



Health Care of Children with Autism: A Policy View from the US

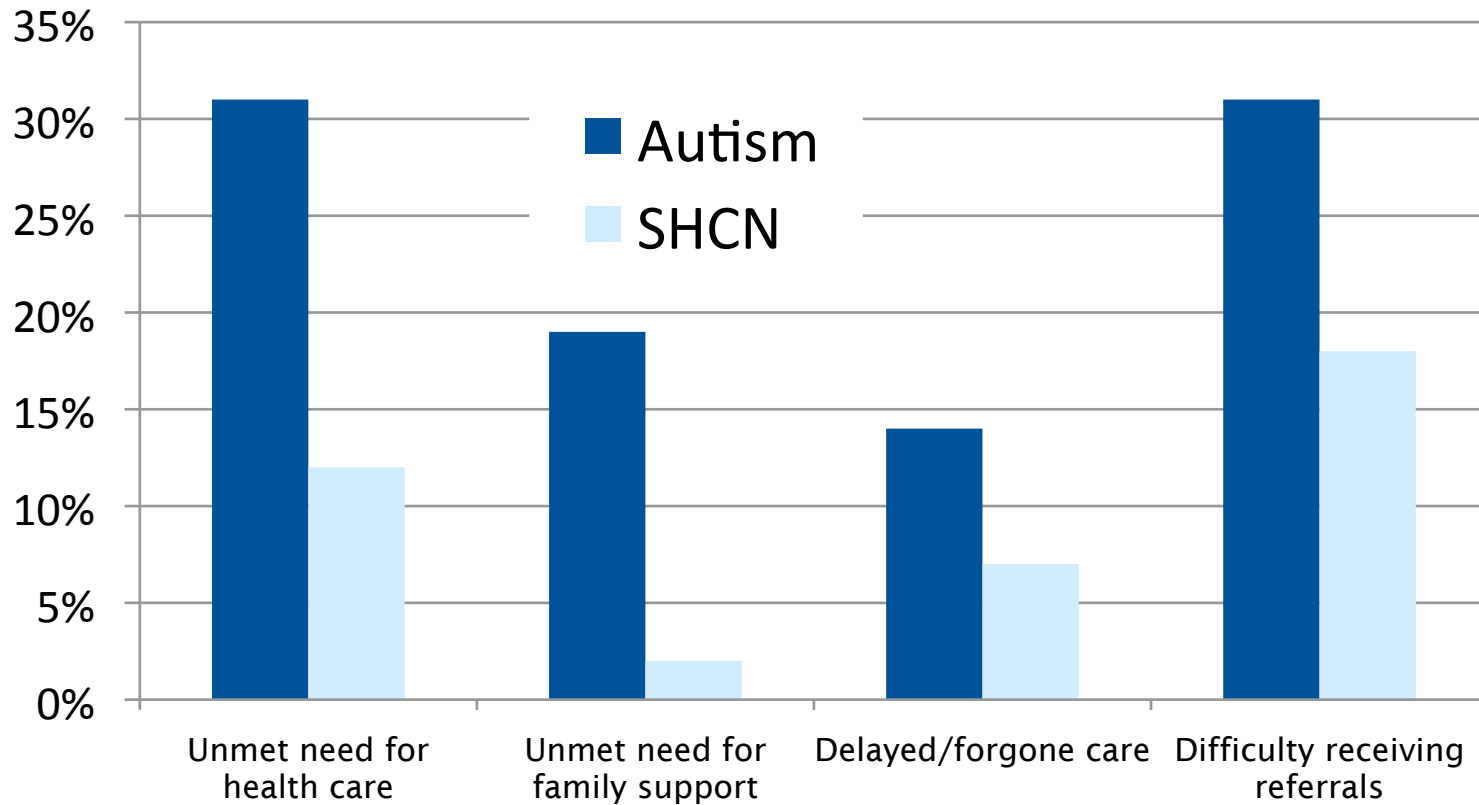
Susan L. Parish, MSW, PhD
Lurie Institute for Disability Policy
Heller School for Social Policy & Management

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Presentation overview

- Context of health care services for US children with autism
 - Importance of Medicaid and states' financial prospects
- Costs of health care for children with autism are expensive
 - To the public health system
 - To families, which have limited capacity
- Marked inadequacies in health care access for children with autism
 - Particularly troubling racial and ethnic disparities in quality of care
- “New” autism insurance mandates in the states: are they working?

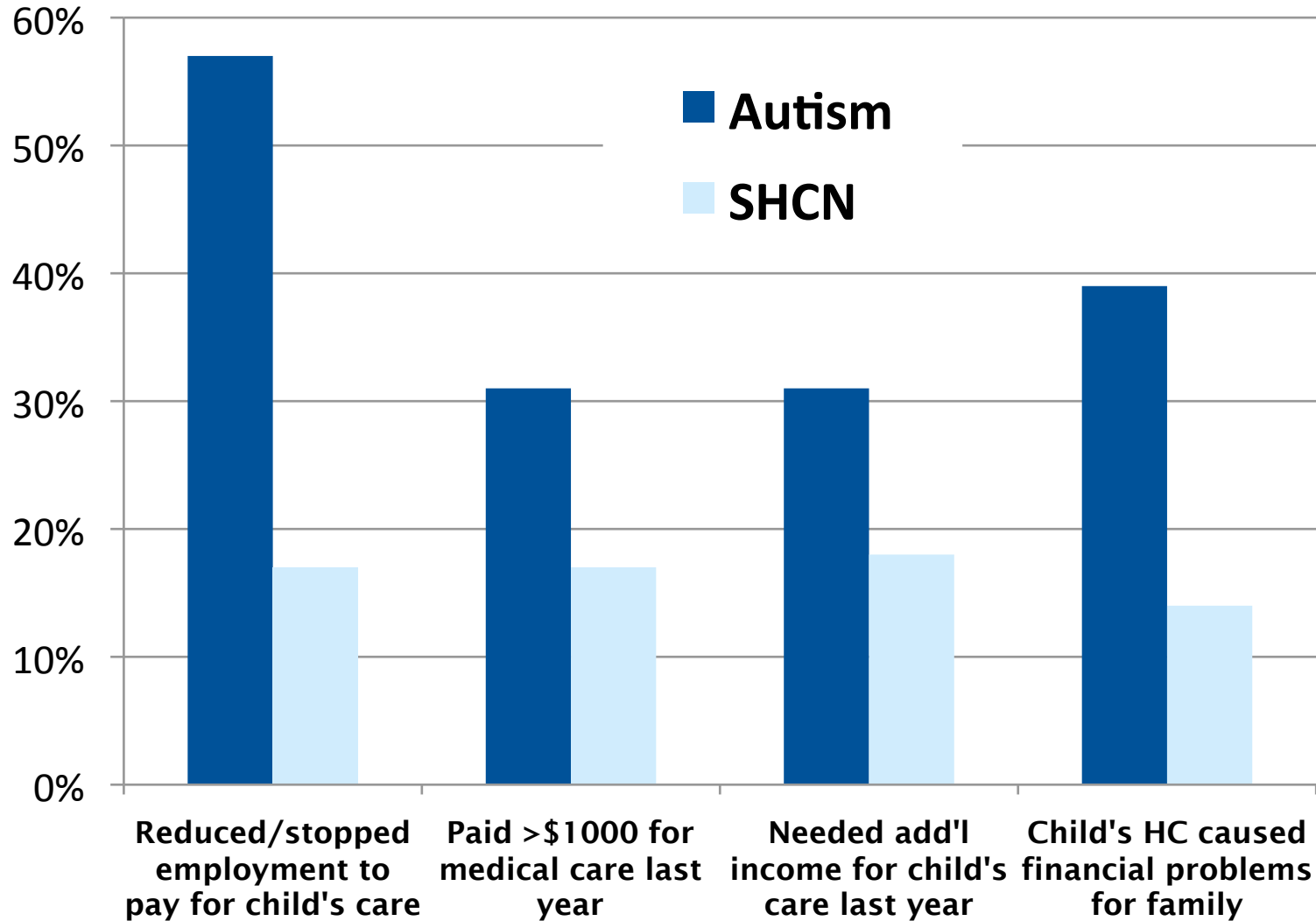
Health care access of children with autism and other special health care needs



Note: $p < .05$ for all; SHCN=special health care needs

Source: Kogan et al., 2008

Children with autism are more expensive than those with other special needs



Note: $p < .05$ for all; SHCN=special health care needs

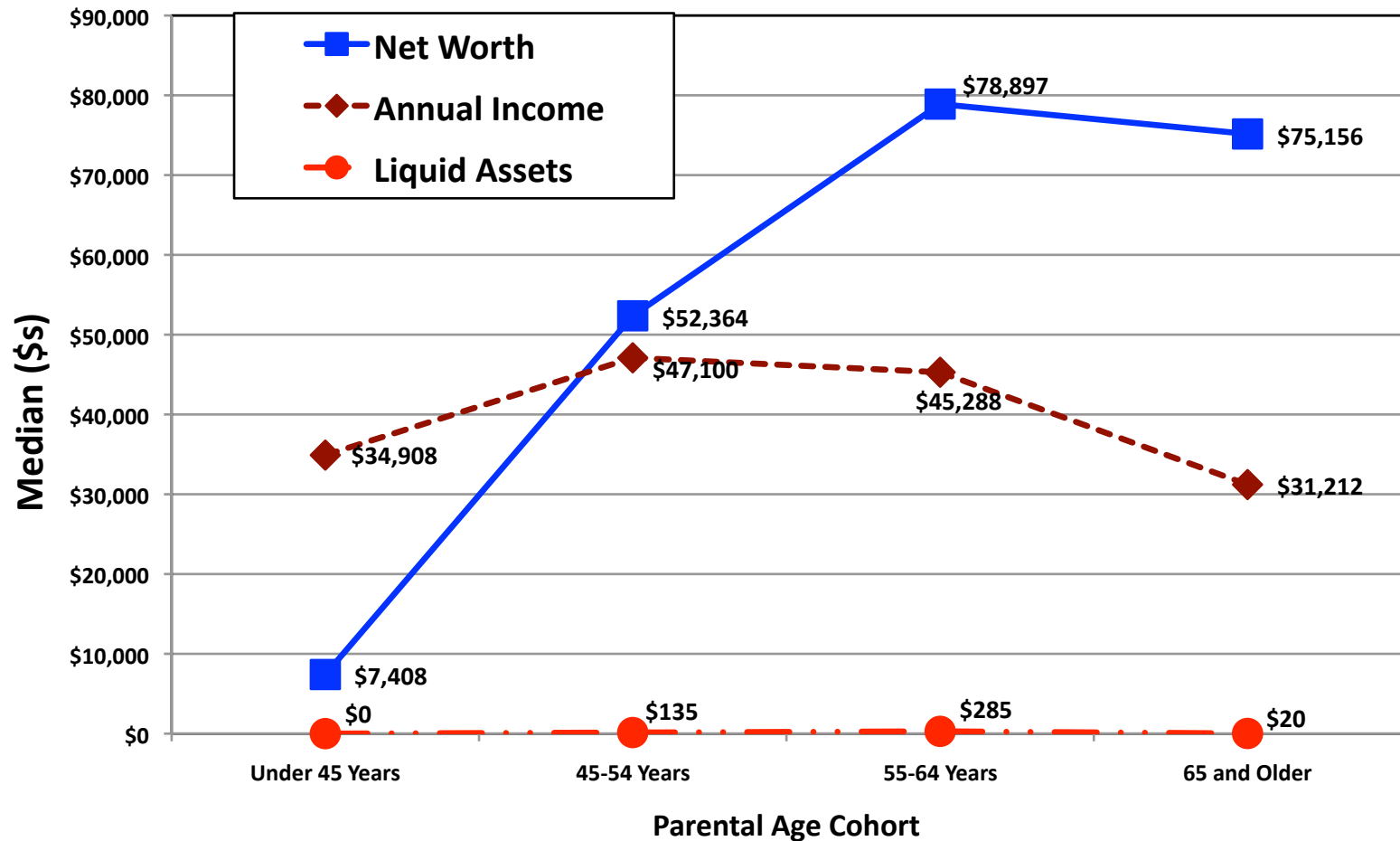
Source: Kogan et al., 2008

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Families raising children with autism and other developmental disabilities lack adequate financial resources

Median income and assets among parents of children with DD by parental age cohort



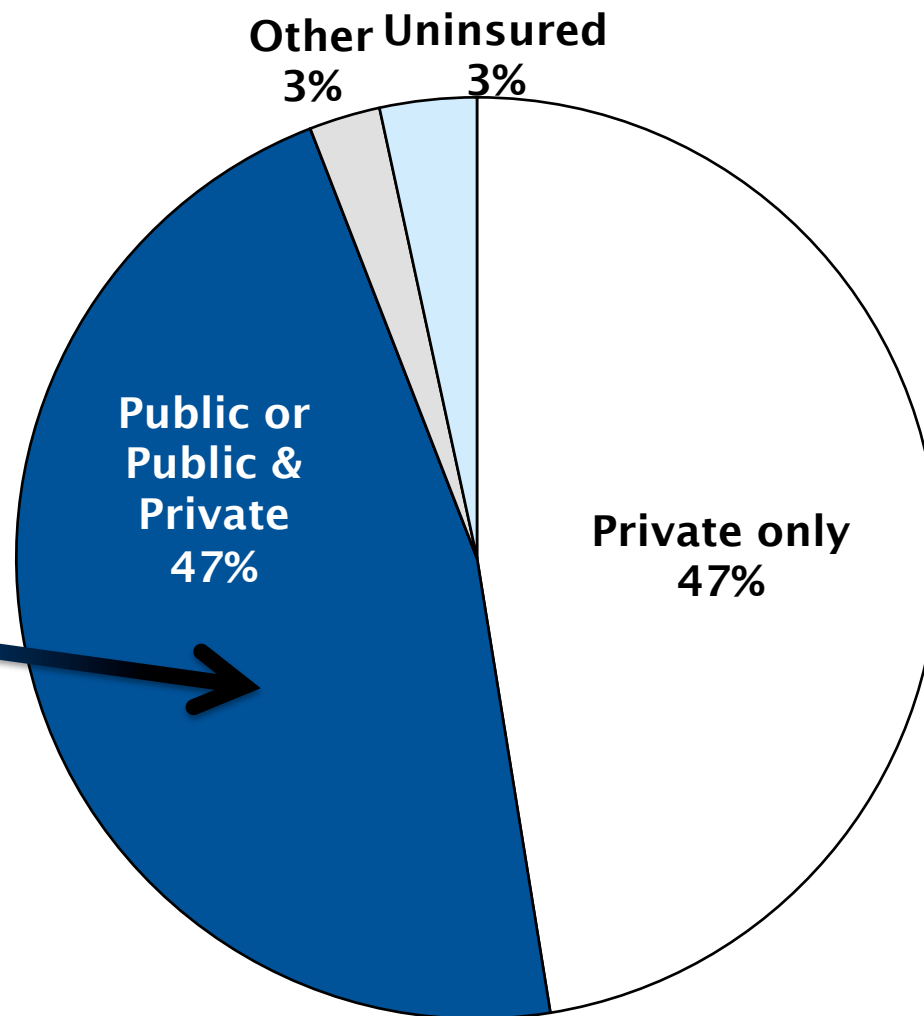
Source: Parish et al., 2010



Public health insurance is vital for children with autism

Insurance coverage of children with autism in the US

Medicaid: State administered health insurance for low-income people and those with disabilities in the US; funded jointly by the federal & state governments



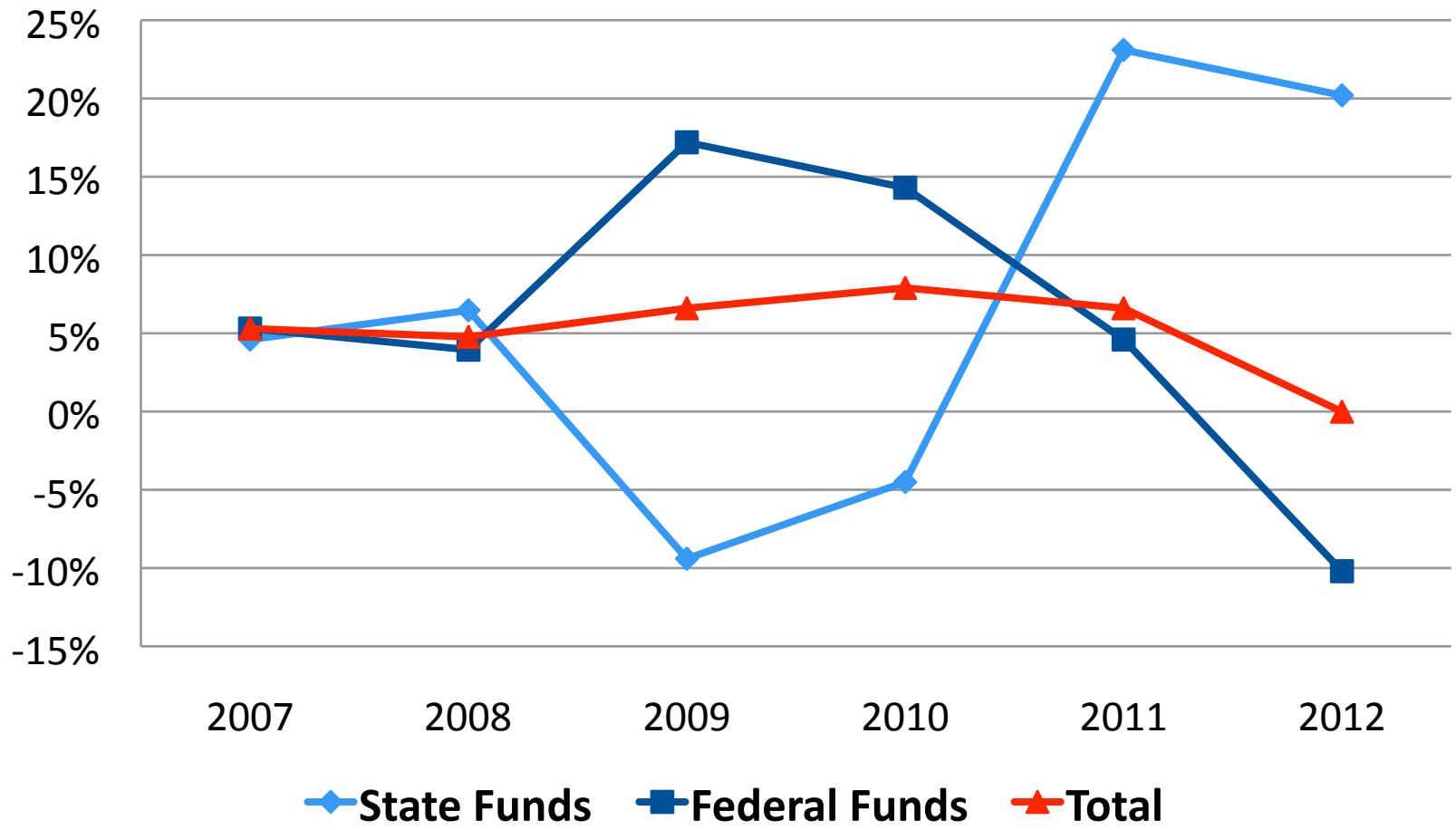
Source: Chiri & Warfield (2011)

State Medicaid spending & families' financial burden

- State Medicaid spending for children with disabilities is critically important
- Families of children with autism in states with higher per capita Medicaid spending are less likely:
 - To have ANY out-of-pocket expenses for their child's health care
 - To have out-of-pocket > \$500 for the year
 - To have spending that > 3% of their total annual income
 - To need additional income to care for their child

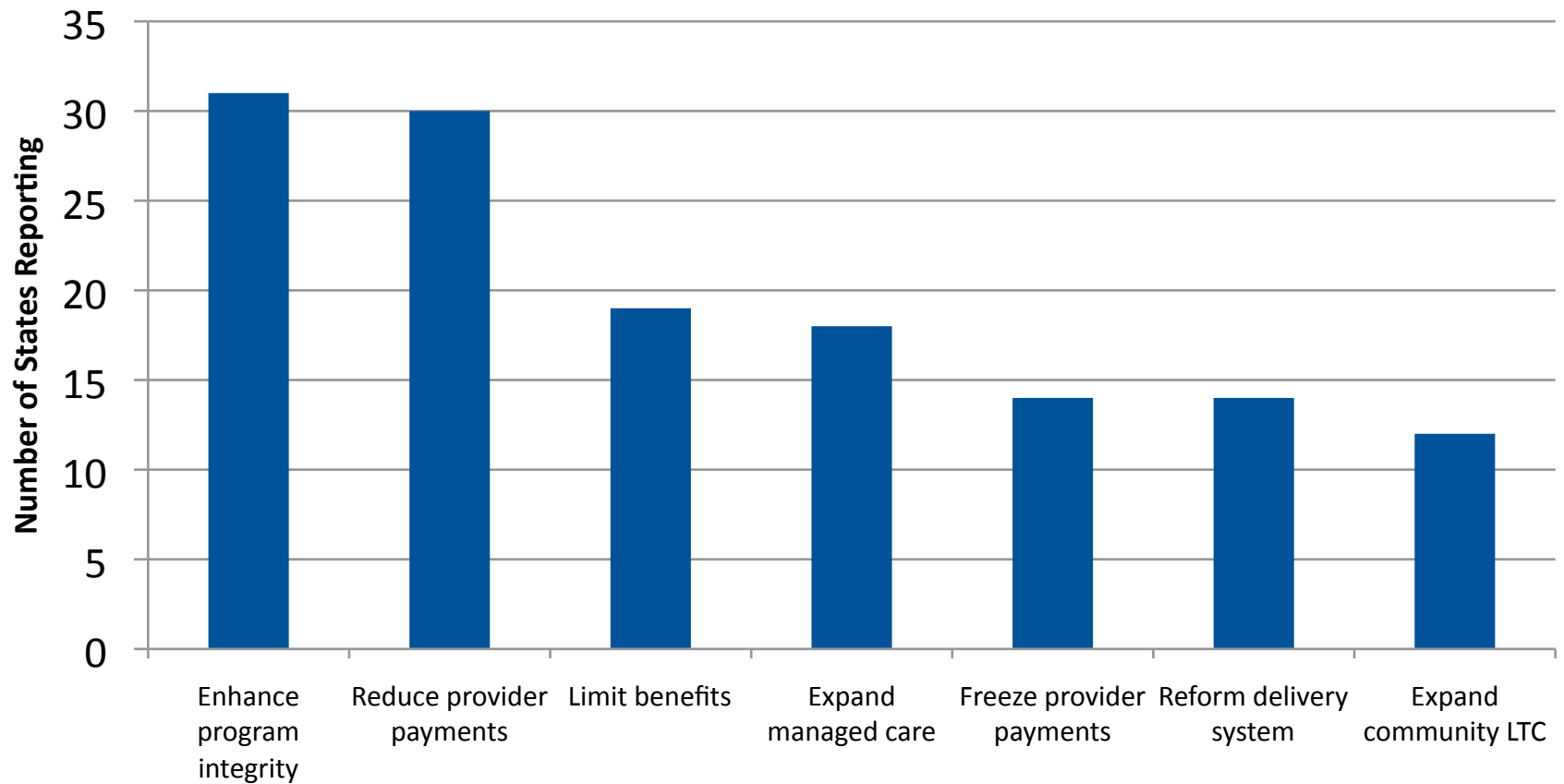
Source: Parish et al., forthcoming

Average annual Medicaid growth



Source: National Governors Association & National Association of State Budget Officers

Number of states proposing Medicaid cost containment strategies, FY 2012



Source: National Governors Association & National Association of State Budget Officers, 2012

How are the states doing?

- The recovery is underway, but not as robust as previous recoveries – high unemployment continues
- 42 states projected to have FY2014 spending above FY2013
 - But 19 states have not recovered to pre-recession levels
 - State spending is still below 2008 pre-recession levels for the aggregated 50 states; mid-year increases may take nominal (not inflation-adjusted) spending above 2008 levels
- Expiration of the 2009 American Recovery & Reinvestment Act funds challenges states, particularly in Medicaid (\$87 billion)
- Increasing demand for state services has not been fully offset by increasing revenue projections
- Medicaid (still) represents the single largest expenditure for state budgets (24% of total spending in FY12)

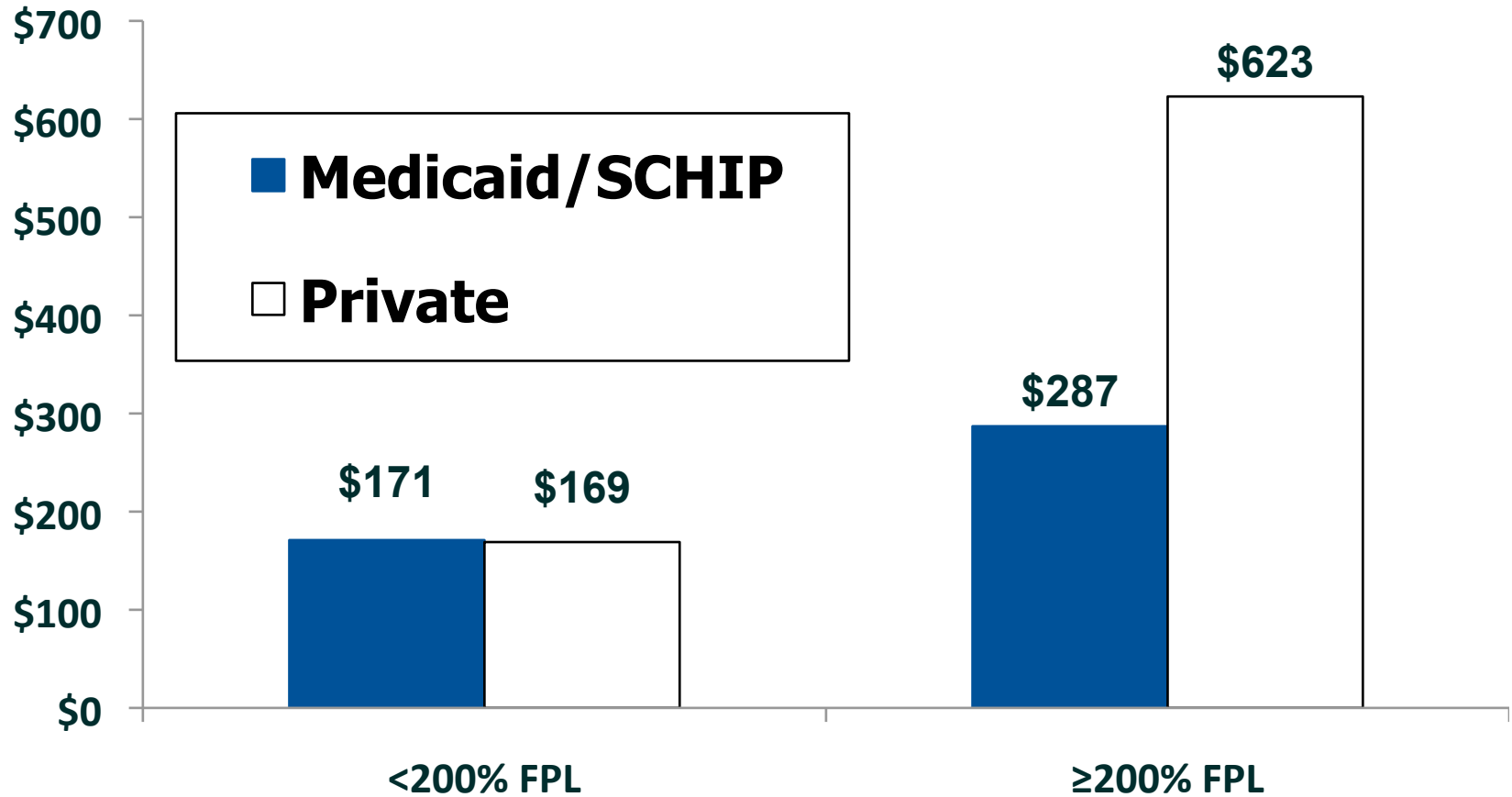
Source: NASBO & NGA, 2013

Relationship between insurance type & families' financial burden?

- 82% of all families had any out-of-pocket expenditures
- Mean out-of-pocket spending \$US 730; median \$US 215
- Mean relative burden \$US 9.70 per \$US 1000 of income; median \$US 2.60 per \$US 1000

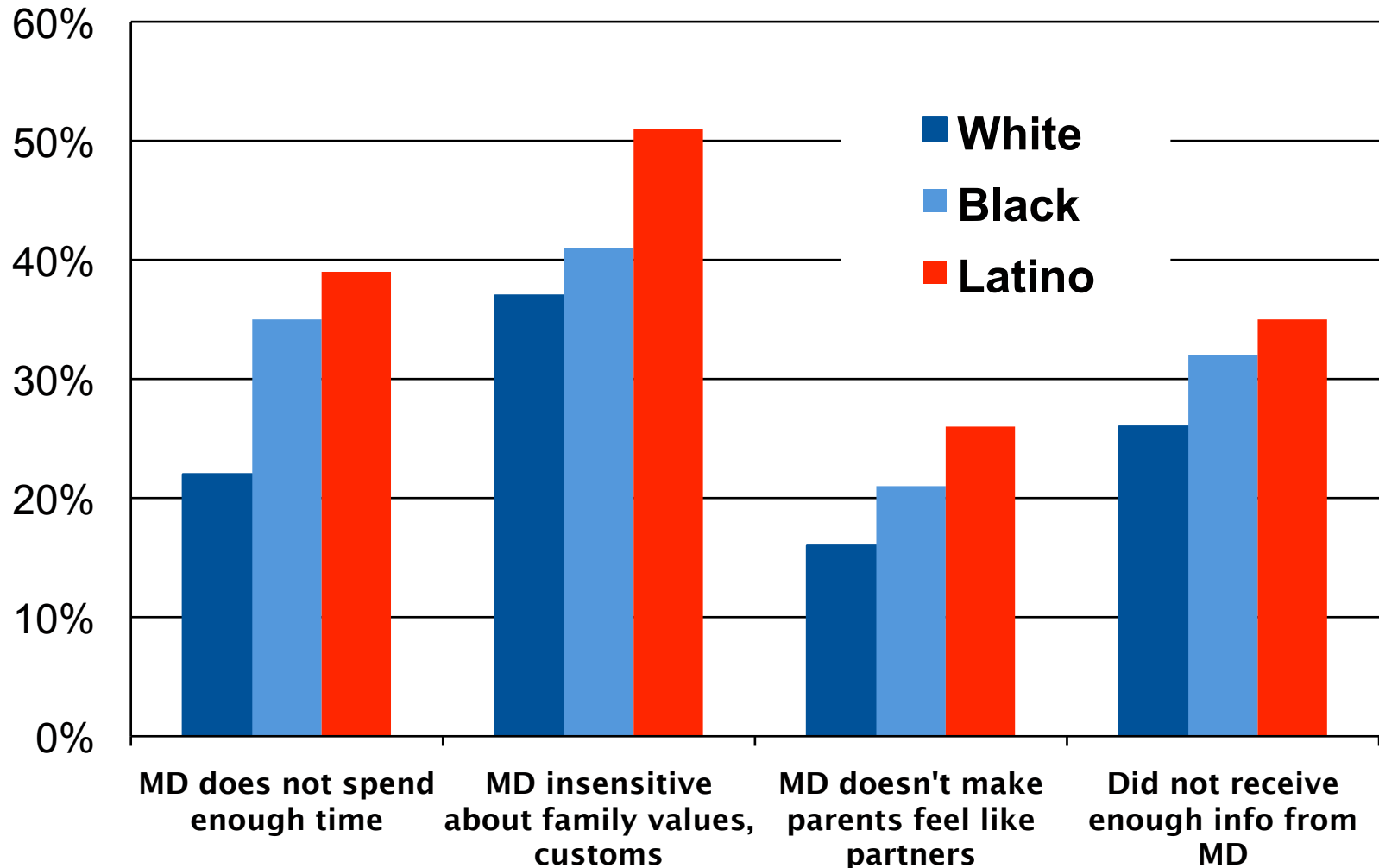
Source: Parish et al., under review (data from the Medical Expenditure Panel Survey, 2000-09)

Median out-of-pocket spending among families with any spending by income and insurance type



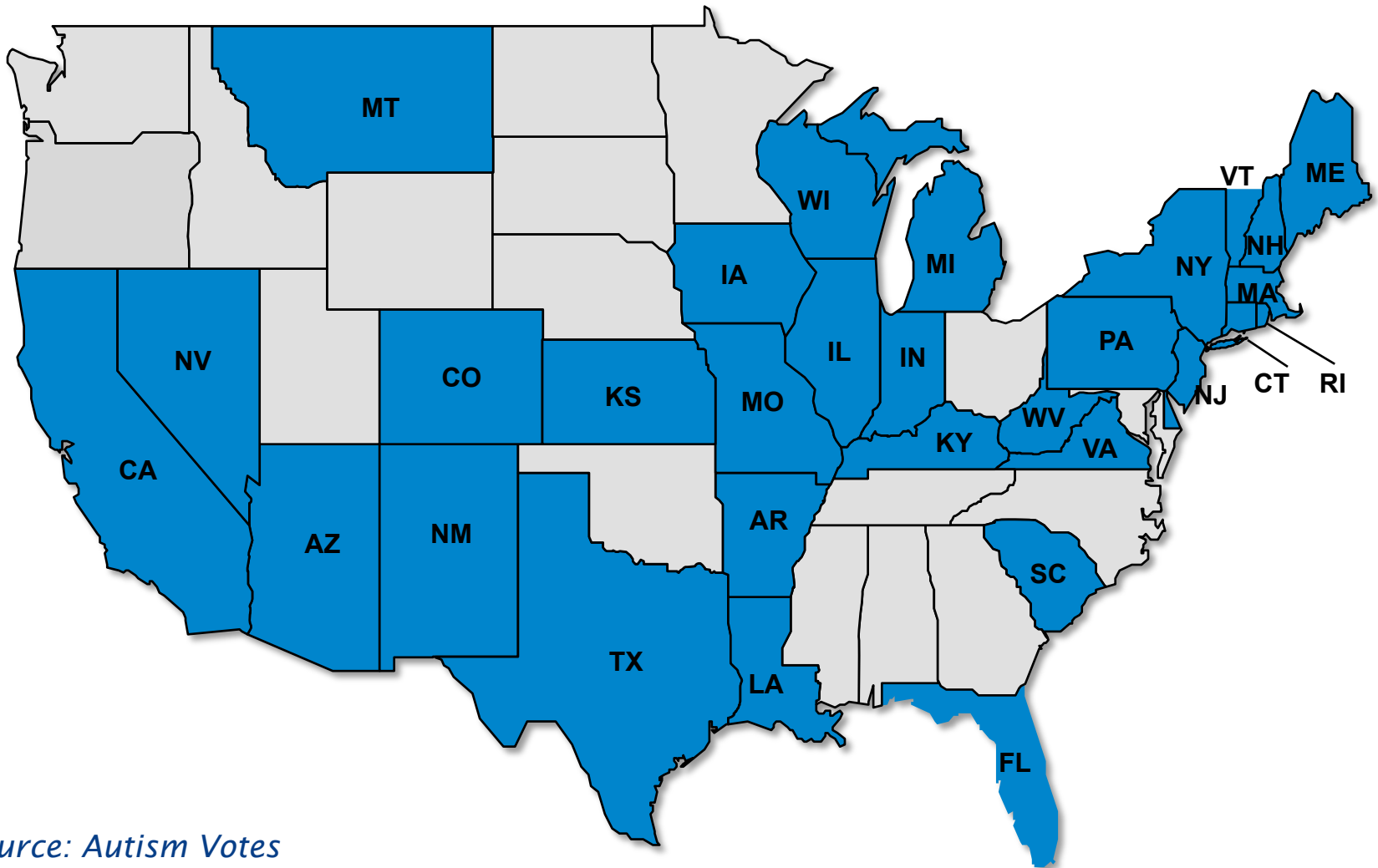
Note: Excludes families that reported no out-of-pocket spending; FPL is the federal poverty level (\$US 22,350 for family of 4 in 2013)

Racial disparities in quality of care for children with autism



Source: Magaña et al, forthcoming; all comparisons with White children $p < .05$

States with private autism insurance reform laws



Source: Autism Votes

New autism mandates reduce families' financial burdens

Families living in states with autism health insurance mandates:

- Are less likely to spend >\$500 annually for out-of-pocket health care costs of their child with autism
- Are less likely to have any out-of-pocket costs

Source: Parish et al., 2012

Implications

- Families raising children with autism incur substantial financial burdens
- Out-of-pocket spending incurred by families of children with autism are higher for children who lack public insurance, even after controlling for socio-economic status and family income
- Families incur out-of-pocket expenses for a varied range of health care services

Conclusion

The time for advocacy has never been more pressing

- State budgets will continue to be strained
- Families continue to struggle to
 - Secure services for their children with autism
 - Stay afloat financially
- Interventions to improve health care access for racial and ethnic minority children with autism are urgently needed
 - Policies must promote high-quality care
- The Affordable Care Act (Obamacare) may increase access to services; the DSM-5 diagnostic changes may or may not reduce access to services



Acknowledgements

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Thank you!