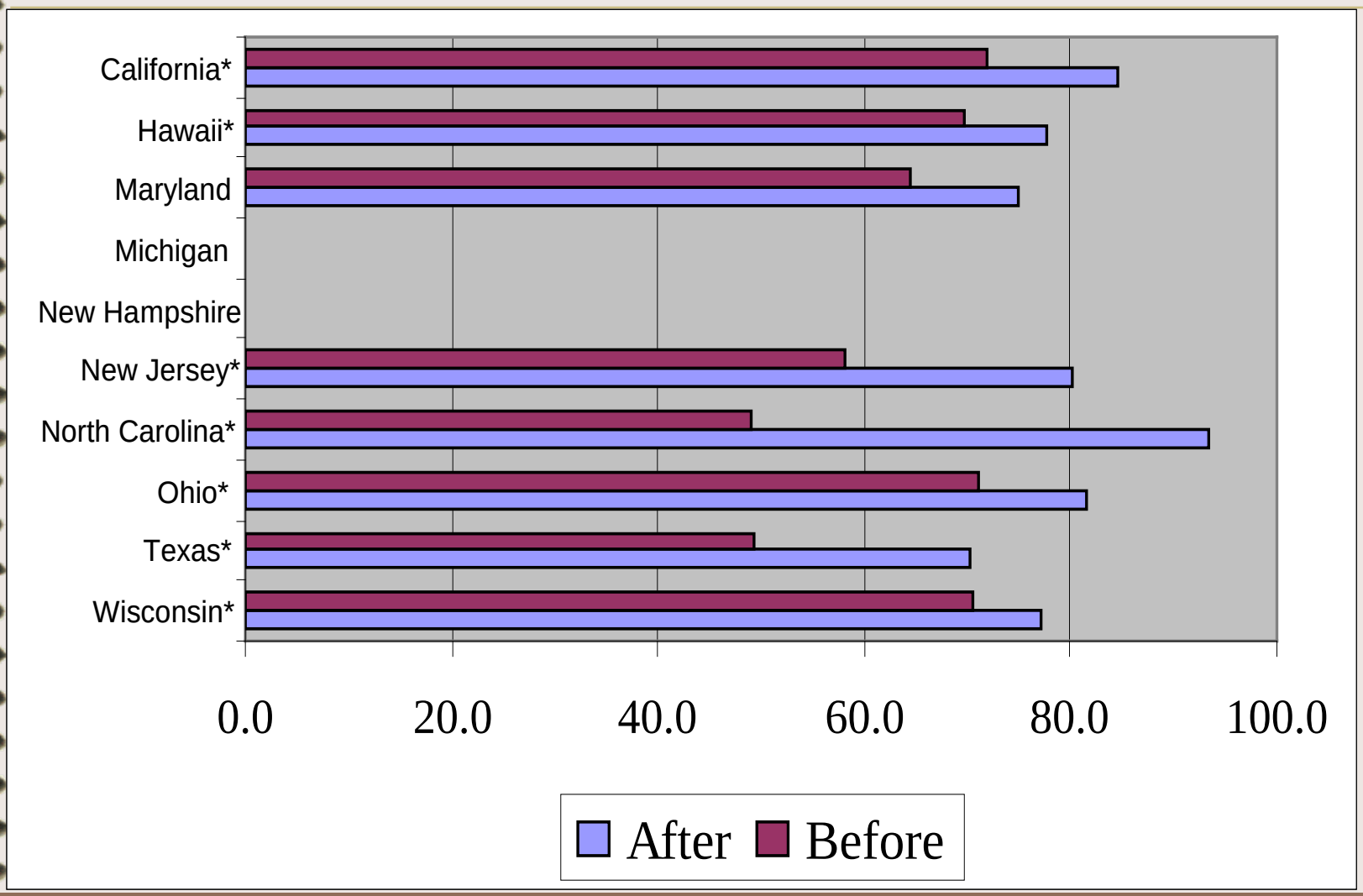
- CA 120
- HI 74
- MD 15
- MI 135
- NH 42
- NJ 200
- NC 40
- OH 62
- TX 50
- WI 89

Total 827

Power and Control

- In order for people to gain power and control over their lives,
- First the individual planning process has to become highly **person-centered**,
- Respecting the wishes and hopes of the person and the person's freely chosen allies first and foremost.

Did Planning Become More Person-Centered?



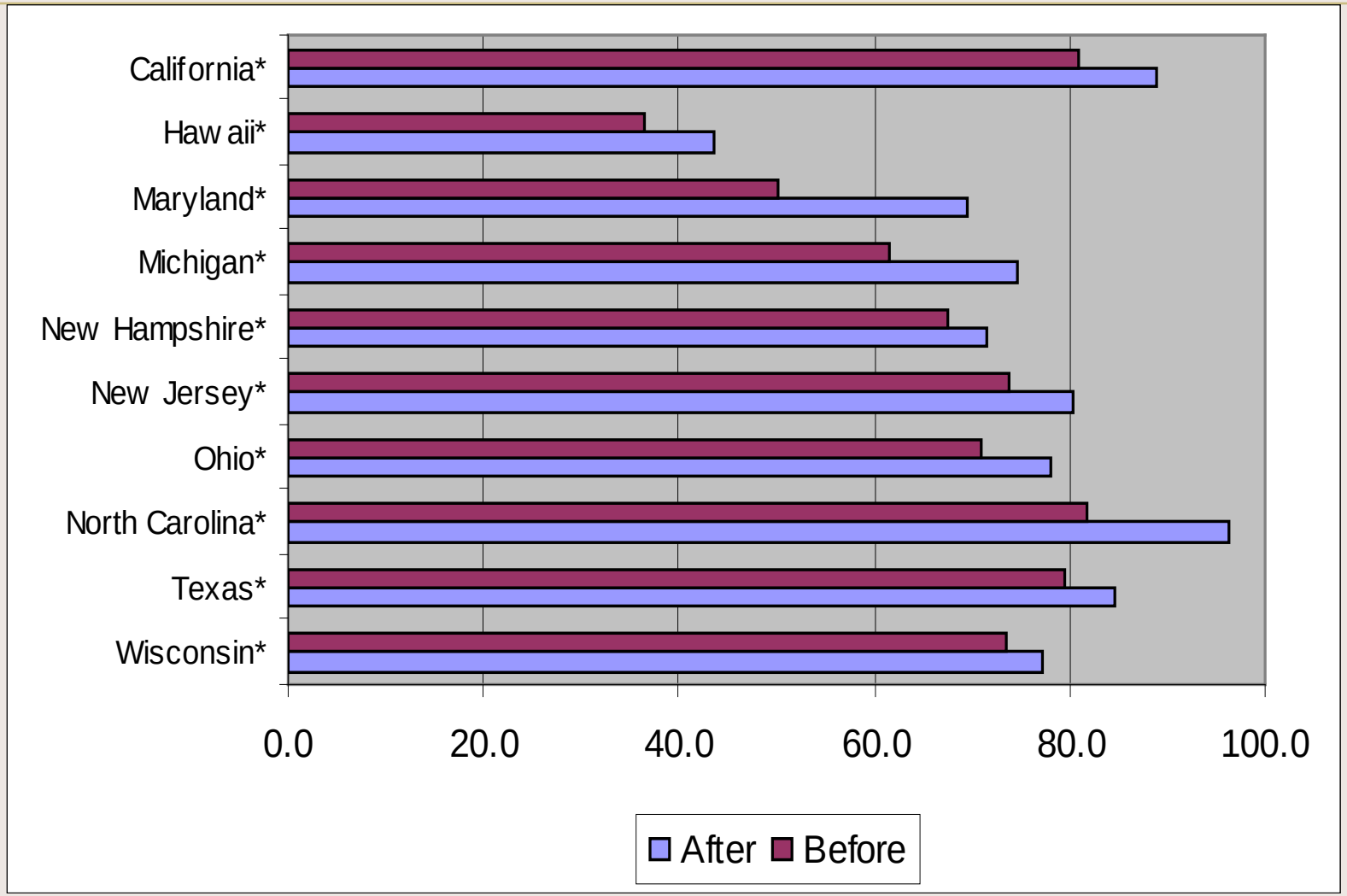
OK, PCP Increased – But Did Power Shift Toward the People?

- It's important to know
- Because PCP is only a process
- A genuine shift in power would be an outcome –
- A change that a lot of people would really like!

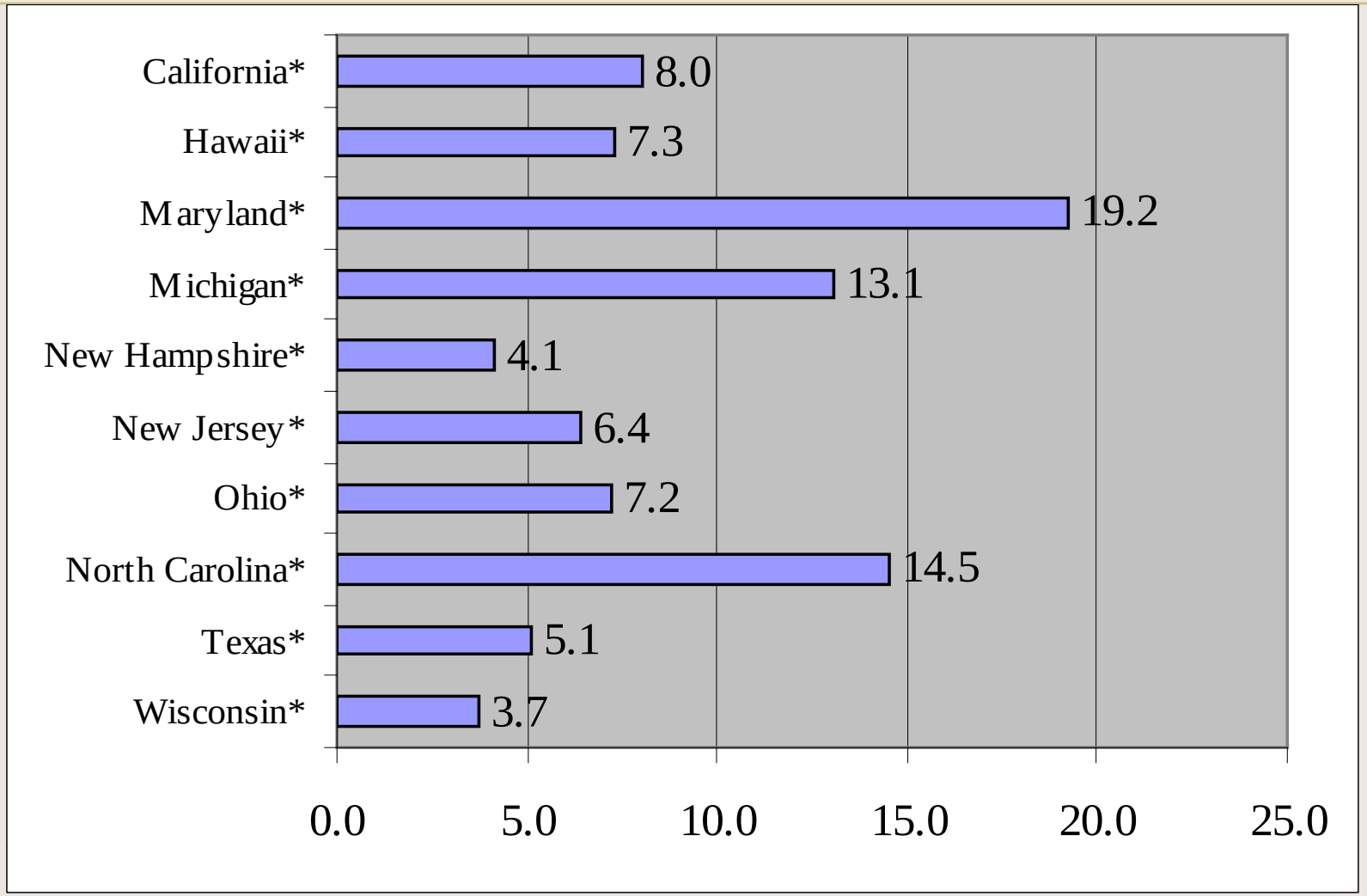
The Decision Control Inventory

- **Asks people (or their allies) to rate who holds how much power**
- **In 35 areas**
- **Paid staff – or you and your allies**
- **Reliable (0.86 interrater)**
- **Measures shift from paid folks to people and their freely chosen allies**
- **Including family, friends, and also paid folks if the person so chooses**

Did Power Really Shift?



How Much Power Shift?



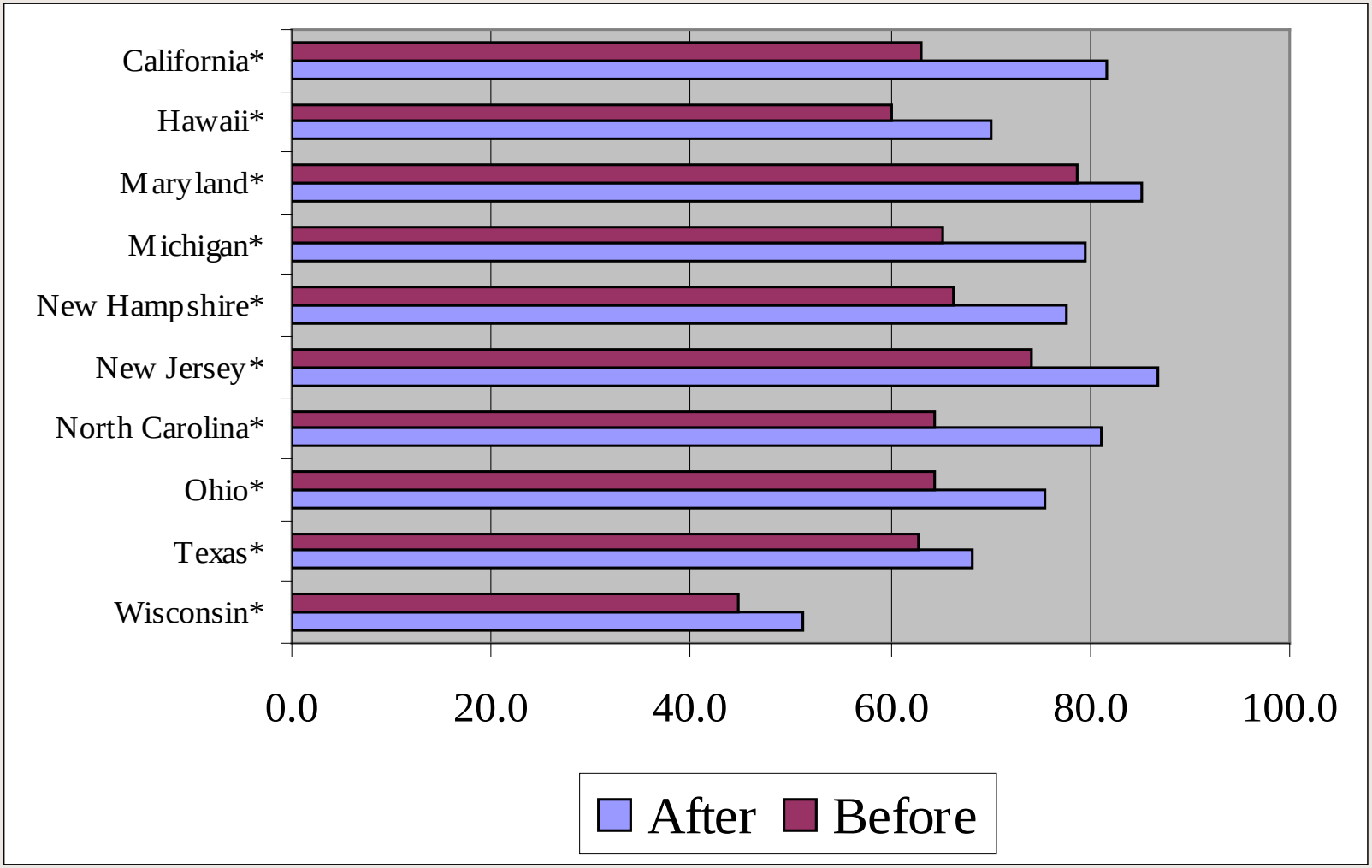
Power Over Resources?

- Yes, that definitely shifted
- Choice of home
- Choice of how personal funds are spent
- Choice of how residential public funds are spent
- Choice of provider
- Choice of support coordinator

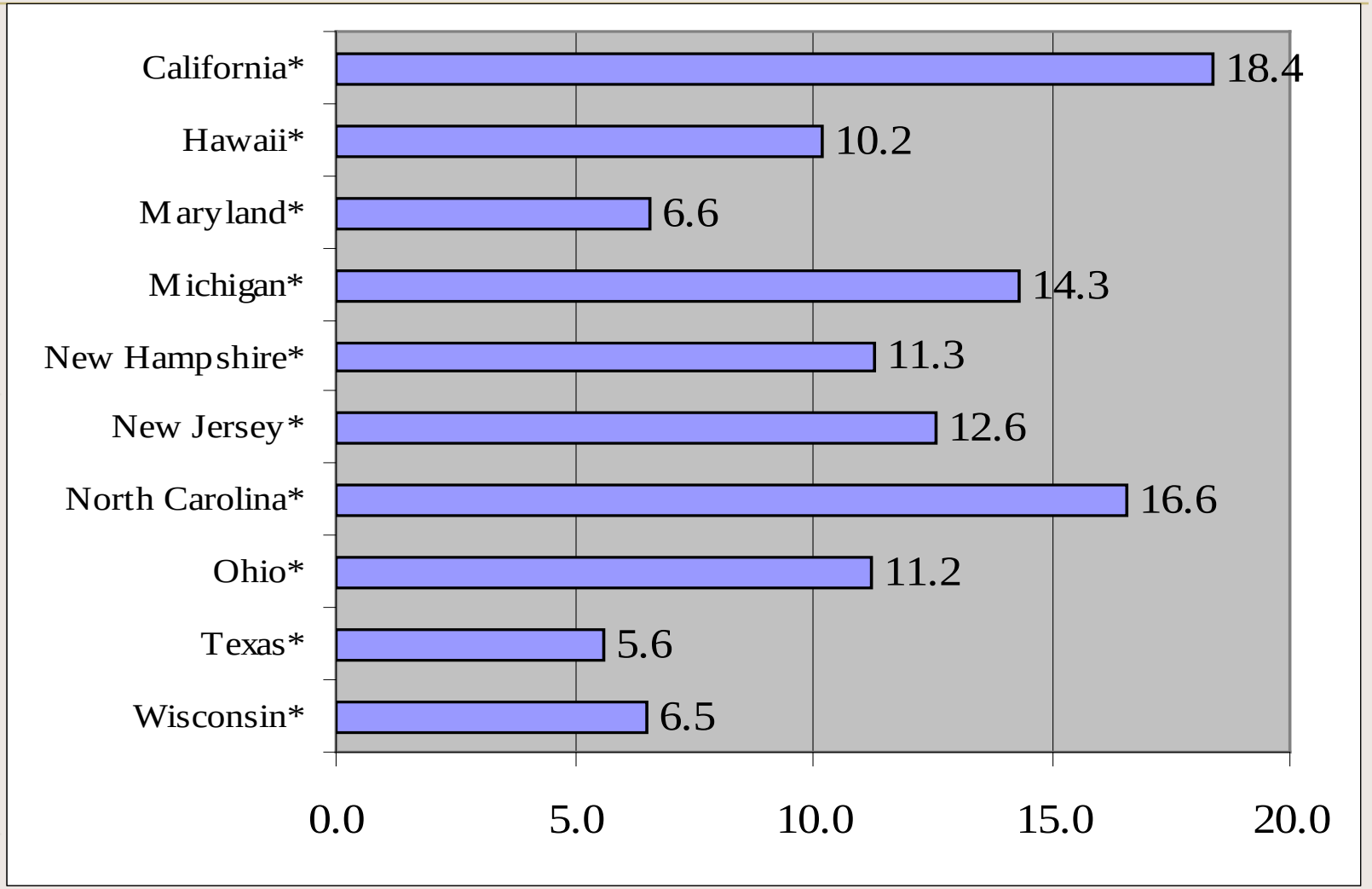
OK, Power Shifted Toward the People – But Did The Qualities of Their Lives Improve?

- The Quality of Life Changes Scale
- Asked people to rate the qualities of their lives
- In 14 areas
- When they were just beginning self-determination
- And at about 3 years into the process
- Data from 9 states:

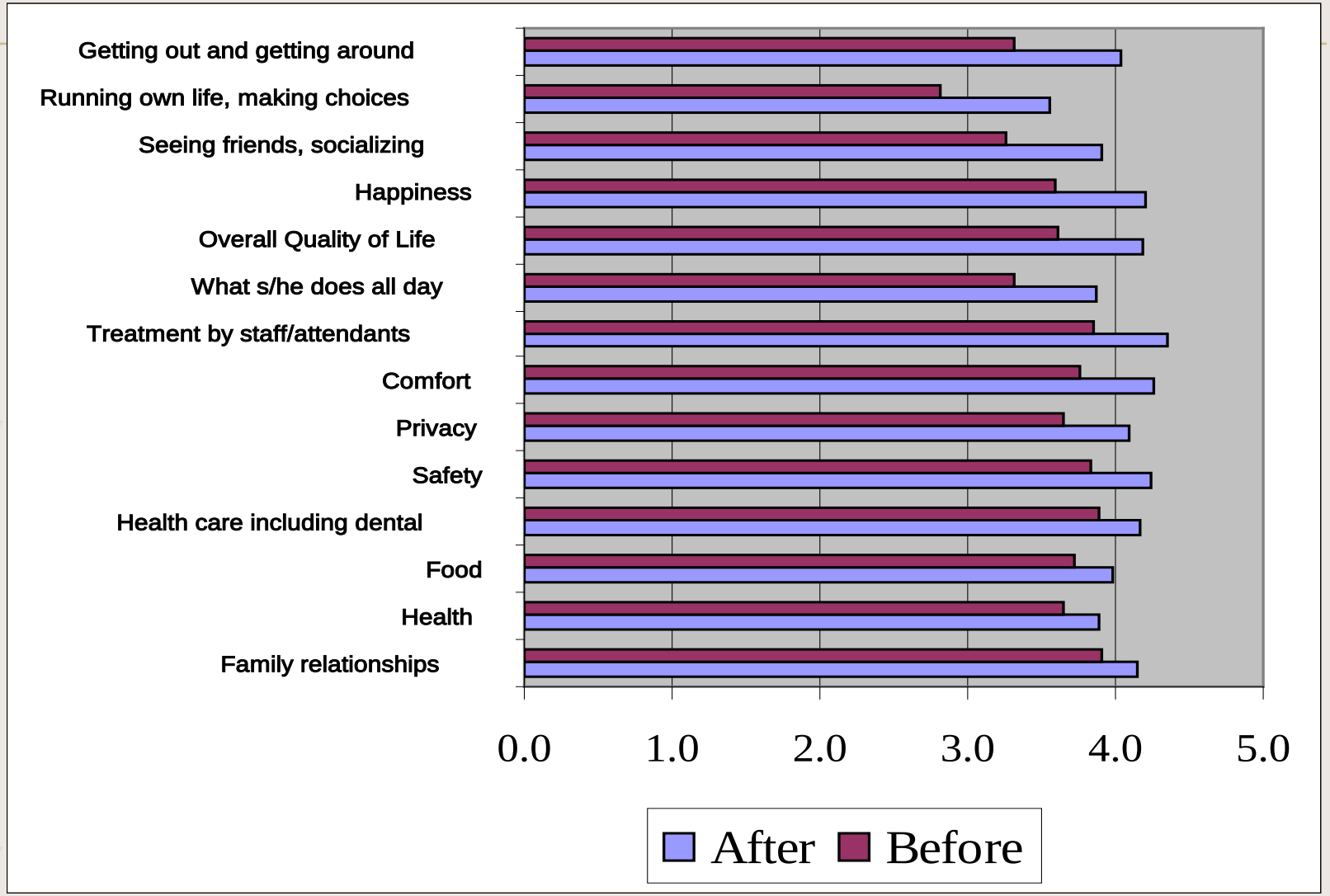
Improvement in Perceived Quality of Life in 14 Out of 14 Areas – in Every State!



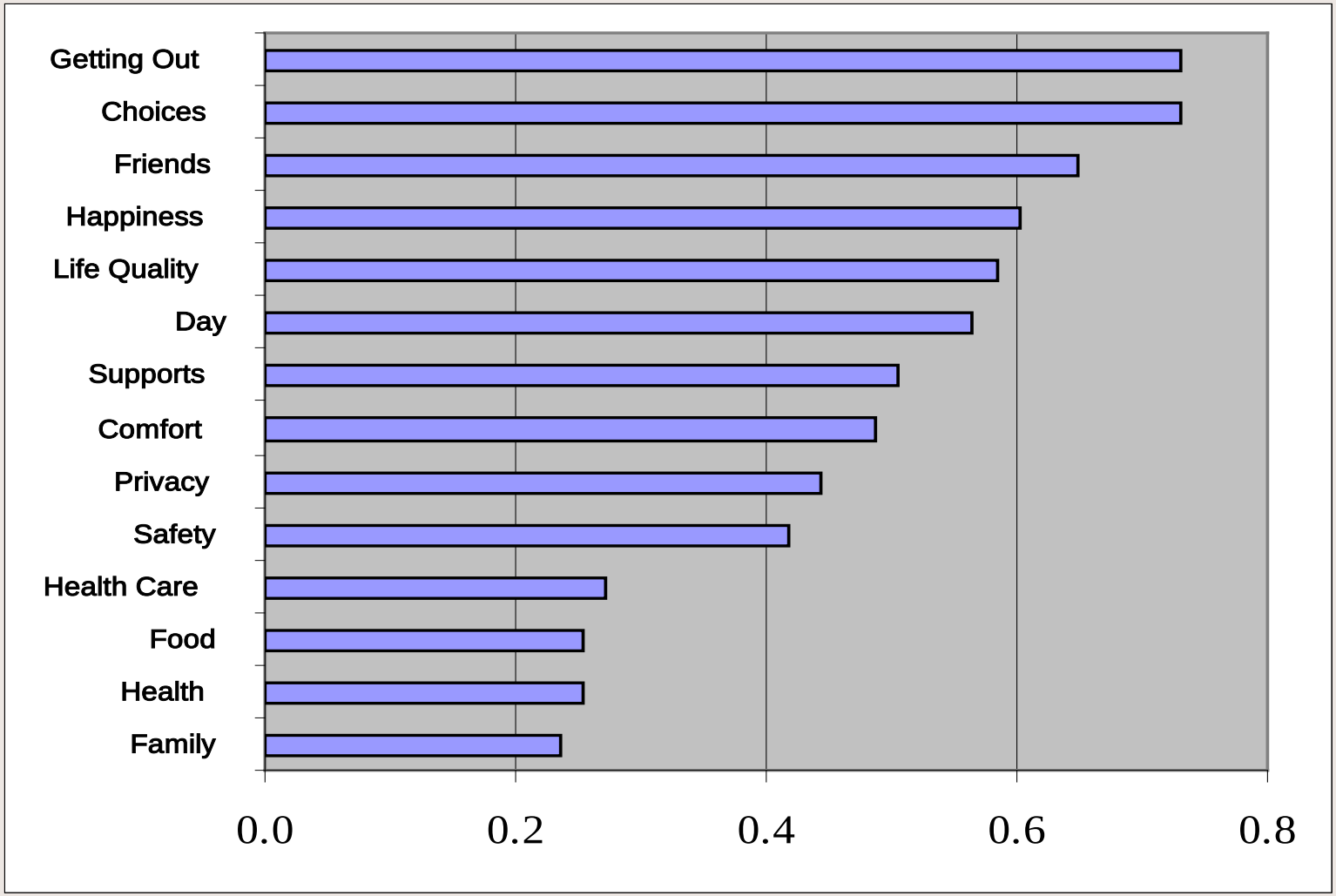
How Large Were These Perceived Improvements in Quality?



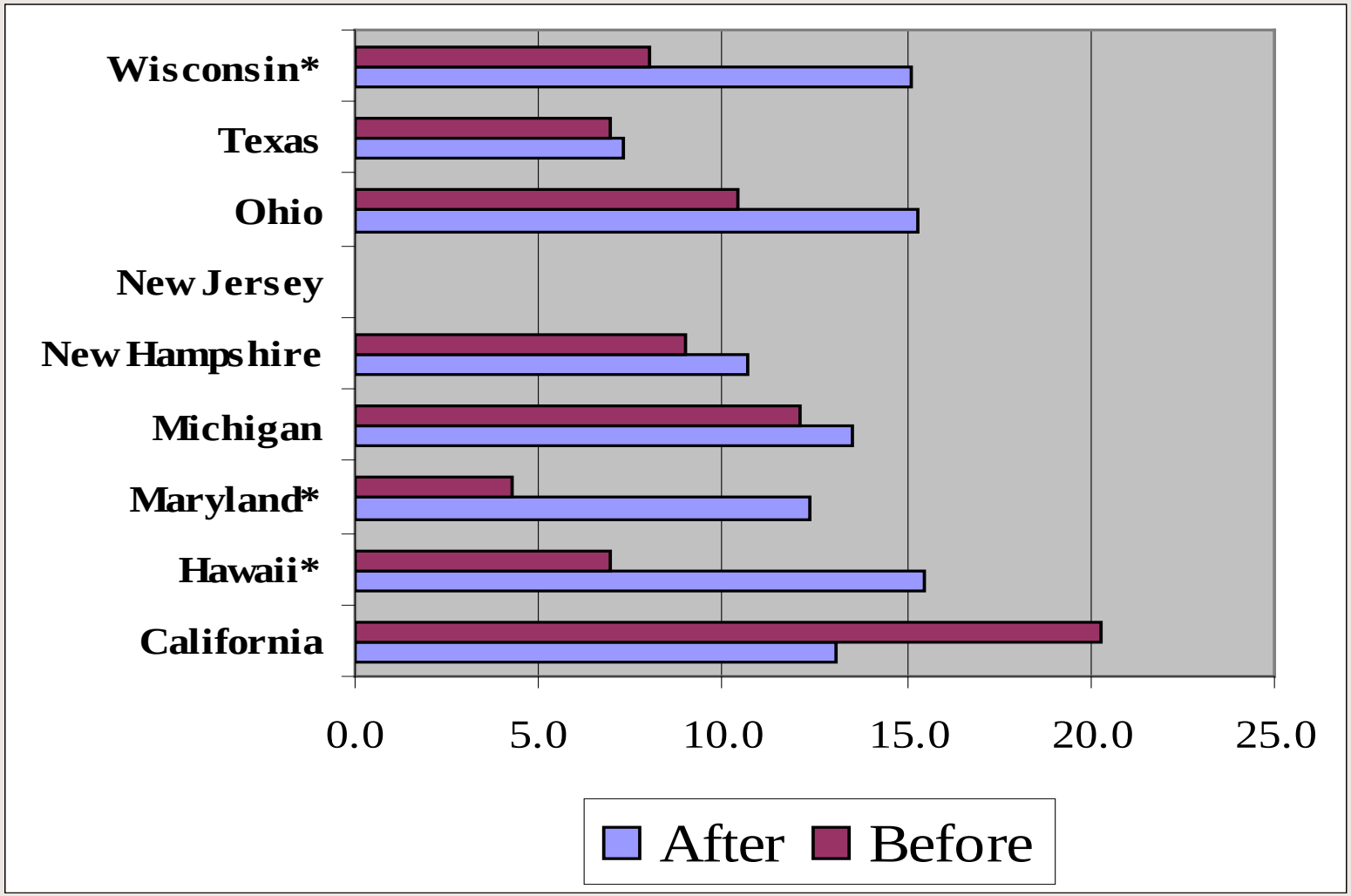
Those Reports Were From the People, and From Paid Folks – What Did the Families Perceive?



What Were the Largest Benefits the Families Saw?



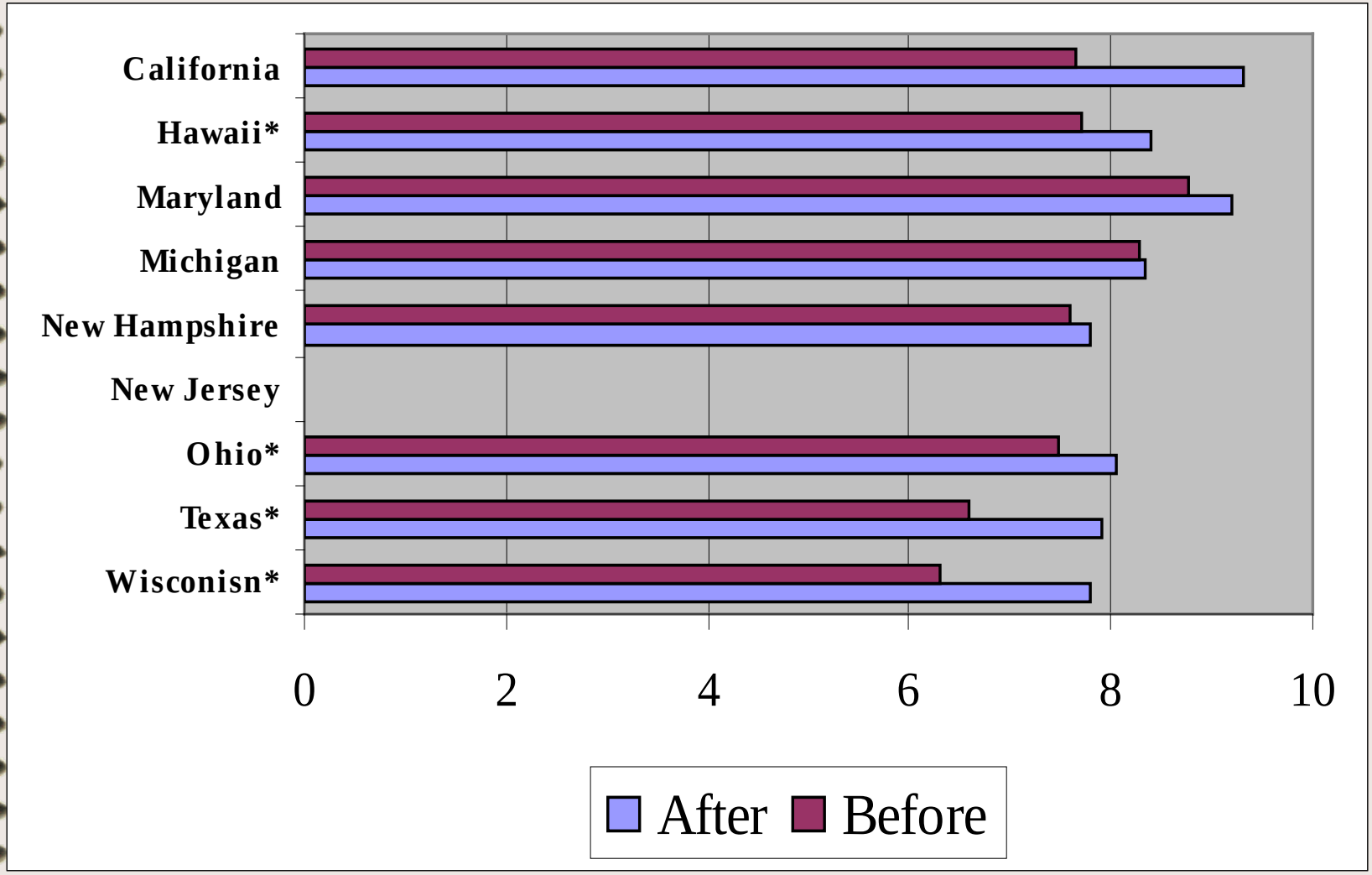
How About Friendships – That's A Very Large Factor in Quality



What About the Workers?

- The workforce is a critical issue, right?
- Workers are really the determinant of quality when all is said and done
- Doesn’t self-determination just make their jobs even harder?
- Isn’t there resentment about giving up power and control?
- Won’t they like their jobs less?

Workers' Qualities of Work Life, Before and After



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?

Four 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

Cost Increases in CA, 2000-2002

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

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