

# Financial Well-being of Children with Disabilities & their Families

**Susan L. Parish, PhD, MSW**  
**Nancy Lurie Marks Professor of Disability Policy**

**June 2011**

Brandeis University



LURIE INSTITUTE FOR DISABILITY POLICY

# US Context



- Relatively low rates of welfare provision
  - Beliefs about independence and individualistic causes of poverty
  - Entrenched historical patterns of racism
  - Balance of power between state & federal governments: states are largely responsible for welfare spending
- Low corporate and income tax rates; high tax expenditures
- Aging population: competition with the disability field for both resources and labor force
- \$13 trillion deficit: driven largely by recession, tax cuts and (to a lesser extent) the wars in Afghanistan and Iraq

# Structure of Support for Children with Disabilities in the US

- Early intervention & special education – right to free, public education
  - Local funding & administration creates variability in the quality of services and the extent of inclusion
- Health care – Medicaid
  - For low-income children with disabilities
- Income supports – Supplemental Security Income
  - For low-income families
- Ancillary, limited supports
  - Respite, family support, case management



# Unique US Challenges

- Different programs have diverse eligibility criteria, funding streams and governmental administration
- Disability supports are often unpopular
  - Reviews of the SSI program
  - Infighting between parents of “gifted” children and those who have children with disabilities



- Political support for poor families in the US has always been limited

# Childhood Disability & Poverty in the United States

- Children with disabilities are significantly more likely to live in poverty
  - 28% of children with disabilities live in poverty (Fujiura)
  - 16% of typically developing children live in poverty
- Childhood poverty is associated with adverse outcomes in:
  - Health
  - Psychological wellbeing
  - Social adjustment
  - Academic achievement
  - Behavior
- Poverty probably has more deleterious impact on children with disabilities but research is scant
- Bidirectional relationship between poverty and disability



# Glimpse at the Research

- Low-income families' spending for their disabled child's health care
- Material hardship and deprivation in families raising children with disabilities



# Low-income Families' Financial Burden



- 61% of families had out-of-pocket expenses for child's health care
  - 1/3 of those with any costs spent > \$500 for the prior year
- Wide state variability
- Fewer families reported high (>\$500) spending in states with more generous public health eligibility standards

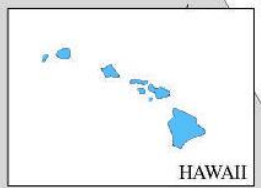
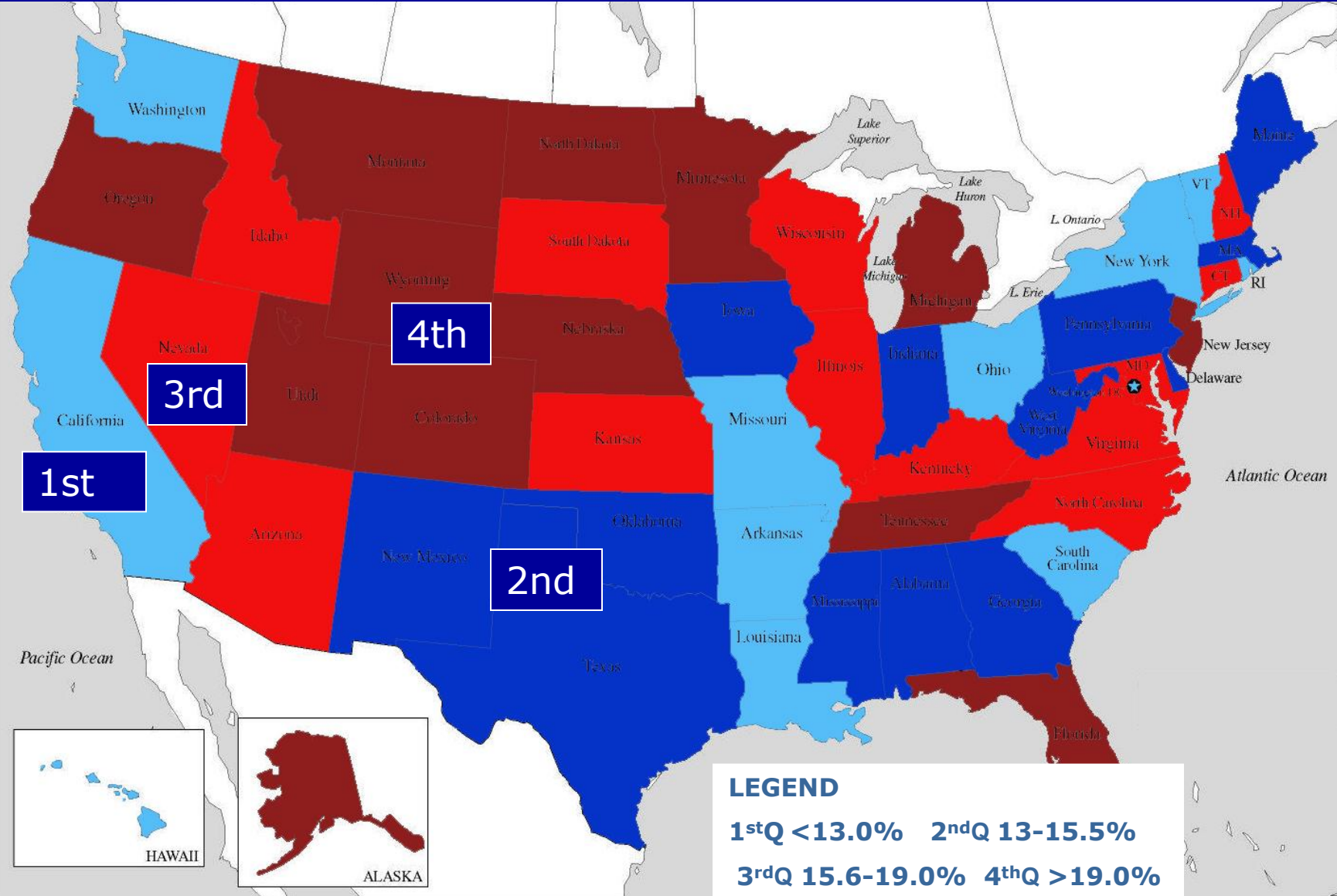
# Spending Relative to Family Income

- 27% of families spent >3% of their total household income on their disabled child's health care
  - For family of 4 with income at \$38,700 (twice the federal poverty level), 3% = \$1,161
- State variability in relative burden >3% of income ranged from 6% of families in the District of Columbia to 20% of families in Colorado, Michigan, Minnesota, Montana, New Jersey, North Dakota, Oregon, Tennessee, Utah and Wyoming
  - Families living in states with more generous public health income eligibility standards spend relatively LESS of their total income for their disabled child's health care





# Quartiles of High (>3%) Spending Relative to Total Family Income



# Deprivation of Children with Disabilities and Their Caregiving Families



# Problematic US Poverty Definition

- Doesn't address changing patterns of family spending since federal poverty level developed in 1960s
  - Inflation of housing & health care costs
  - Child care costs following women's entry into work
- Doesn't address elevated costs some families incur (particularly those with a member with disabilities)
- Doesn't include noncash income
- Doesn't address geographic differences in cost of living (median 2010 home price in Syracuse: \$125,100; median in Boston: \$357,300)
  - Federal Poverty Level (FPL) for family of 4 = \$22,350 in 2011 (subsistence in the US generally regarded as requiring twice this amount)
  - The real issue is not theoretical: the FPL is used to determine eligibility for >100 social welfare programs in the US

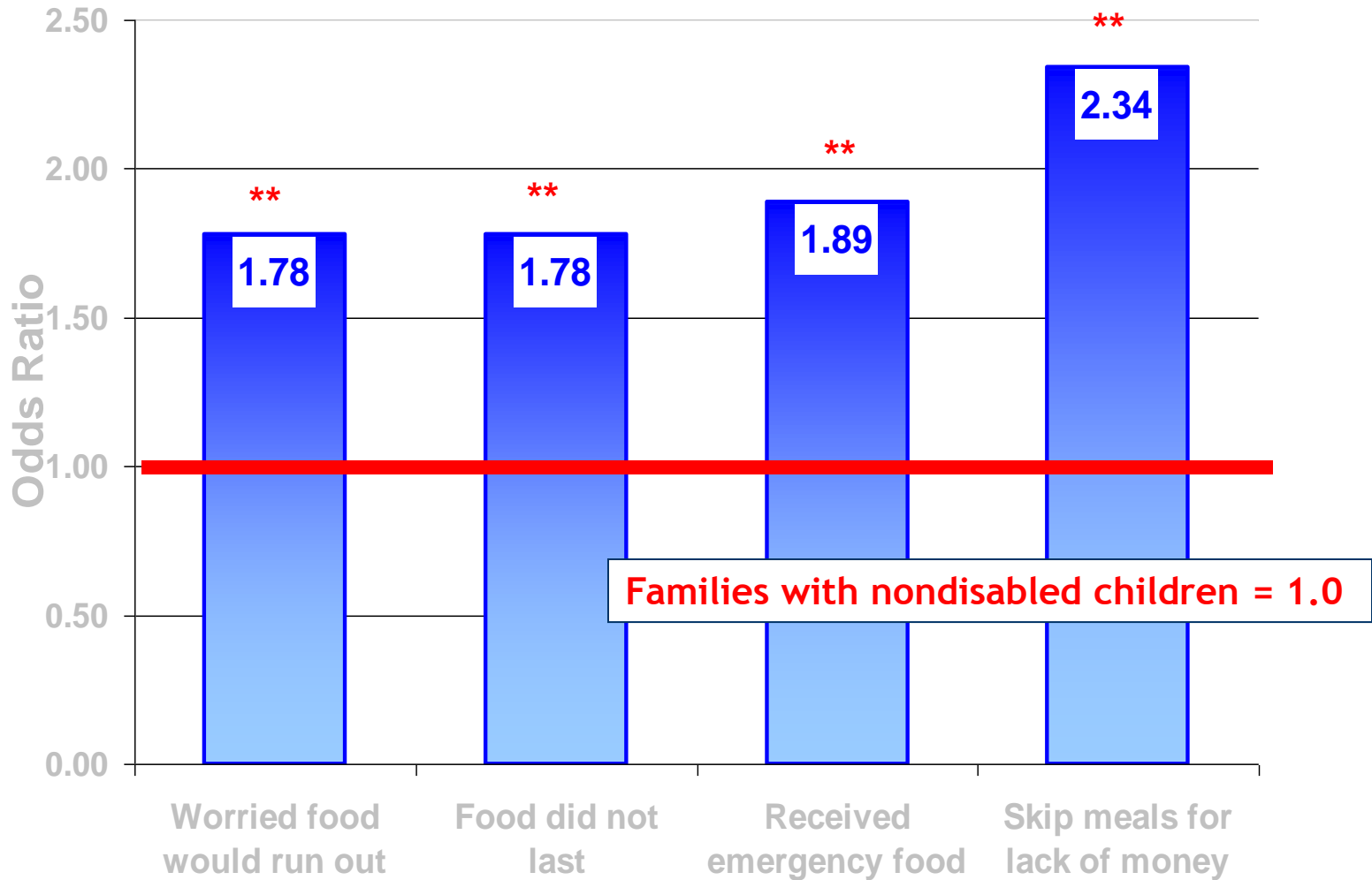


# How do we understand financial well-being?



- Alternative measures of poverty
  - From the EU relative measures (i.e., income < 40, 50 or 60% of median income nationally)
  - Asset poverty
  - Poverty measures that include the value of income transfers, in-kind goods, medical care
- Material hardship or deprivation: food insecurity, housing instability, health care access

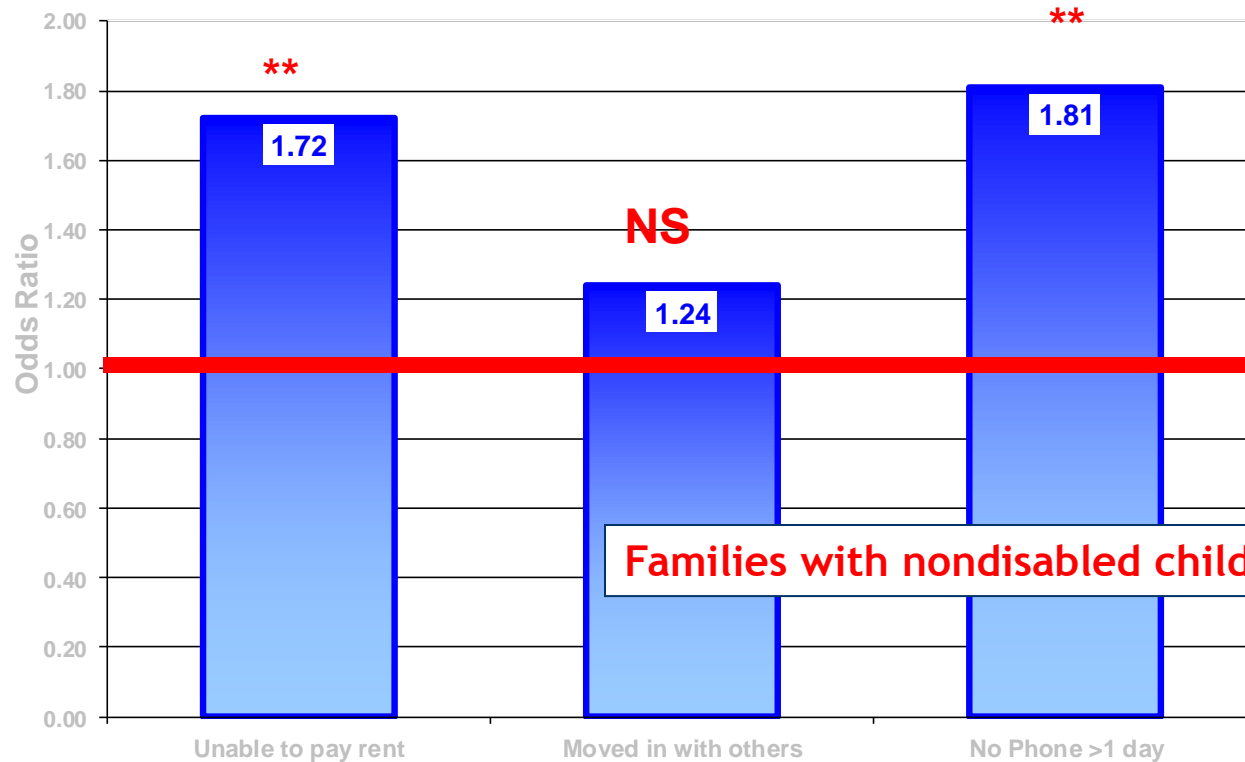
# Disabled Children's Food Insecurity



\*  $p < .05$ ; \*\*  $p < .01$



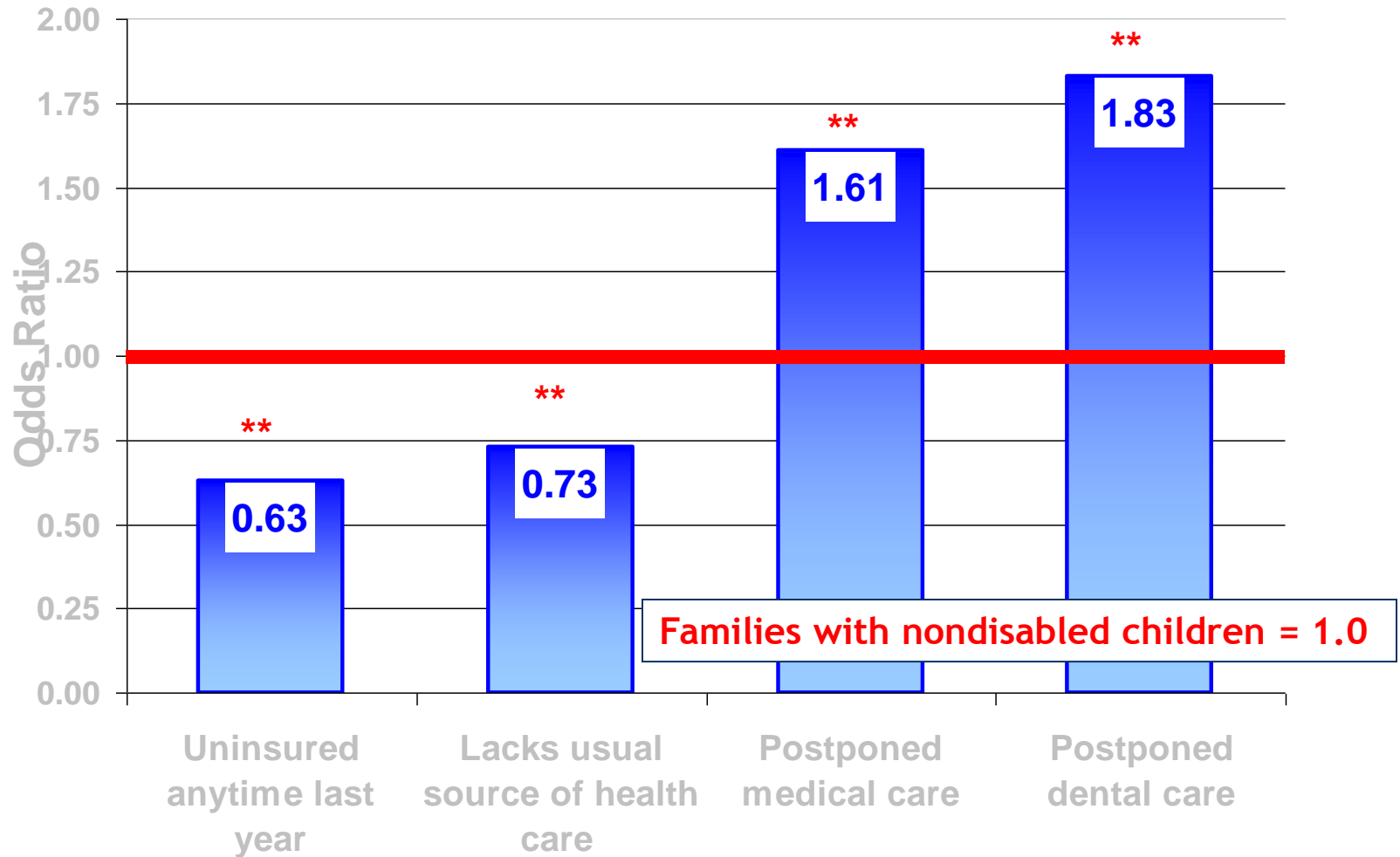
# Disabled Children's Housing & Telephone Instability



Families with nondisabled children = 1.0

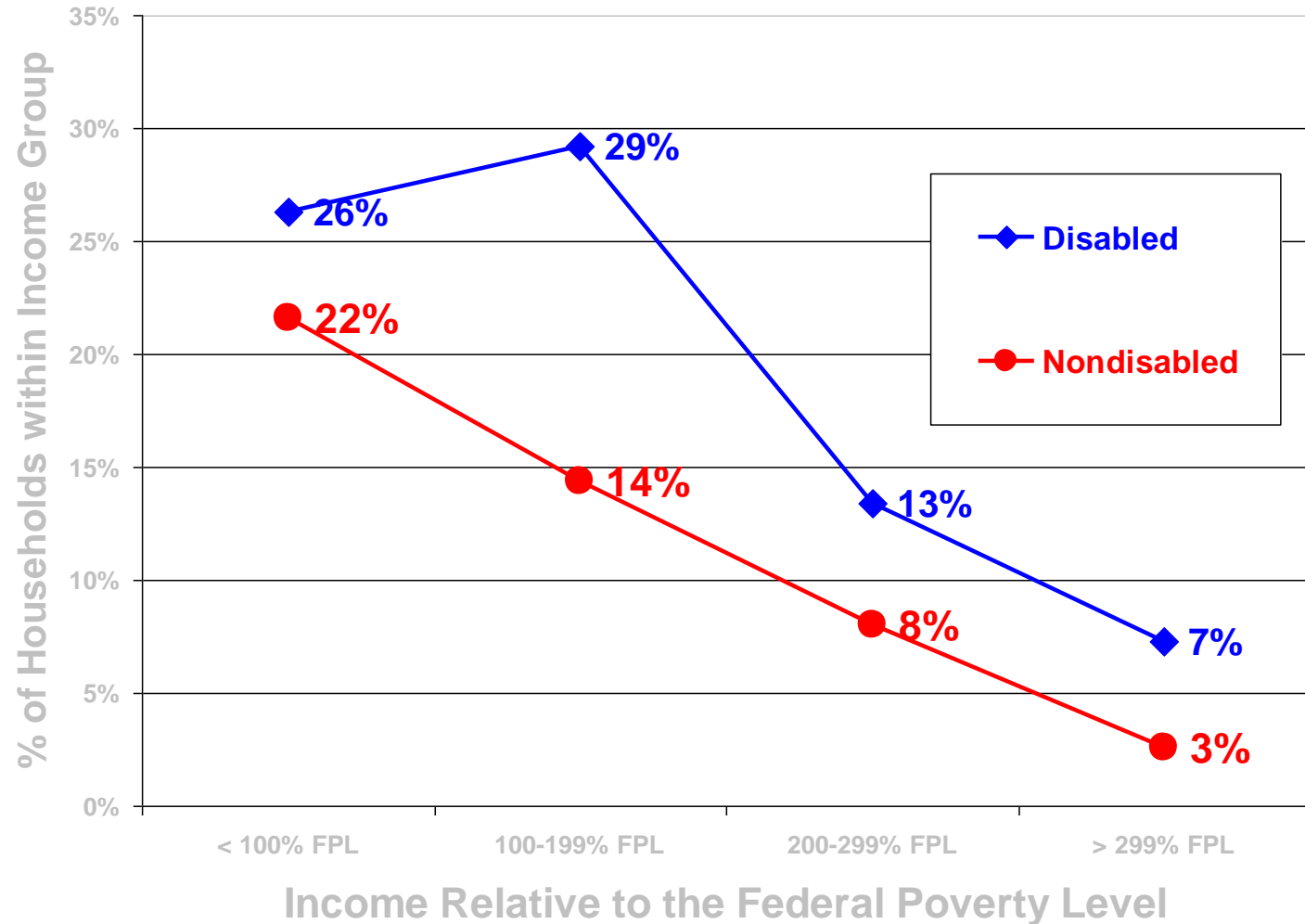
\*  $p < .05$ ; \*\*  $p < .01$ ; NS not statistically significant

# Disabled Children's Health Care



\* p<.05; \*\* p<.01

# Hardship in 3 Domains: Housing/Utilities, Food, Medical Care





# Implications for the US



- It is expensive to parent a child with disabilities in the United States – costs are high and growing, and existing supports are inadequate
- US children with disabilities and their families experience deprivation, even well into middle-income ranges
  - The federal poverty level used in the US to determine eligibility for services is notoriously inaccurate for children with disabilities and their families
- Children with disabilities and their families are particularly at risk for adverse outcomes in the current Congressional budget debates and state budget crises – Medicaid, SSI
- Generosity of state Medicaid policies has particularly large effect on families' out-of-pocket spending for their children with disabilities

# Implications for Japan?



- Defining service eligibility on the basis of an absolute income standard will miss many needy families
- Policymakers interested in targeting resources to those who are most in need should not exclusively rely on an absolute income standard of need
- Disability surveillance is critical, but at the level of government that administers programs – local, county, regional, state
  - Surveillance needs to measure well-being in multiple ways: income, assets, material deprivation
  - Accurate, multi-modal approaches to surveillance are necessary when disability is highly stigmatized and families hide their child's conditions

**Thank you!**

