

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

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Purpose Today

- Get some definitional clarity
- Provide two points of reference
 - State government
 - Program evaluation
- Examples
- Outcomes
- Fiscal Implications from good studies

Principles of Self-Determination

- Freedom
- Authority
- Support
- Responsibility
- Confirmation

- *All in the context of person-centered planning*

The Original Concept

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

Jack – Hard Times

- Orphaned early
- Life of terror and abuse in institutions
- Over-medicated
- Unable to walk or speak up for himself due to cerebral palsy
- For more than 30 years he lived in his room on his knees – door locked from inside
- Sent to psychiatric hospitals for any action he took to try to free himself

Jack - Progress

- Placed in a community home with Harold – similar background
- Not homeless, but not happy
- Many ‘incidents’
- July 1992 used a “brokering” system financed with state and Medicaid funding
- Jack invited a close friend and her son (similar age as Jack) to move in with him
- Harold invited a close friend and her family to help him find a home that they could share

Jack - Victory

- With sister's help, business owner
- No intensive outbursts, no psychotic occurrences, reductions in psychotropic medications
- Most clinical supports have been replaced by having a REAL life and no “program”
- The net savings was \$60,000 annually

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



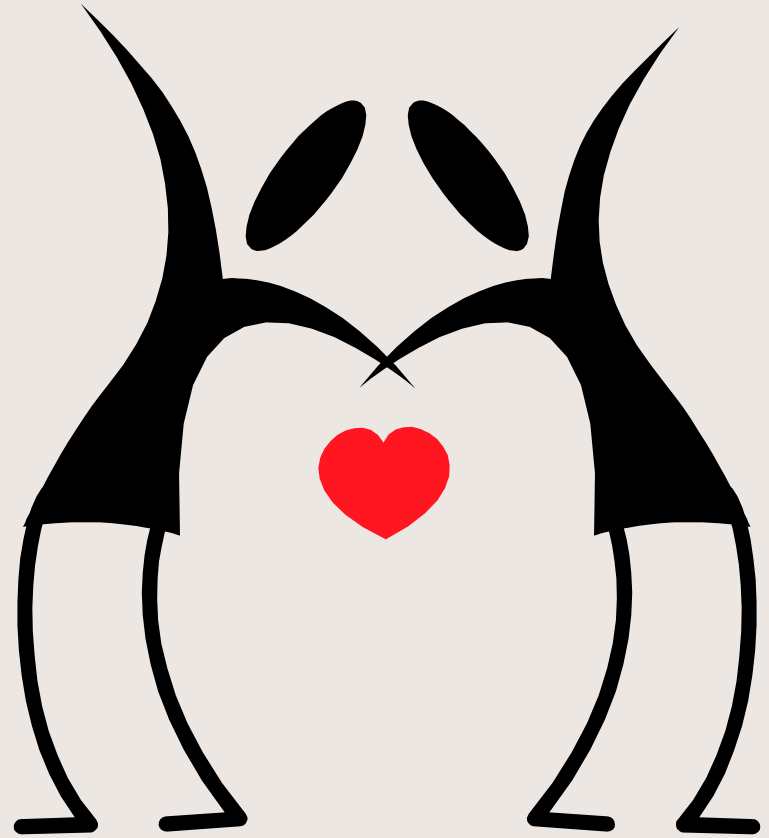
Sean's Parents Asked:

- 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”

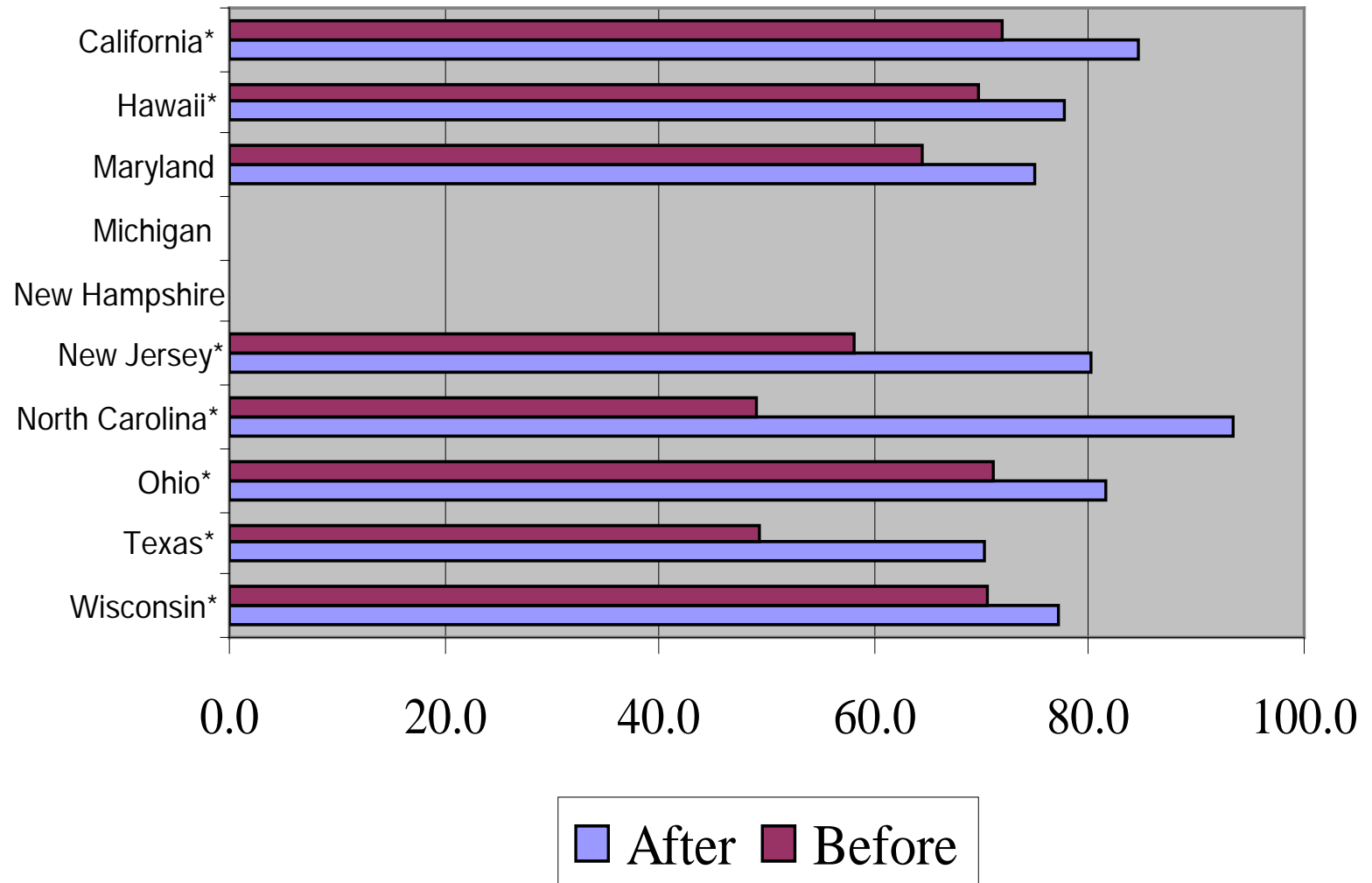
Sean Came Home

- 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

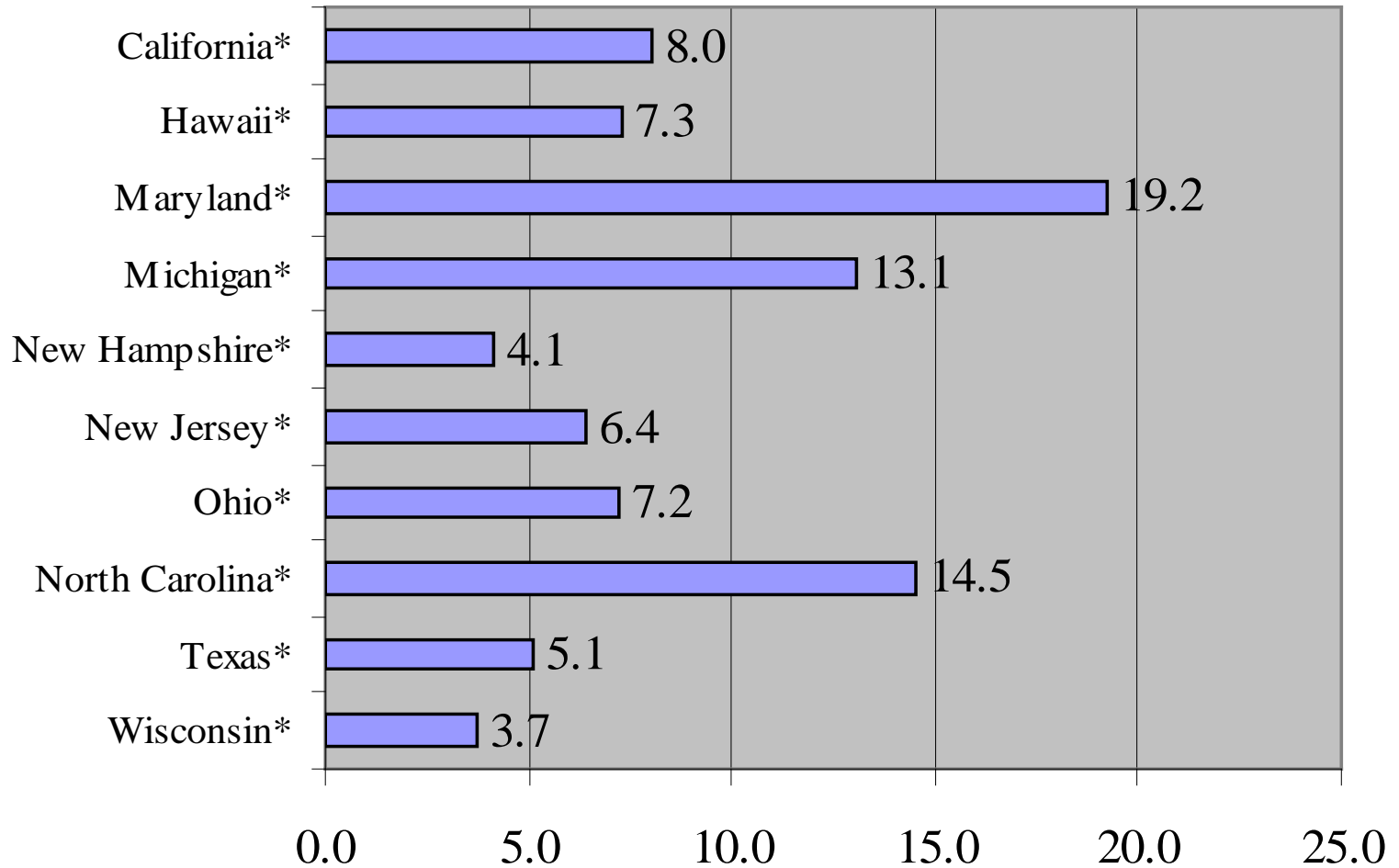
Is There Any Good Science Available About This?

- 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

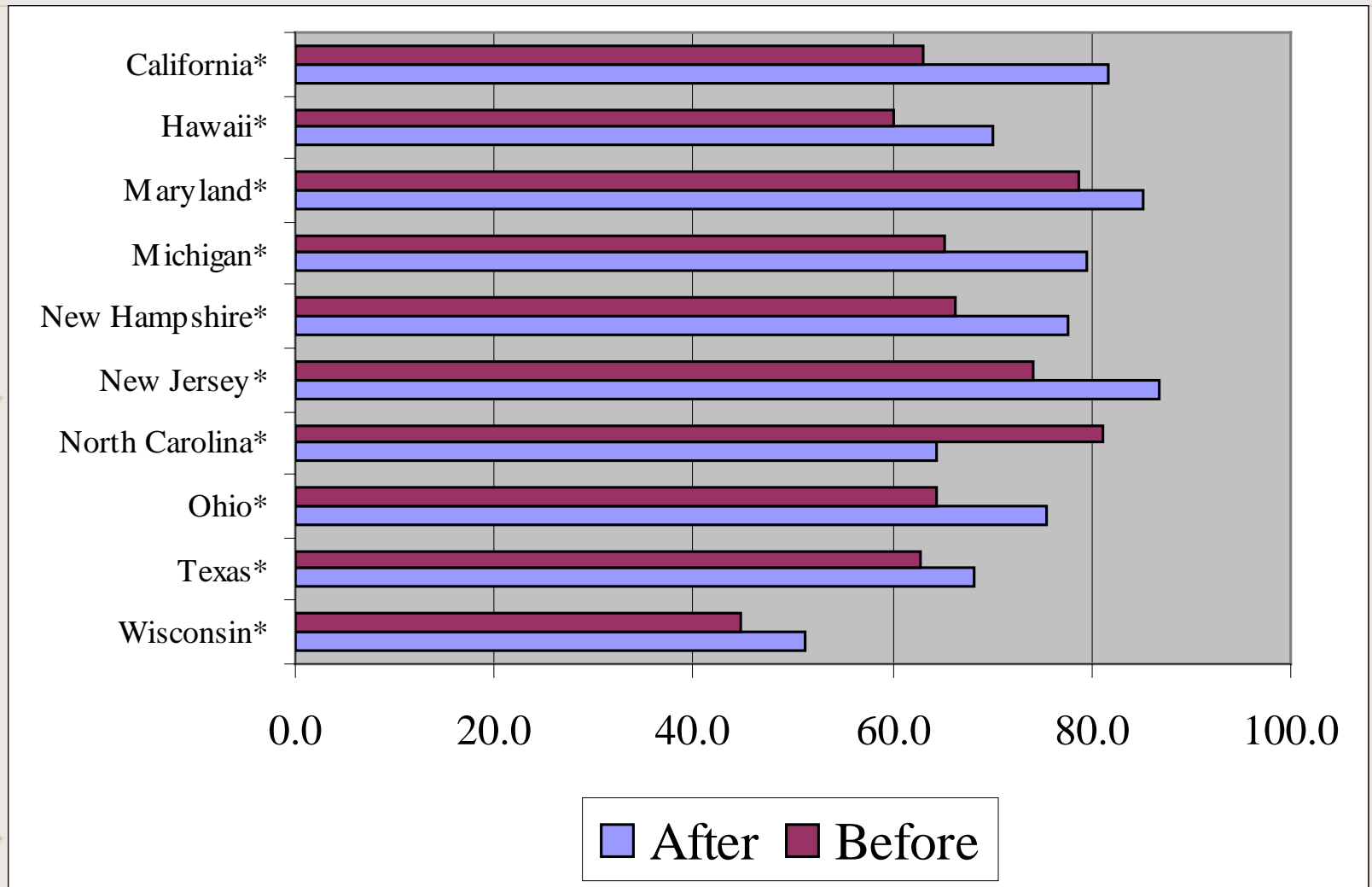
Did Planning Become More Person-Centered?



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%

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