

New Approaches To Quality: Rethinking Quality in the Context of Self-Determination

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And

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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.**

Why should others believe that self-determination works?

- Stories
- Scientific research
- Always need both --- depends on audience
- How does policy really work?
 - Reforms As Experiments; Political system sells certainty, solutions, sure things

How Have We Been Thinking About Quality for the Past 100 Years?

- **Standards, licensing, accreditation, ICF/MR or ICF/DD reviews, Waiver look-behinds, surveys, etc.**
- All facility-based, not individually based
- All process (paper and procedures)
- All assume that “good” process leads to “good” outcomes
- Usually focusing on Health & Safety

But What Is Quality?

- Isn't it pretty much the same for everyone?
- Regardless of disability?
- Haven't we been confusing
 - Quality of Services
 - with
- Quality of Life?



What Are the Common Foundations of Quality?

- Having something meaningful to do
 - (most common first question - what do you do?)
- Having friends
- Being loved
- Being welcomed into the life of the community
- Having control over your life
- And doing it as well as you can
 - (taking pride in work or contributions, an activity identity)
- And being a friend
- And loving others
- And welcoming others into your own life
- And sharing control with those you trust

We Must Start Over

- **One Example:**
- **Transportation**
- The degree to which the person can, in a planned and spontaneous way:
 - § Decide to “go out”
 - § Plan an evening or weekend trip
 - § Get to work on a regular basis
 - § Offer transportation to a friend

This Has Been Done Before

- Over the past few decades, there have been several initiatives
- NASDDDS Reinventing Quality series
- QualityMall.org
- But we have to do it again now,
- Because of all we've learned via self-determination



Multiple Problems to Solve

- Ask the questions in ways people will understand
- In ways people can answer accurately
- Or that close allies can answer accurately
- That will be reliable (scientific necessity)
 - Between interviewers
 - Over time (a week or two)
- And valid – measure things that are really important to people

In the Self-Determination Initiative, We Have Come Far

- Learning what to measure
- Learning that from the people themselves
- Thousands of people
- Across a decade
- (e.g. power, friendships, involvement in groups, worship)
- But we must now take it much further
- Abandoning the Human Services foundation in favor of common human wants and needs

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 have 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

Numbers: National Evaluation

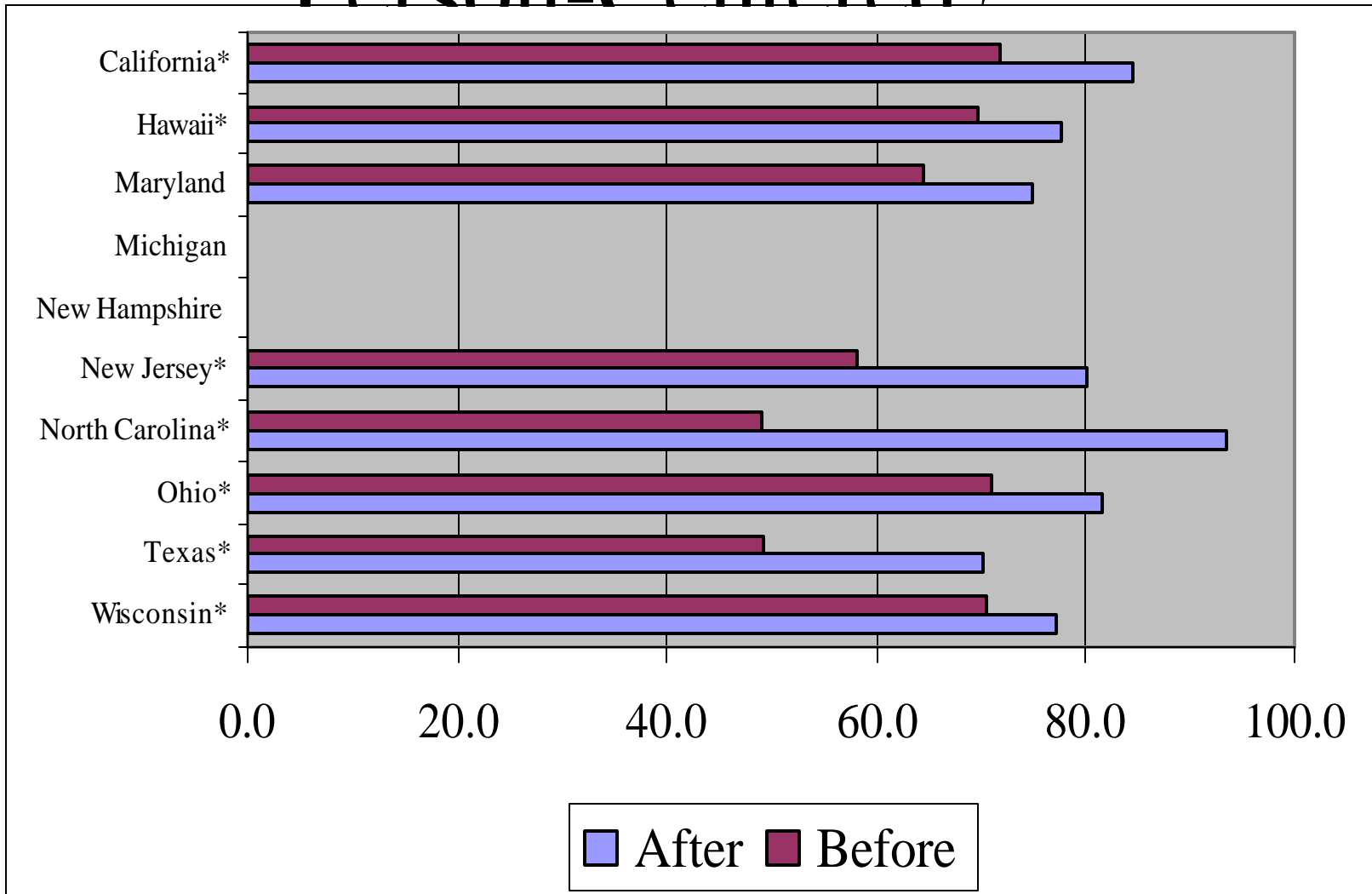
- CA 120
- HI 74
- MD 15
- MI 135
- NH 42
- NJ 200
- NC 40
- OH 62
- TX 50
- WI 89

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?

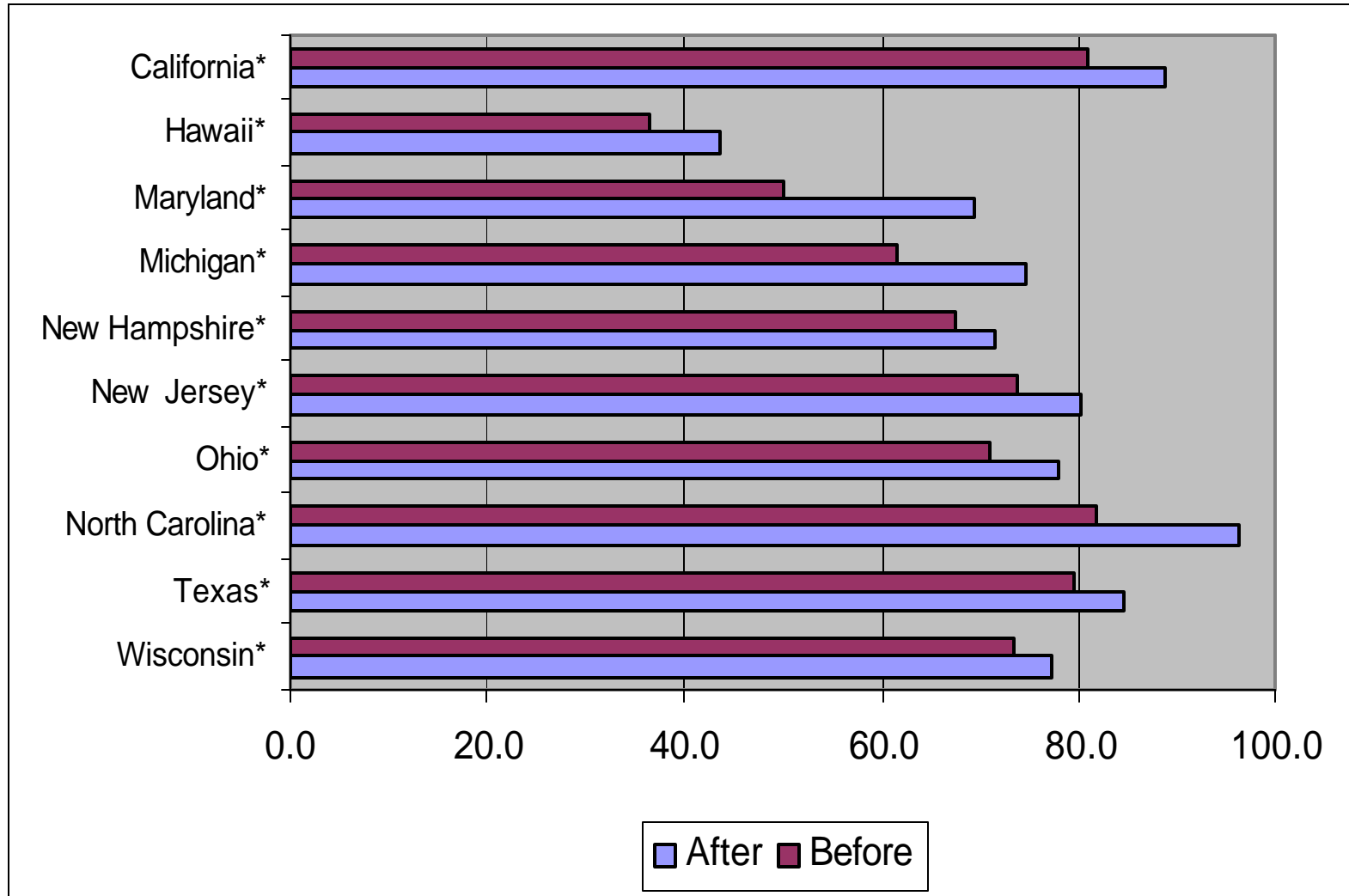
- It's important to know
- Because PCP is only a process
- A genuine shift in power would be an outcome –
- A change that a lot of people would really like!



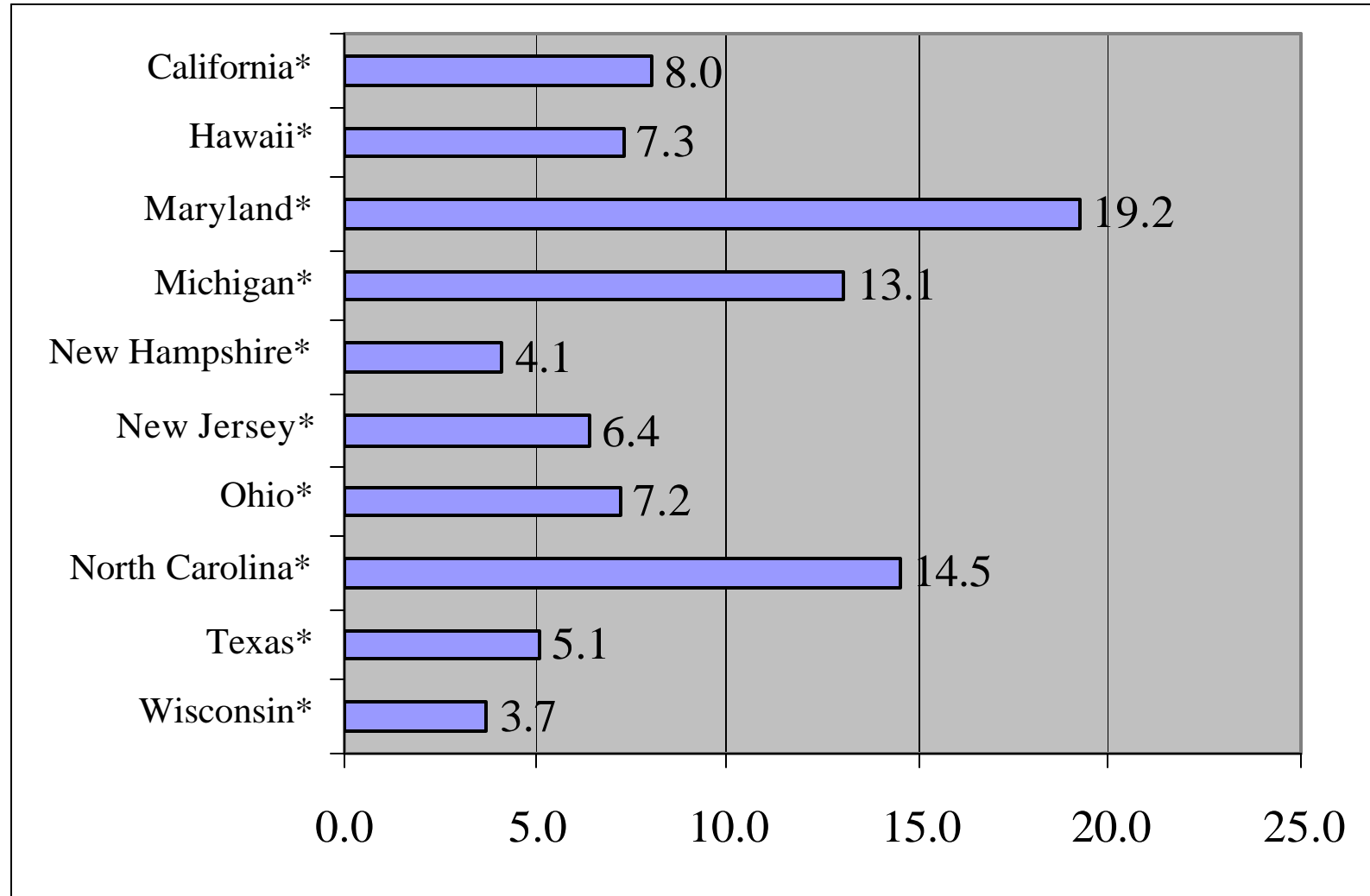
The Decision Control Inventory

- **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?



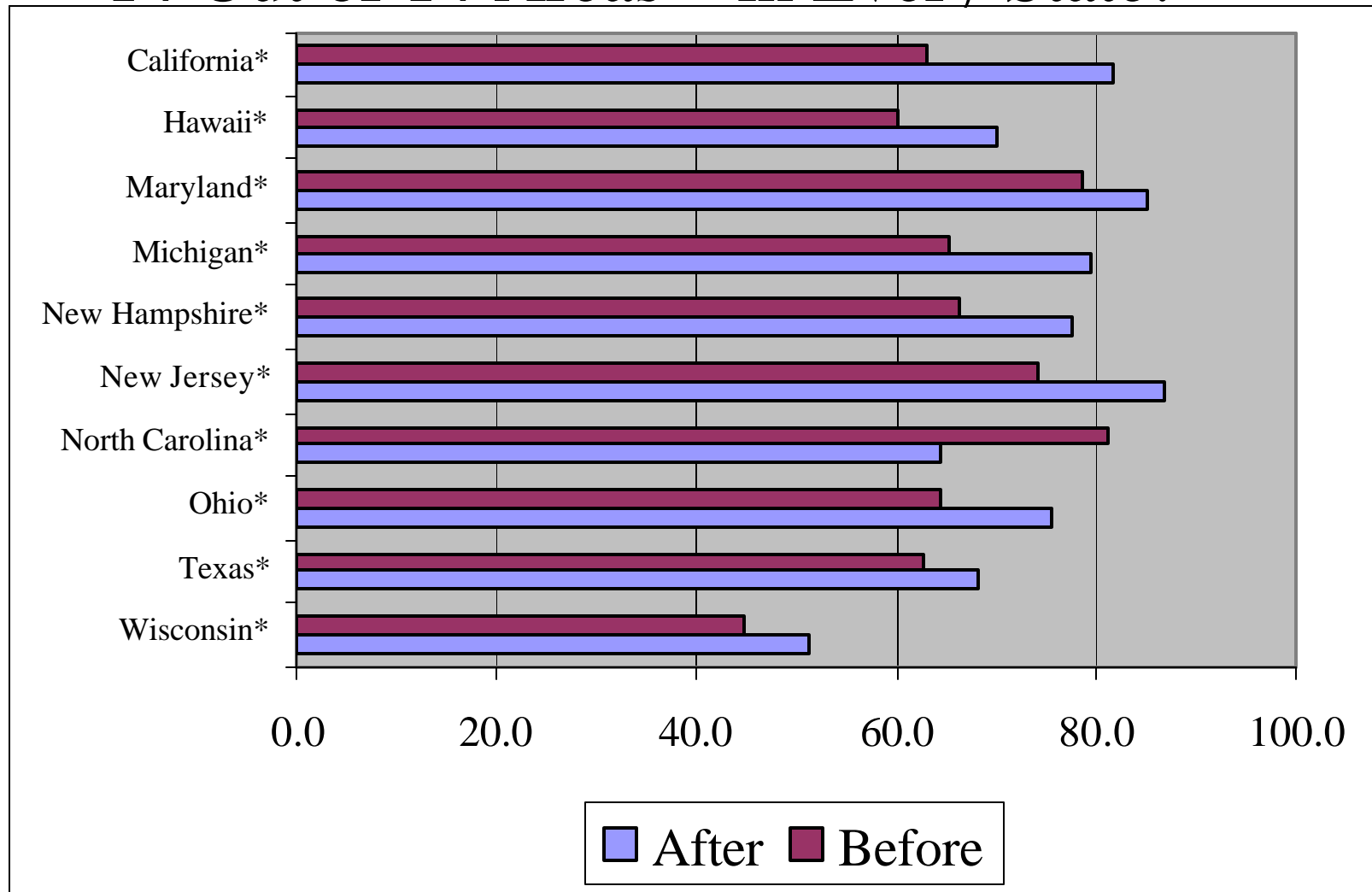
Power Over Resources?

- 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

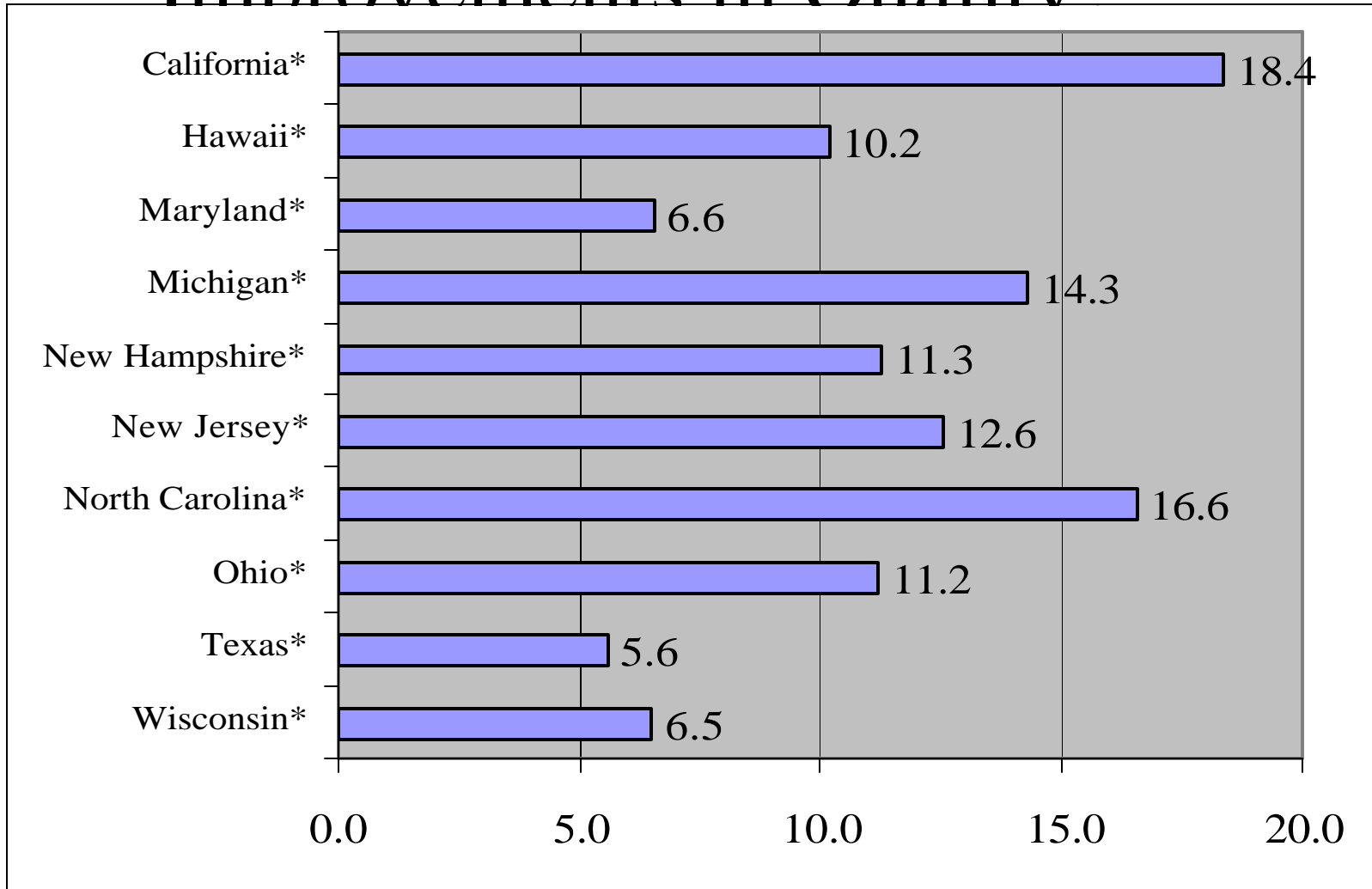
OK, Power Shifted Toward the People – But Did The Qualities of Their Lives Improve?

- 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:

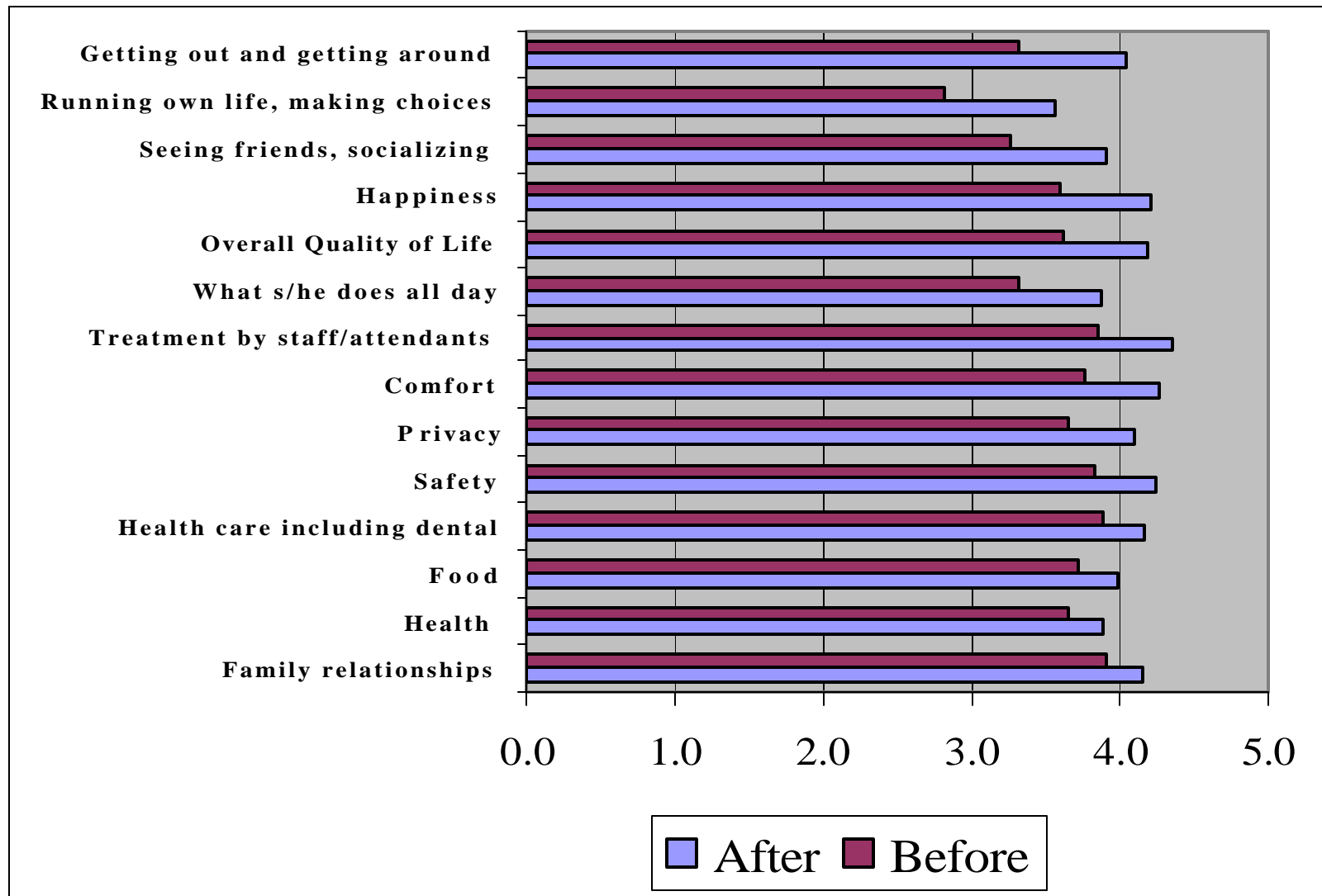
Improvement in Perceived Quality of Life in 14 Out of 14 Areas – in Every State!



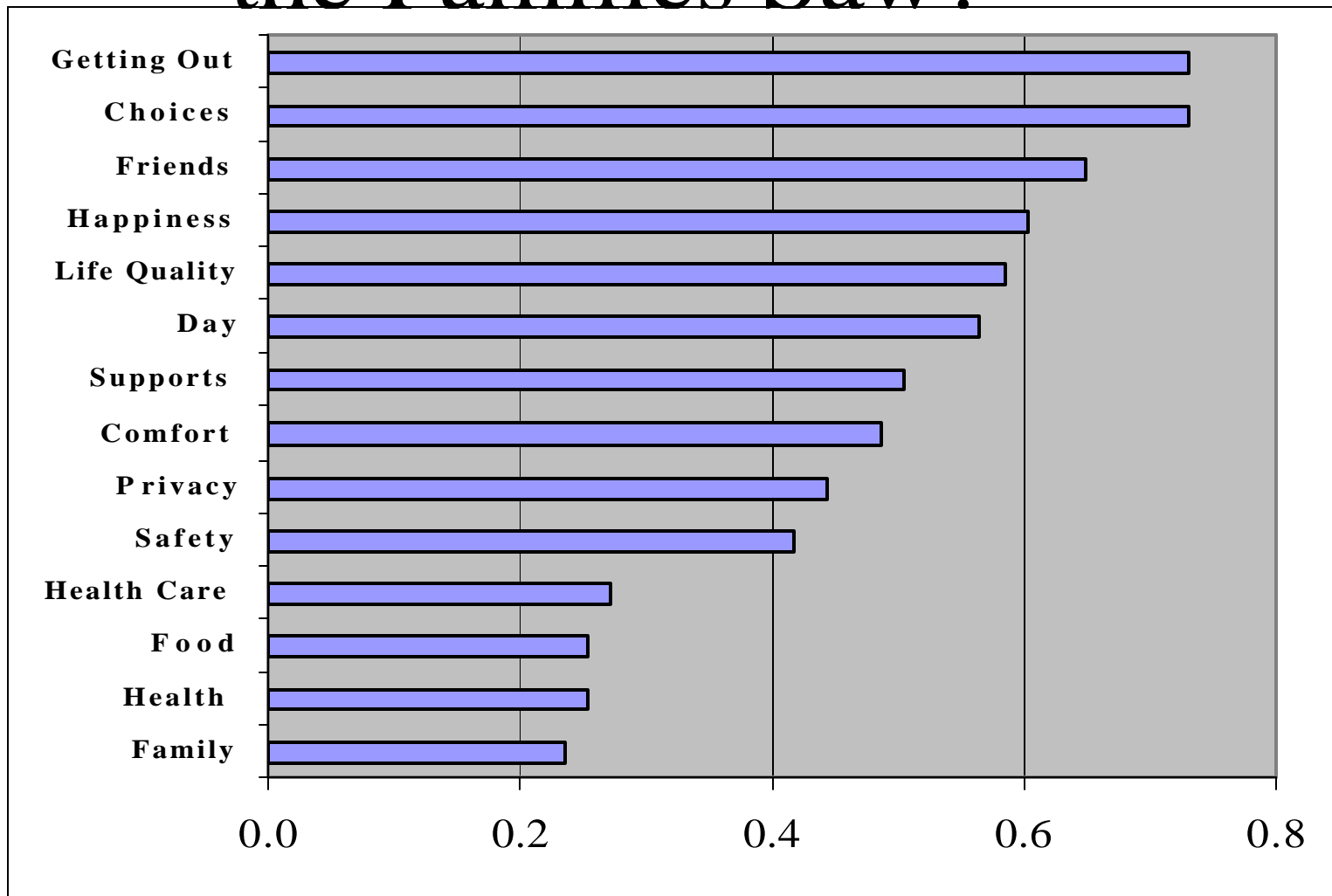
How Large Were These Perceived Improvements in Quality?



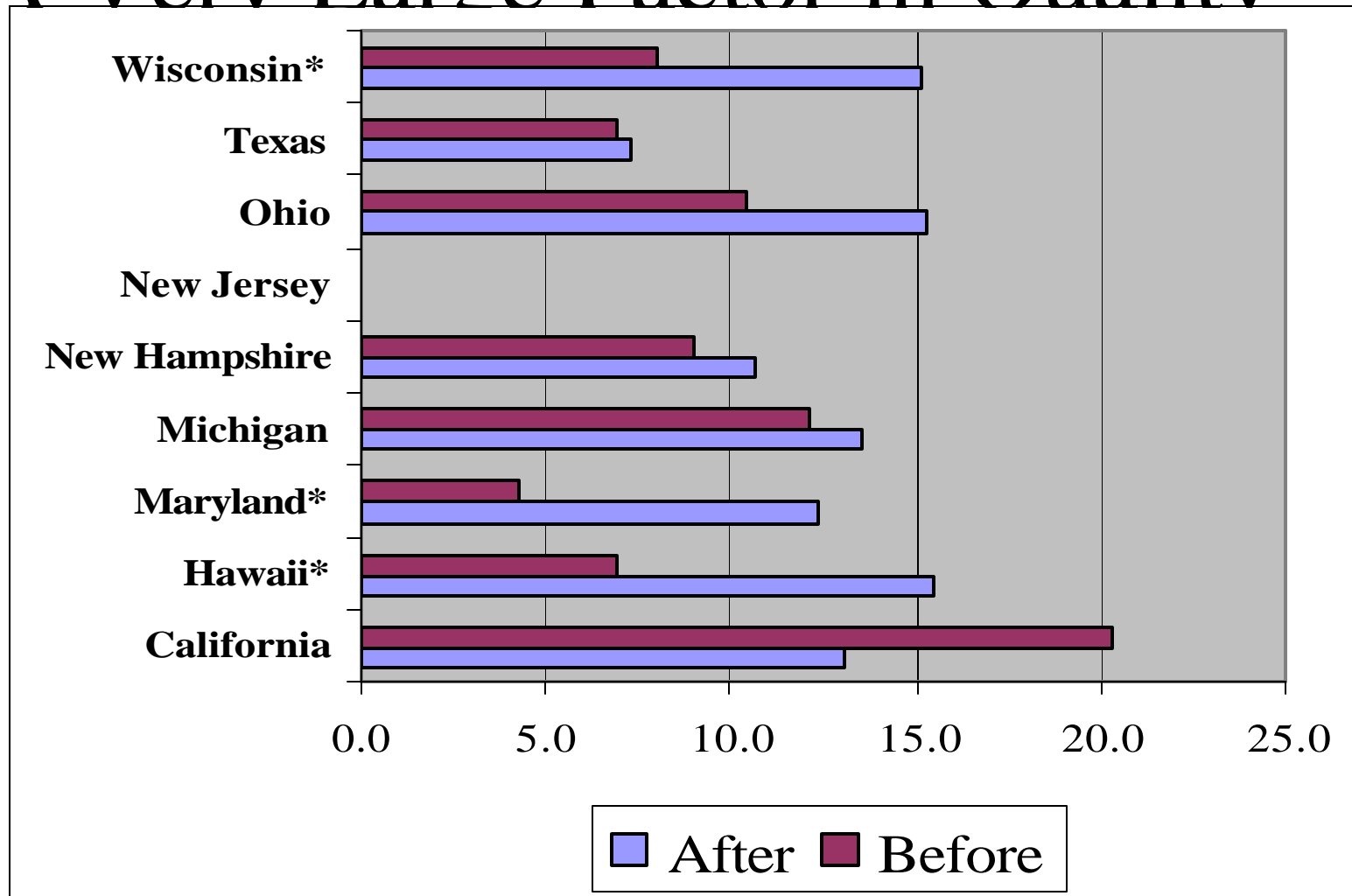
Those Reports Were From the People, and From Paid Folks – What Did the Families Perceive?



What Were the Largest Benefits the Families Saw?



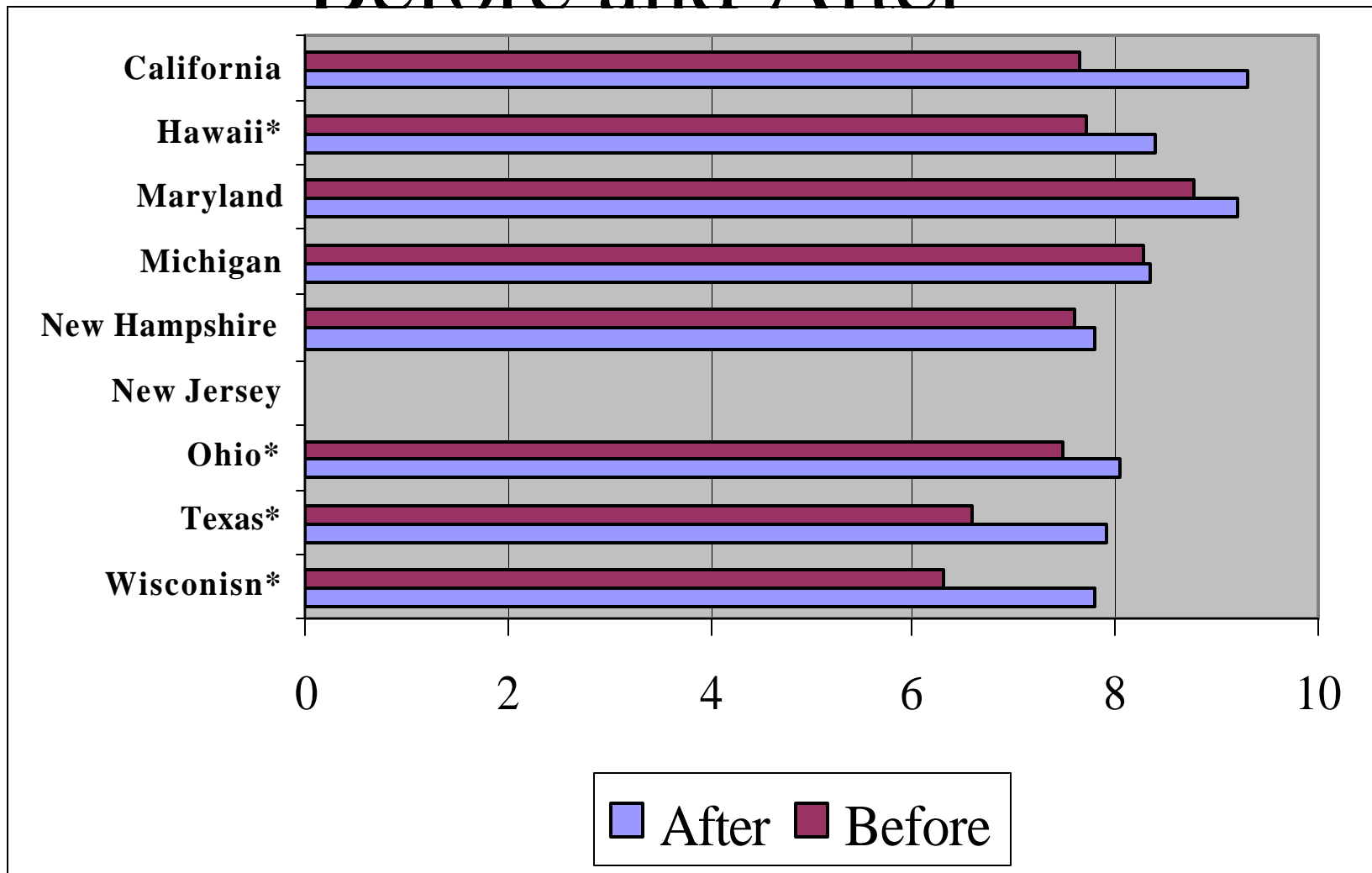
How About Friendships – That’s A Very Large Factor in Quality



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 NINE 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

What did all this teach us about the nature of quality?

- Simple, common hopes of any citizen
- It's not the AMOUNT, but the DISCREPANCY
- We found that 1 close friend was fine for some people; but 10 close friends were not enough for others
- And the same for power – some people want control, some don't.
- It's the DISCREPANCY that really defines the quality of our lives.

The New Instrument

- Pilot testing
- Revision
- Reliability and validity tests
- Publish the findings
- Begin larger scale tests with multiple populations
- Test alongside other methods in QA systems, e.g., Michigan and Oklahoma