



Empirical Portrait of Families and Developmental Disabilities in the United States

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Overview

- Unique characteristics of family members who provide care to a loved one with intellectual and developmental disabilities
- Magnitude of the population
- Demographic characteristics
- Health and financial well-being of family caregivers
- Policy context of family caregiving



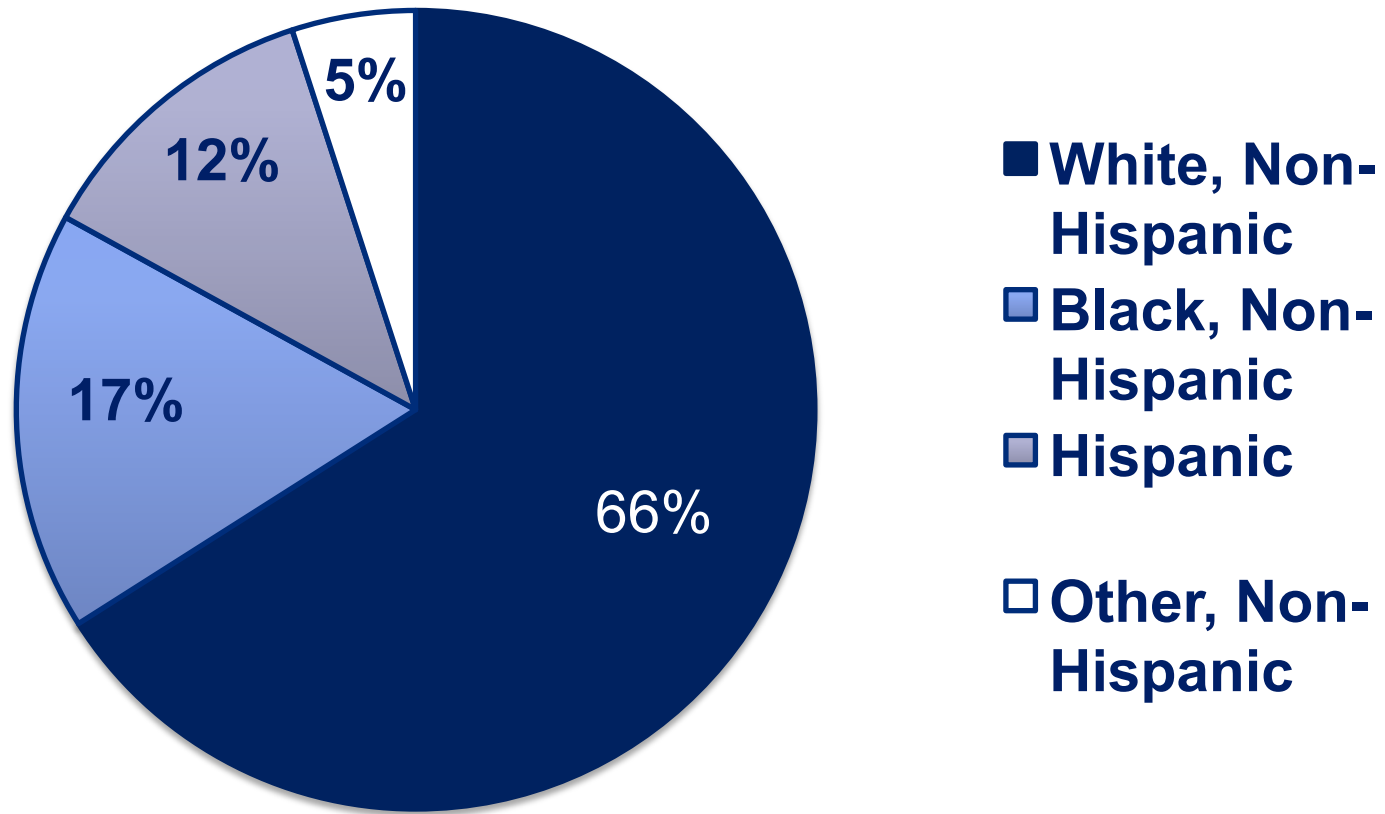
Unique family caregiving characteristics

- Caregiving is typically lifelong
- Requires specialized knowledge to navigate multiple formal systems of care and service: early intervention, education, pediatric health, adult health, long-term care, vocational, case management
- Caregiving is expensive – insurance often fails to pay for the elevated care needs of people with developmental disabilities
- Caregiving is often chronically stressful and takes a heavy emotional toll
- Emerging evidence suggests caregiving takes a physical toll
- *Yet caregivers are resilient, resourceful and feel rewarded by their experiences*

Family home or residential services?

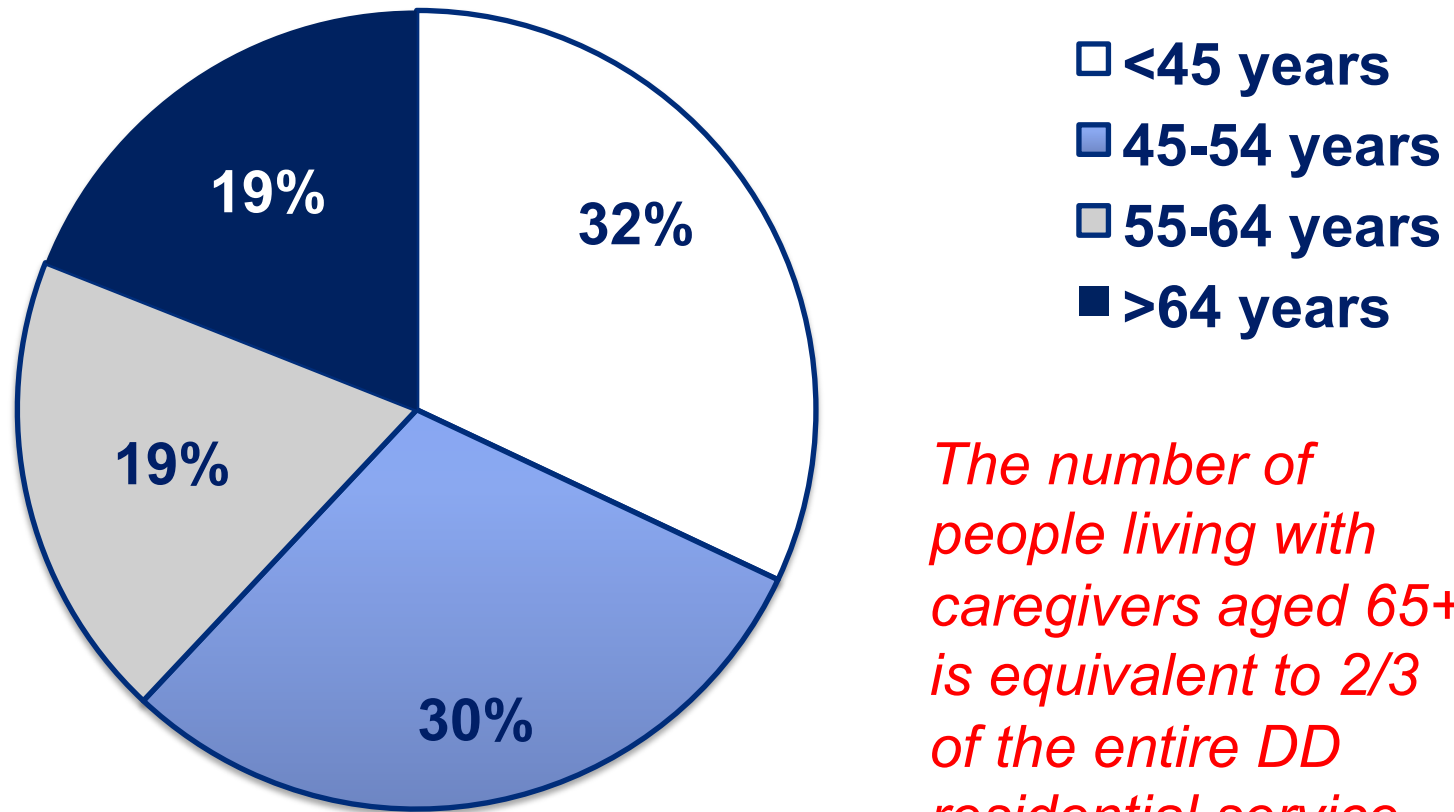
- ~2.65 million children and adults with DD (aged >5) in the US, live in community; **80%** live with family caregivers (Burke & Fujiura 2013)
- ~613,000 people with developmental disabilities receive residential services in the US (*Braddock et al., 2013*)
- Residential services waiting list >73,000 Americans with DD (12% of the total number of in residential services; *U of Minn RTC, 2013*)
- Family support consumes **7%** of the \$56.7 billion developmental disabilities system expenditures; ~468,000 families (*Braddock et al., 2013*)

Race and ethnicity of US heads of household that include people with DD



Source: Pooled SIPP 2004 & 2008 data, author's calculations, weighted

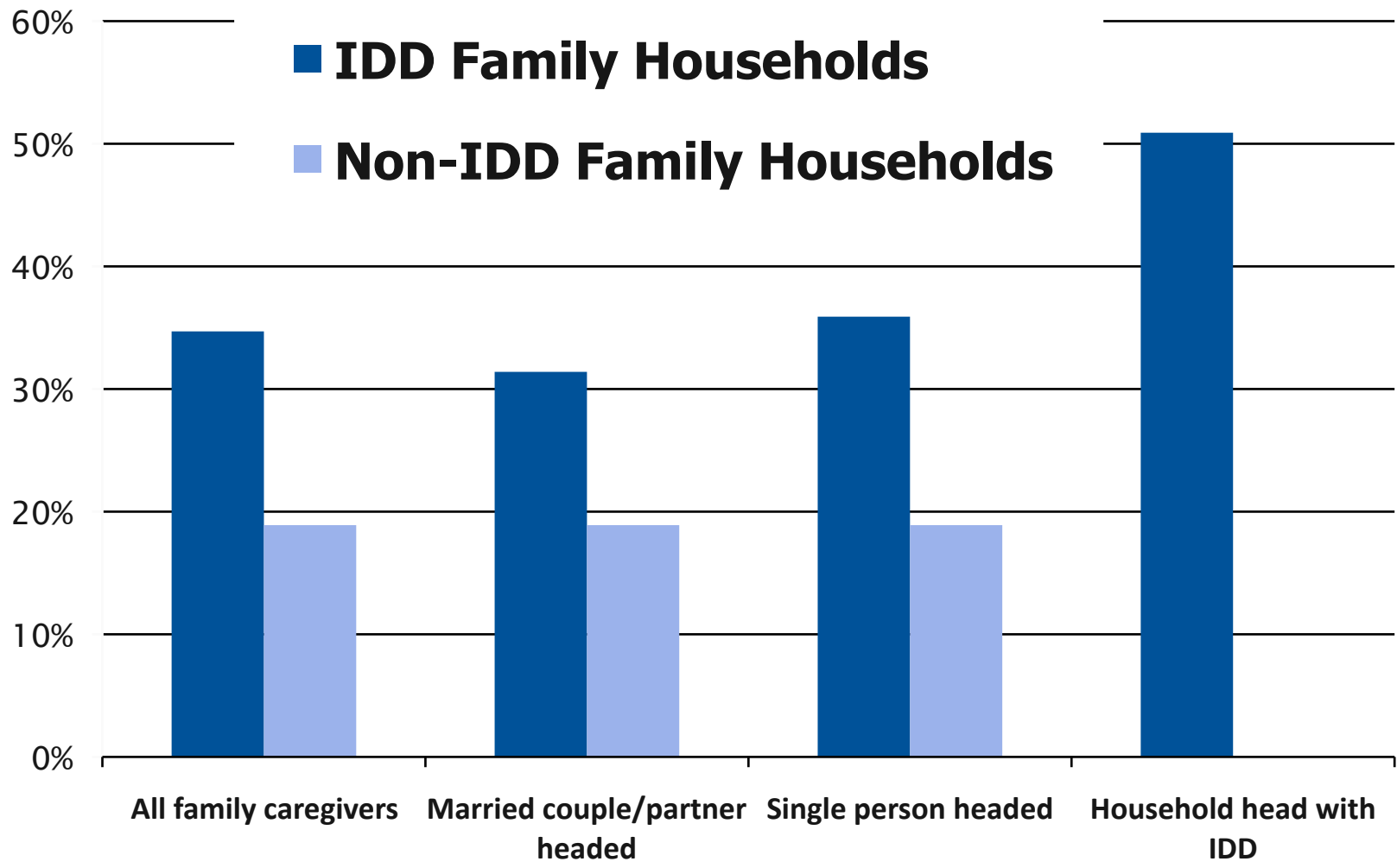
Age distribution of US heads of household that include people with DD



The number of people living with caregivers aged 65+ is equivalent to 2/3 of the entire DD residential service population

Source: Pooled SIPP 2004 & 2008 data, author's calculations, weighted

Family caregivers report poor health



Source: Burke & Fujiura, 2013

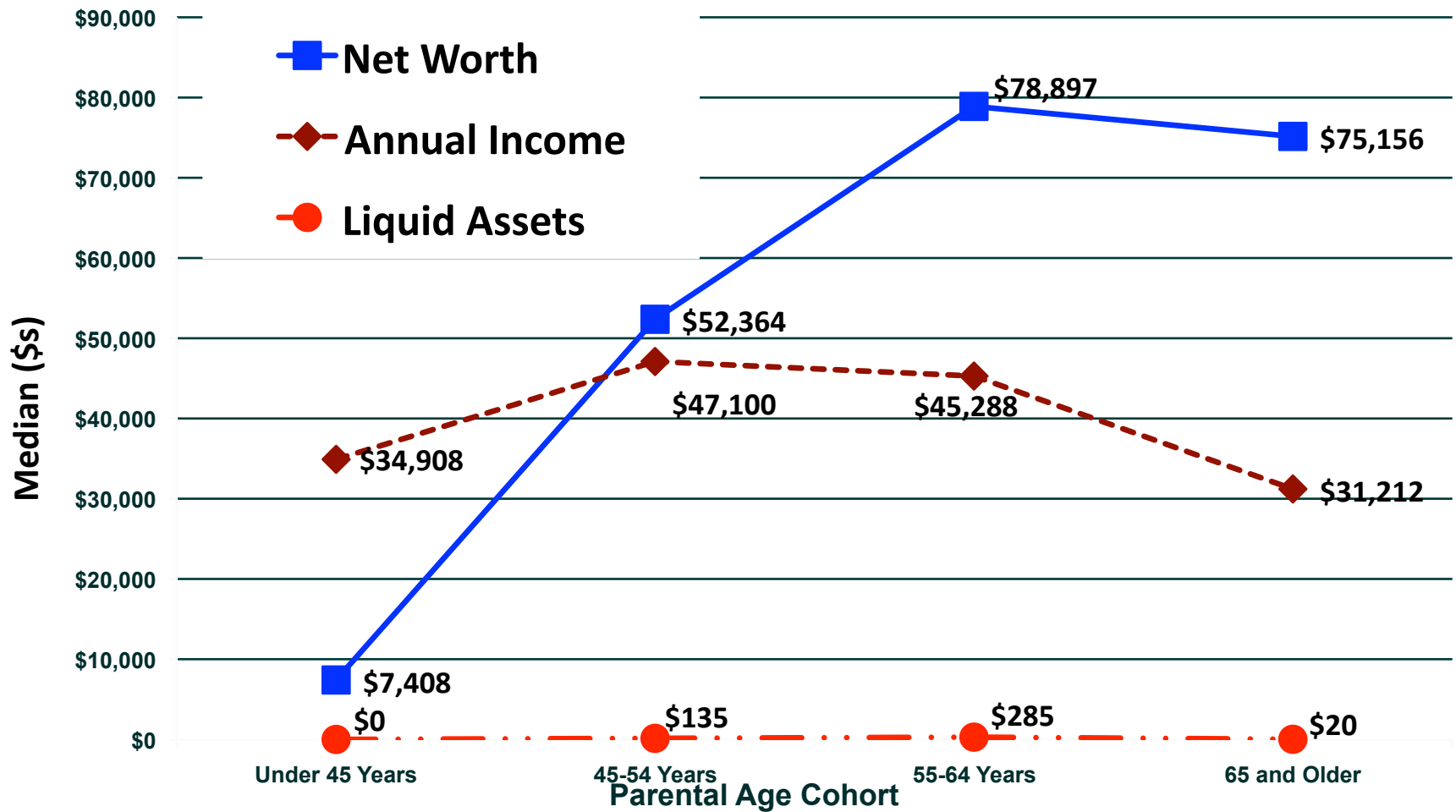
Health impacts of lifelong caregiving

- Marsha Mailick: chronic stress and fatigue take a physical toll on mothers of adult children with autism
- Cortisol studies show hypoactivation, similar to the responses of parents raising children with cancer and people with post-traumatic stress disorder
- Similar findings likely for caregivers of adult children with other developmental disabilities, particularly those with behavior problems and significant health conditions

Racial and ethnic disparities in health effects of caregiving

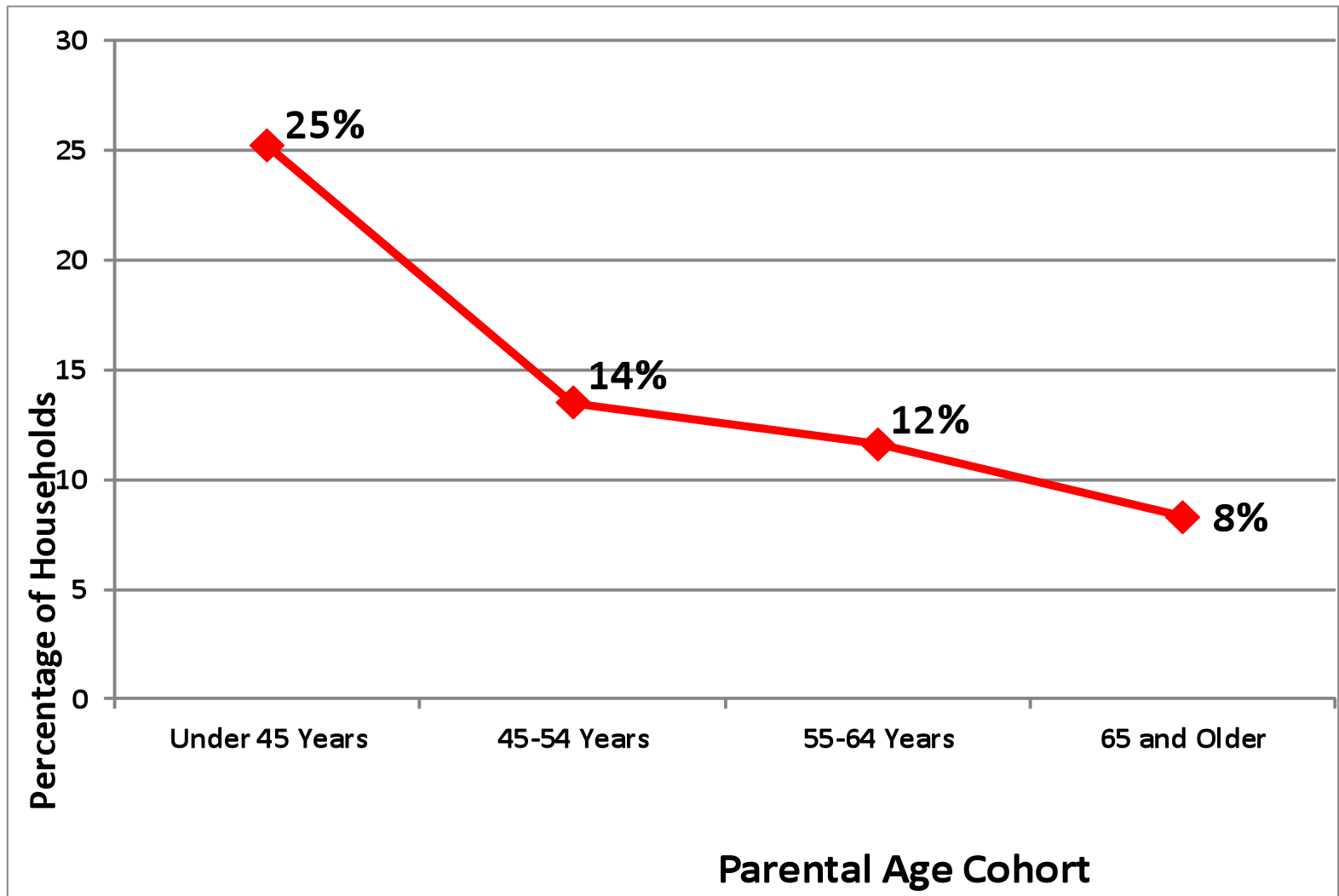
- Sandy Magaña: Cumulative adverse effects on Latina and Black American mothers who care for adult children with developmental disabilities
 - Arthritis, depression, poor overall health (Magaña & Smith, 2006; Magaña, Seltzer, & Krauss, 2004)
- Some evidence of more positive emotional health outcomes for African-American caregivers (Magaña, 2004)

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



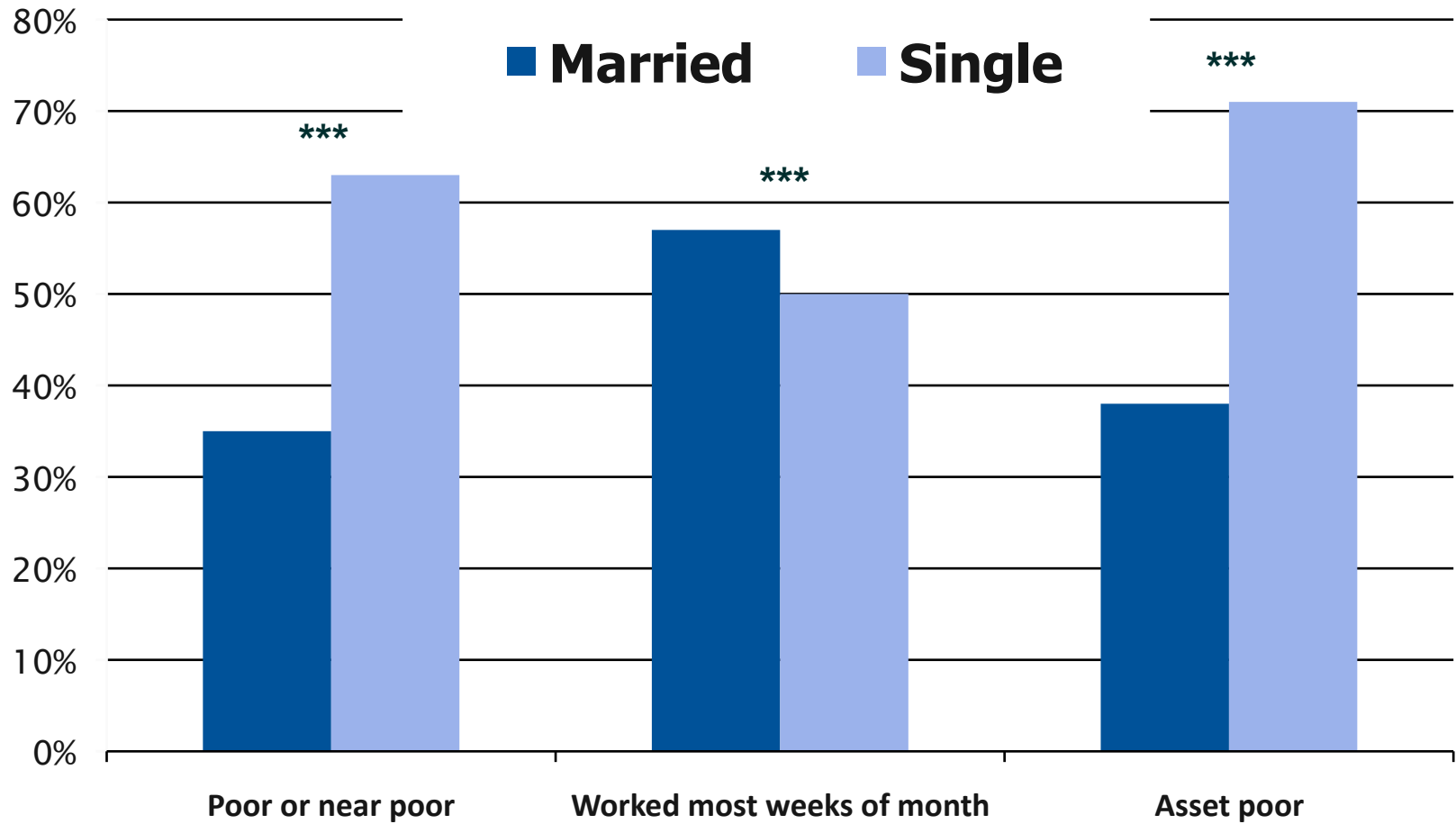
Source: Parish et al., 2010

Families of children with DD with zero or negative liquid assets



Source: Parish, Rose & Swaine 2010

Well-being of single and married mothers



***= significant at $p < .001$

Source: Parish et al., 2012

Policy context

- Medicaid represents the single largest expenditure for state budgets (24% of total spending in FY13) Medicaid spending growth peaked 2007-2011
- Medicaid and SSI require families to impoverish themselves (the asset cap on eligibility is \$3000 for a married couple)
- For FY2014, total Medicaid spending was estimated to grow by 13%, state funds increasing by 6%
 - State funds continue to be strained and economic recovery remains sluggish
- Projected annual average Medicaid growth between 2013-2022 is 7%, faster than 5% average annual GDP growth
- Few ACA provisions address the needs of caregivers

Source: NGA & NASBO, 2014; Young 2014



What *really* matters? Where families live!

- Families living in states with higher income inequality have greater financial burden raising their children with disabilities (*Parish et al., 2012*)
- 13% of US families receive family support services (but range was 0-34%) (*Braddock et al, 2013*)
- 22 states provided family support to fewer than 10% of family caregivers (*Braddock et al, 2013*)
- Families living in states with more generous Medicaid programs have *lower* out-of-pocket health costs for their children with disabilities (*Parish et al., 2009*)

In conclusion, some questions...

- How will states address the needs of aging parent caregivers, as individuals with DD live longer than ever before?
- What are the long-term consequences of chronic poverty and deprivation in these caregiving families?
- How will technology help families navigate the difficult world of fragmented service systems?
- How can technology help families meet their obligations to provide increasingly specialized care?
- How can technology help eliminate racial and ethnic disparities in the physical health burdens of caregiving?



Acknowledgements

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Thank you!

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