

The background of the slide is a photograph of a university building at sunset. The sky is a gradient of orange and yellow, transitioning to a pale blue at the top. The silhouettes of the building's spires and trees are visible against the bright sky. The text is overlaid on this image.

A National Picture of Developmental Disabilities

Presentation for the NC IOM
Task Force on DD Transitions

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Overview of Presentation

- Looming issues – economic and political context of the DD service system
- Current DD service system
 - NC in comparison to the nation
- Issues related to 3 Transitions



System Constraints

- Poverty and deprivation in the DD population
- States' fiscal realities
- Unmet needs for care, particularly residential care

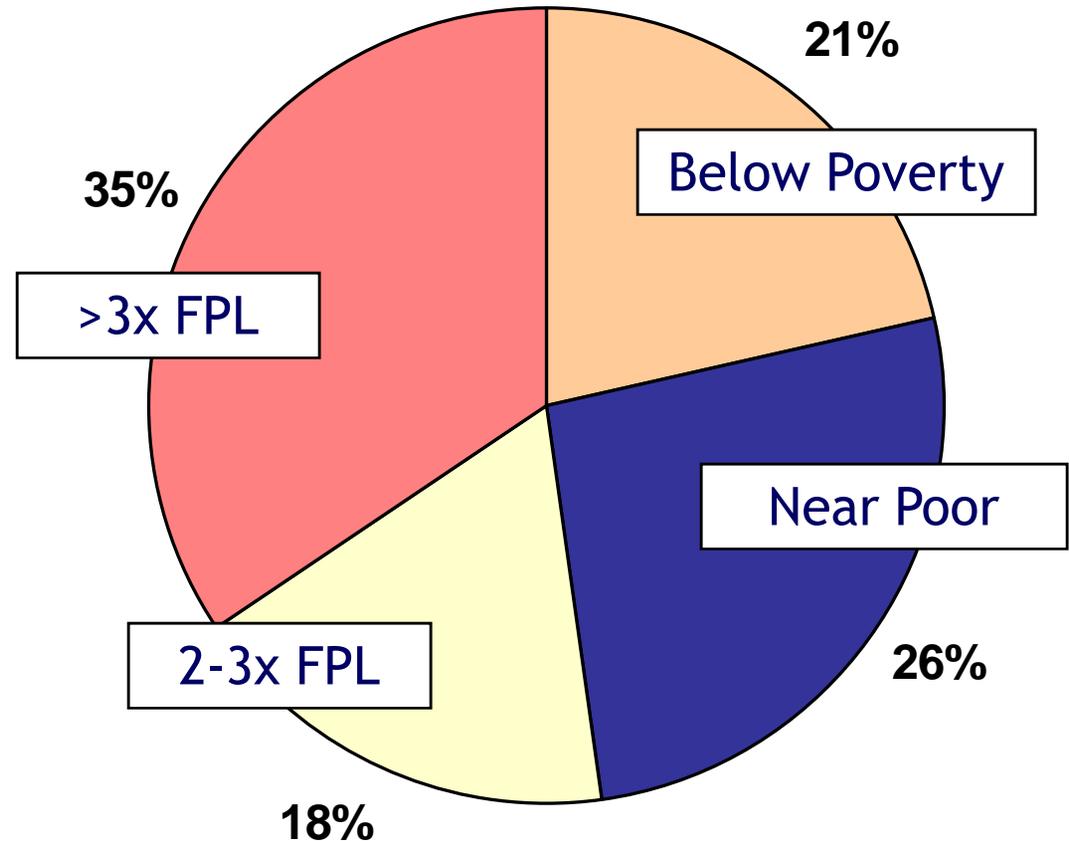


Poverty & Material Hardship



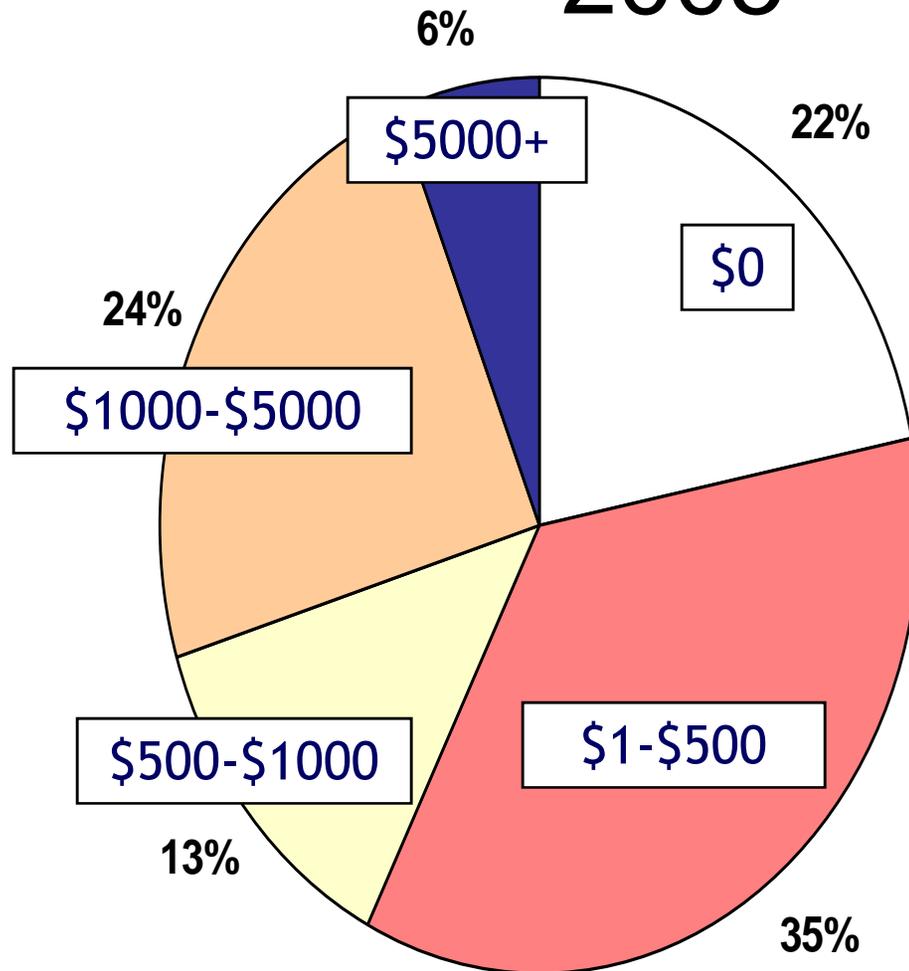
NC Children with DD by Household Income relative to the FPL

FPL is federal poverty level; \$21,200 for family of 4 in 2008



Source: Parish & Rose (2008), unpublished data, National Survey of Children with Special Health Care Needs

Annual Out-of-Pocket Costs for NC Families Raising Children with DD, 2005



Source: Parish & Rose (2008), unpublished data, National Survey of Children with Special Health Care Needs

Material Hardship & Disabilities

- Families of children with disabilities significantly more likely to live in poverty than other families
- Deprivation is common: food insecurity, housing instability, telephone disconnection, inadequate health care
- Deprivation exists even in middle-class
 - The costs of caring for children with disabilities are high; services are limited and not comprehensive

Source: Parish, Rose, Andrews, Grinstein-Weiss & Richman (2008)



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States' Fiscal Realities



Immediate State Budget Problems

- FY 08 was turning point as states began experiencing fiscal difficulties
- 18 states have proposed general fund spending for FY 09 that is $<$ FY 08
- 13 states cut their FY 08 budgets AFTER enactment
- State recessionary patterns differ from the national picture & are typically worse – longer recovery

Source: National Association of State Budget Officers (2008)



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Future State Budget Concerns

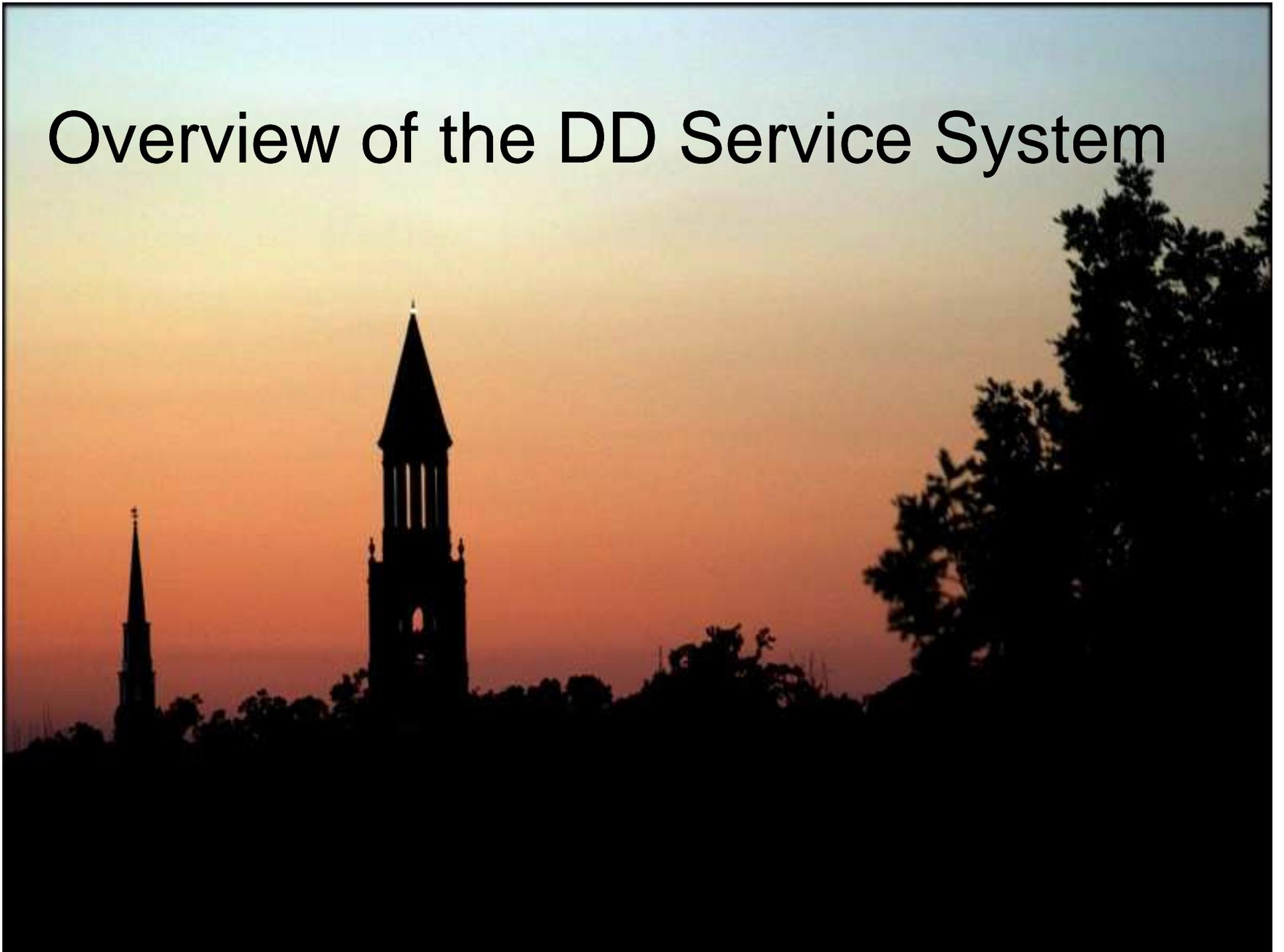
- Ongoing state Medicaid commitments will continue to strain state budgets
 - Medicaid accounts for 22% of total state spending (NC: \$11.3 billion in FY 07)
 - Estimated annual growth of 8% 2008-2018
 - Every state instituted cost containment since 2002
- Current federal commitment to bail-out, growing federal deficit, and need to address Medicare & Social Security shortfalls may reduce federal assistance in future

Source: National Association of State Budget Officers (2008)



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Overview of the DD Service System



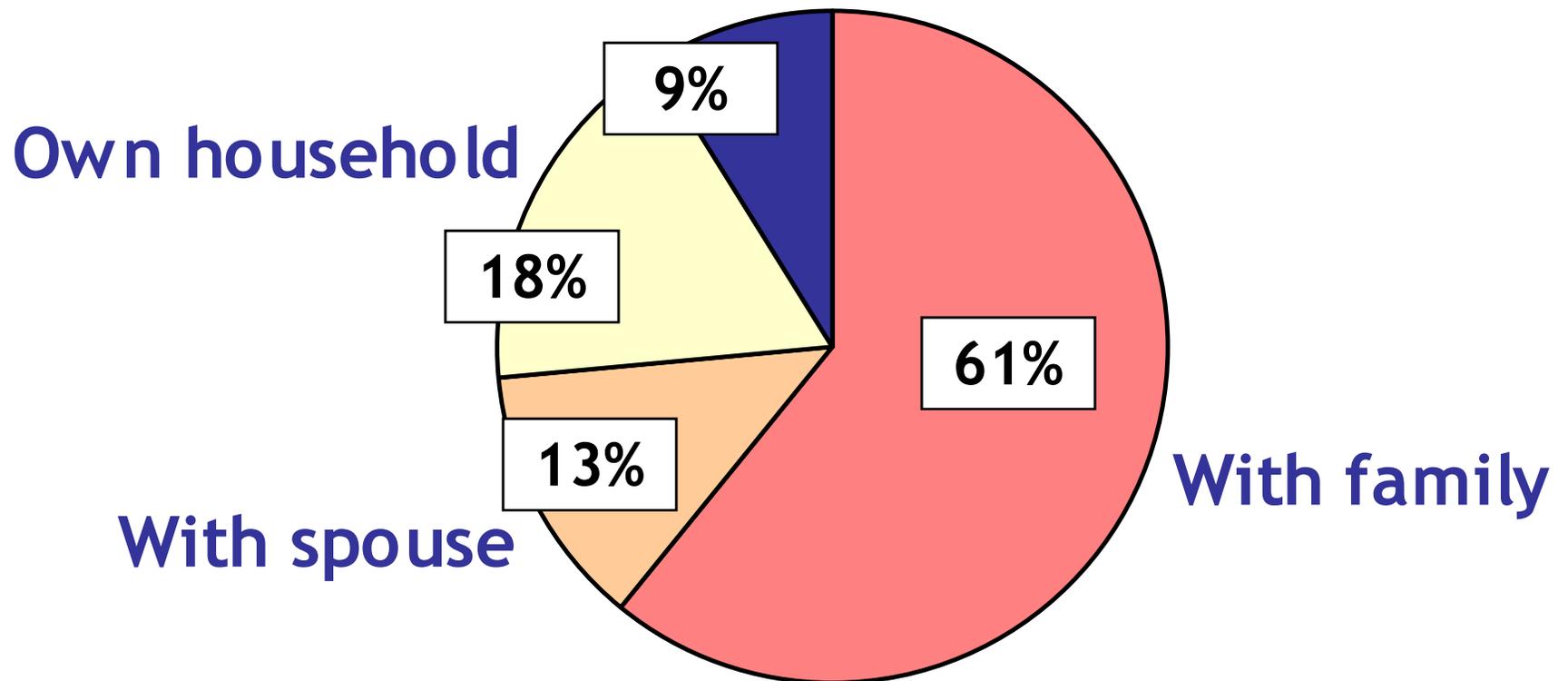
Parts of the DD Service System

- Residential
- Family Support
- Vocational
- Education
- Health & Mental Health Care
- Income Transfers (SSI, SSDI)
- Transportation
- Recreation
- Case Management



Where People with DD live in the US

Residential facility



Source: Parish (2008) unpublished data from 2001 Survey of Income & Program Participation

The DD Service System

- Medicaid is largest source of funding for DD services (78% nationally, 77% in NC)
- HCBS Waiver = 57% of Medicaid funding
- ICF/MR = 36% of Medicaid funding
 - In NC, Waiver = 34% of Medicaid funding
- Vast majority of funding goes to residential services

Source: Braddock, Hemp & Rizzolo (2008)



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Demand for LTC Far Exceeds Supply

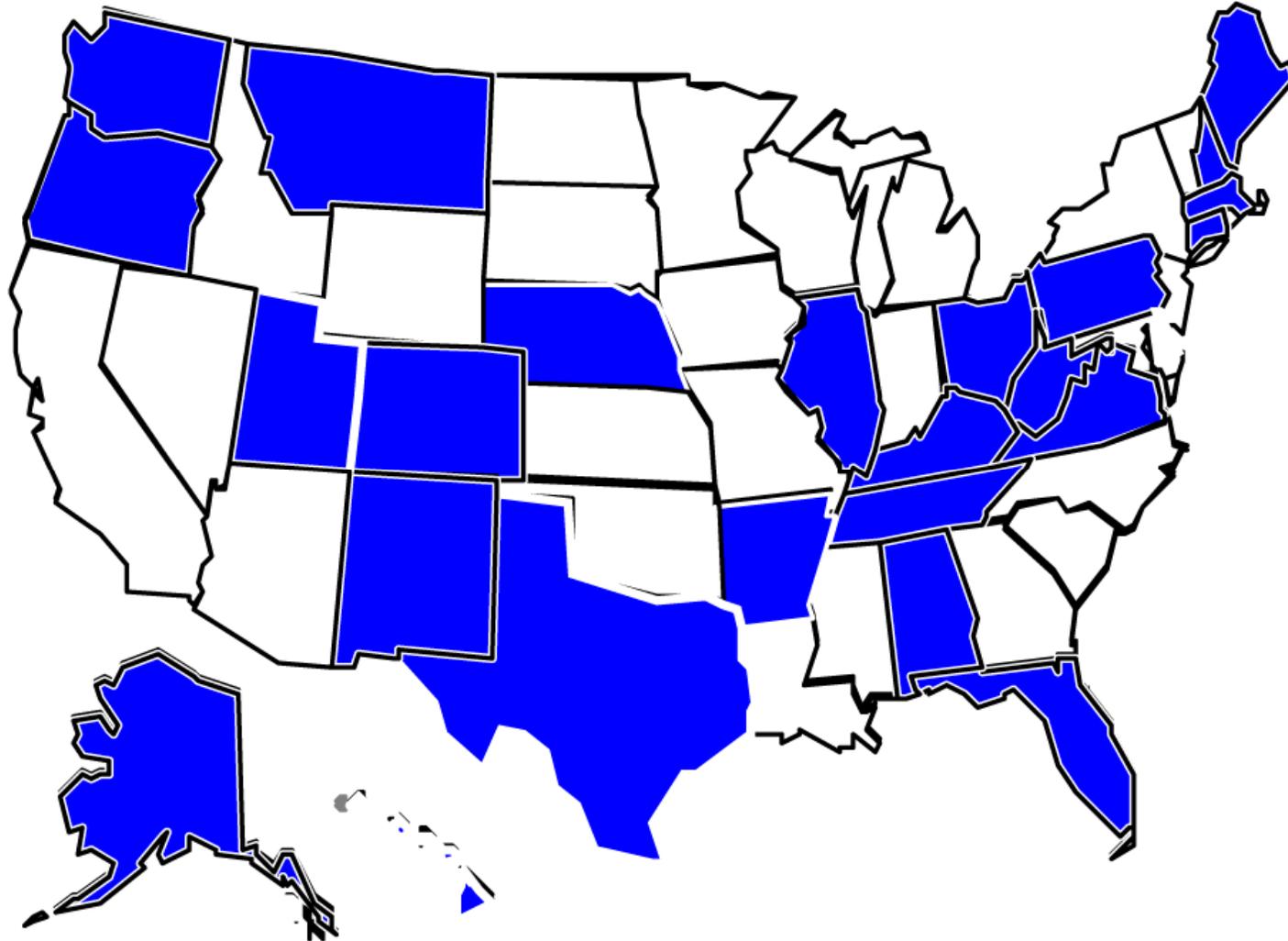
- Waiting list data are problematic (est. >85,000)
 - Some states don't track the numbers
 - Some families do not seek services until crisis
 - Some families decline services when offered
- The “real” number of needed residential placements is not known
 - In NC, 272 people receive residential services per 100,000 of state population; in Iowa = 411
 - Catching Iowa would require development of 12,190 new residential placements (a 52% increase over the current number in NC)

Sources: Prouty & Lakin (2008)



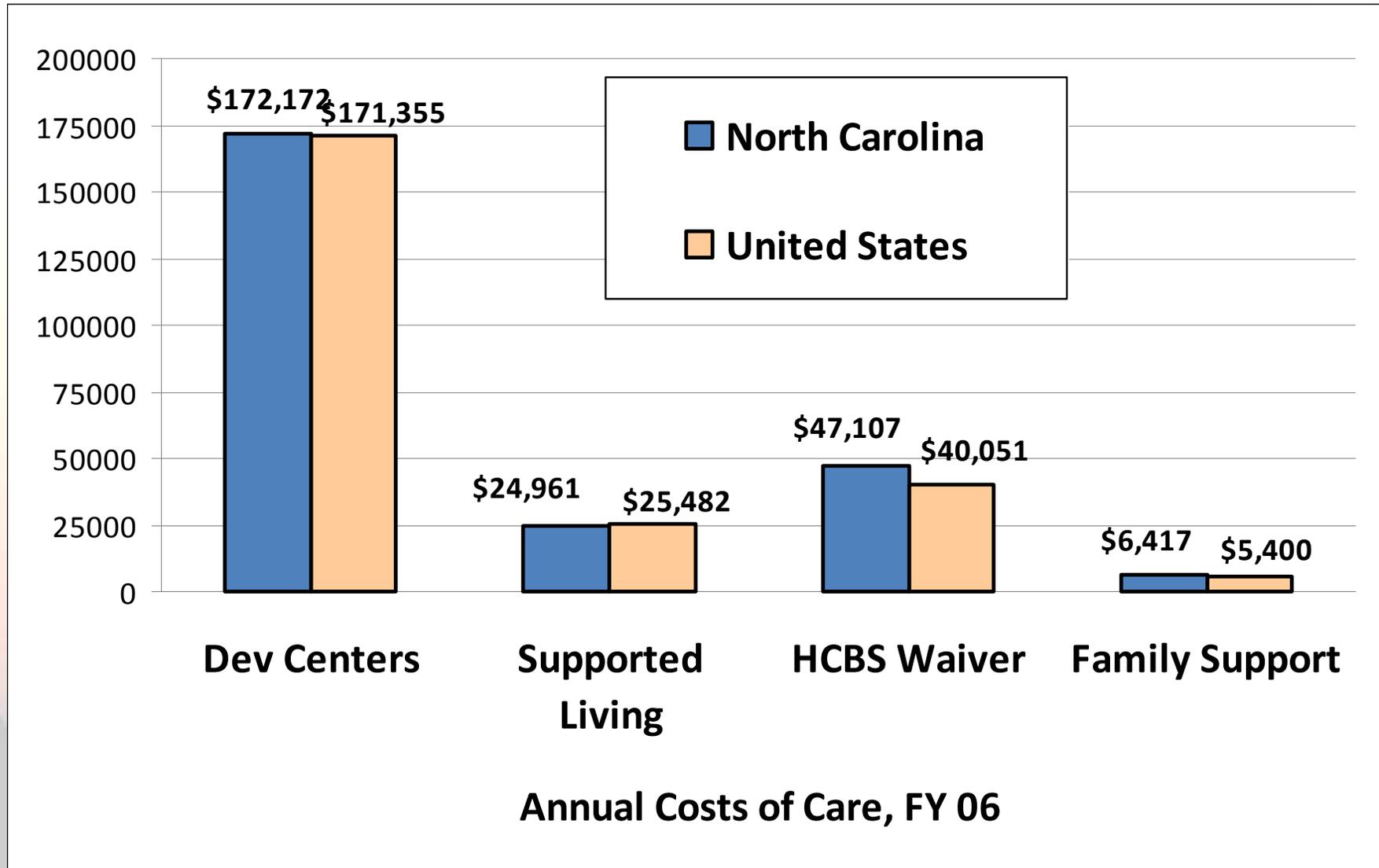
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States with “Community” Lawsuits



Source: Smith (2006)

Annual Costs of Care, FY 06

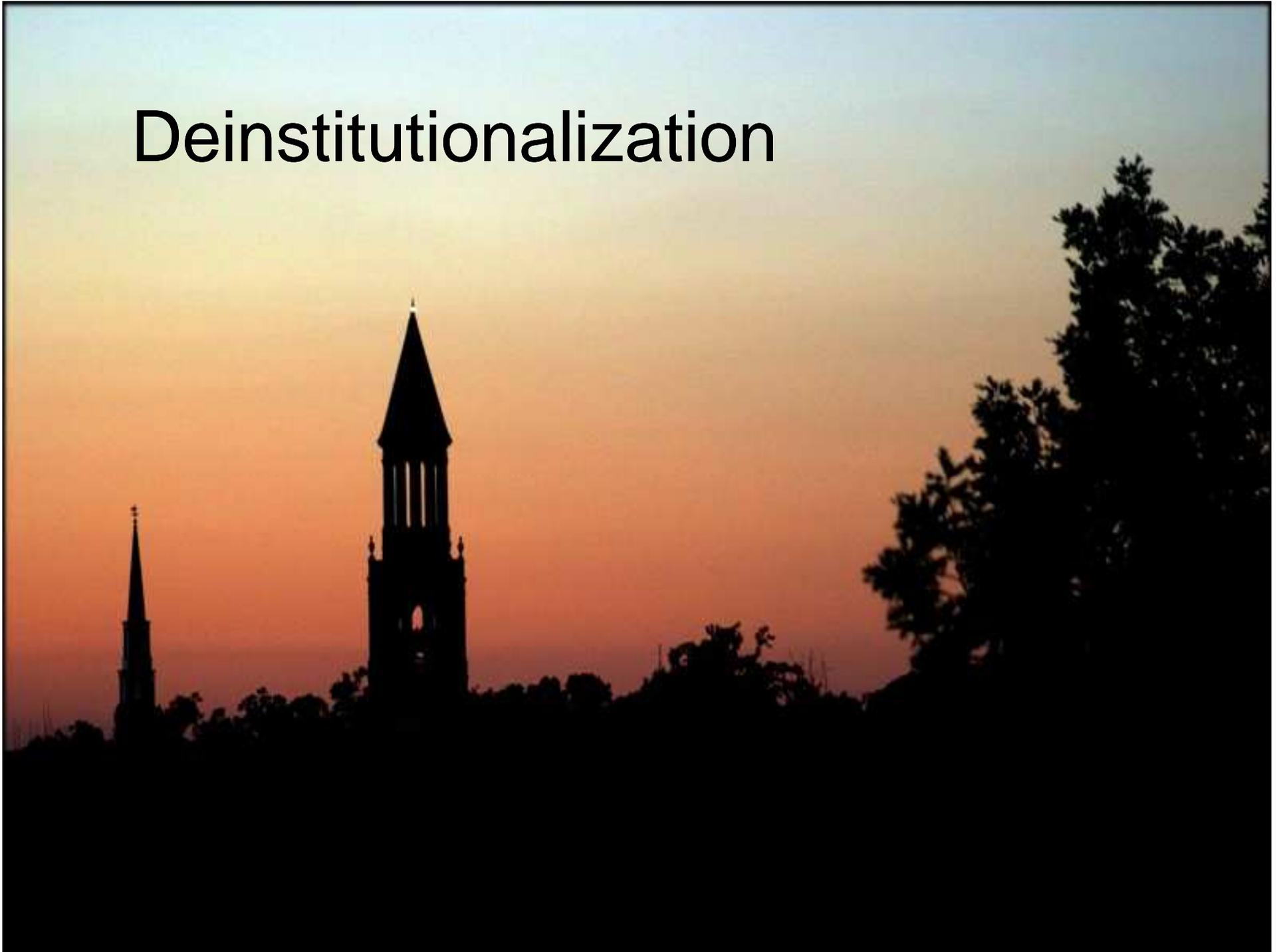


Source: Braddock, Hemp & Rizzolo (2008)



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Deinstitutionalization



Deinstitutionalization

- Public DD institutional census peaked in 1967 at ~195,000 residents
- 141 public institutions closed or projected to close between 1970-2010
- Stimulated by
 - Class action lawsuits
 - Enforcement of ICF/MR regulations
 - State recessions in the 1980s
 - The need for prison space

Sources: Parish (2005); Braddock et al (2008)



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States without Public Institutions

New Hampshire (1st state to close all institutions, with Laconia's closure in 1991)

Vermont (1994)

Rhode Island (1994)

District of Columbia (1994)

New Mexico (1995)

Alaska (1997)

Maine (1999)

Hawaii (1999)

West Virginia (1999)

Minnesota (2000)

Indiana (2007)

Source: Prouty & Lakin (2008)



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Research Overwhelmingly Supports Community Living

- Preferred by advocates, families & people with disabilities
- Better outcomes in
 - Adaptive Behavior
 - Social Participation
 - Choice-making
 - Self-determination
 - Functional Behavior



Institutional Reliance Today

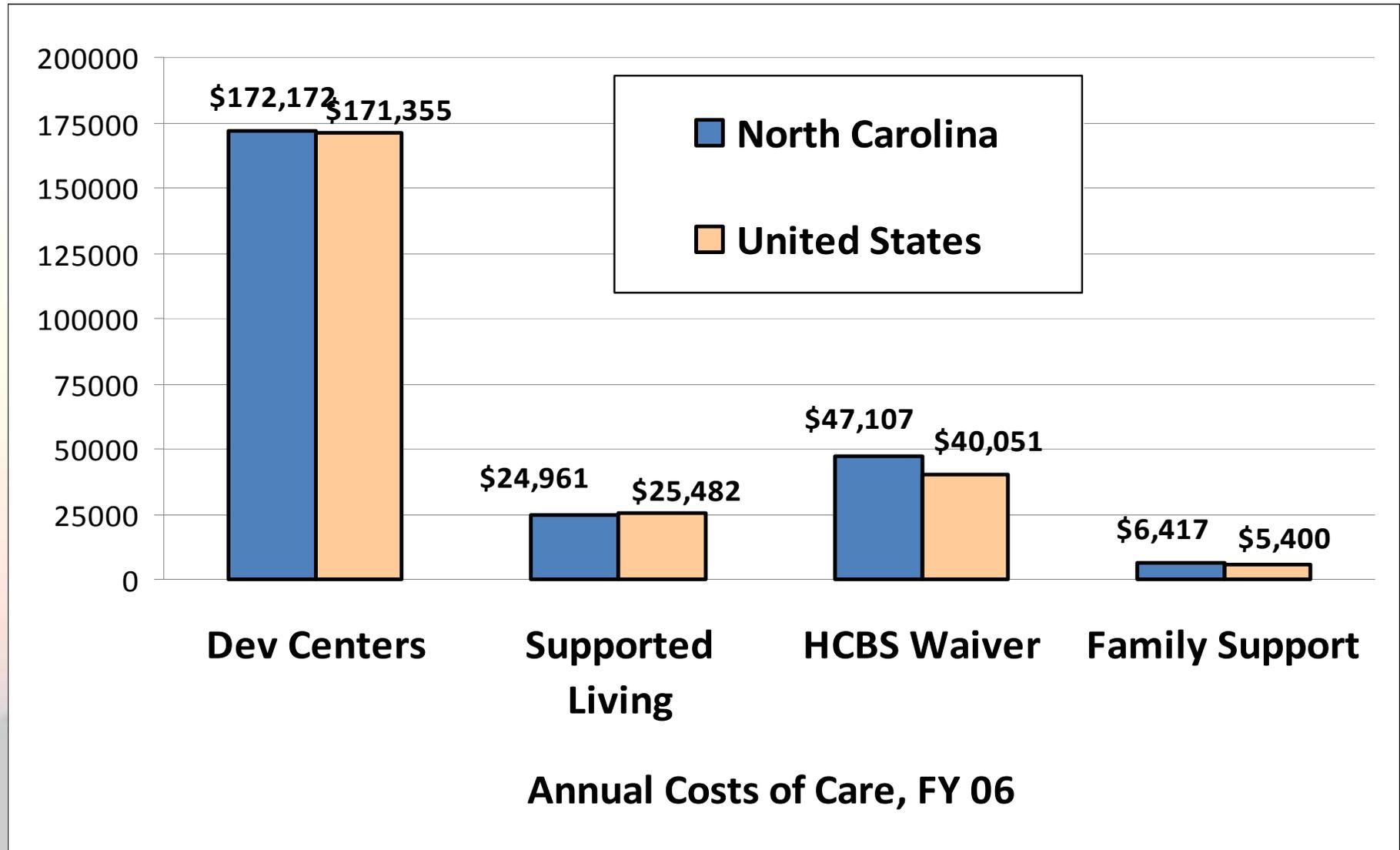
- A handful of states still have extensive systems of institutional care
 - NC has **more** public institution residents than all states **except**: CA, IL, NJ, OH, NY & TX
 - NC's public institutions have downsized 3% annually since 1998
- Operating dual (community and institutional) systems of care is expensive
 - Institutional costs are dramatically higher than community costs
 - Facility & staff costs don't diminish as people move out

Source: Braddock, Hemp & Rizzolo (2008)



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Annual Costs of Care, FY 06



Source: Braddock, Hemp & Rizzolo (2008)



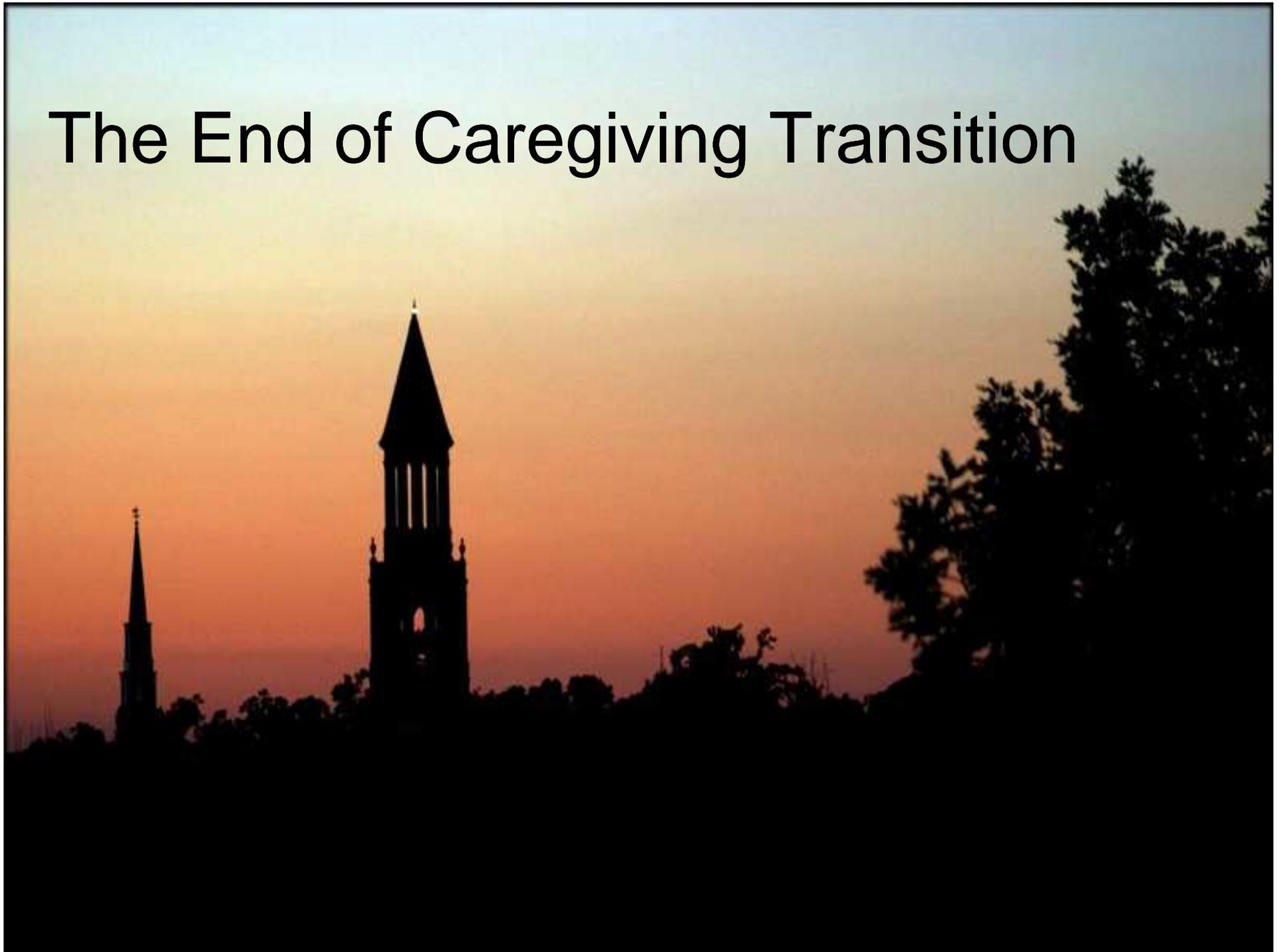
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Current Closure Practices

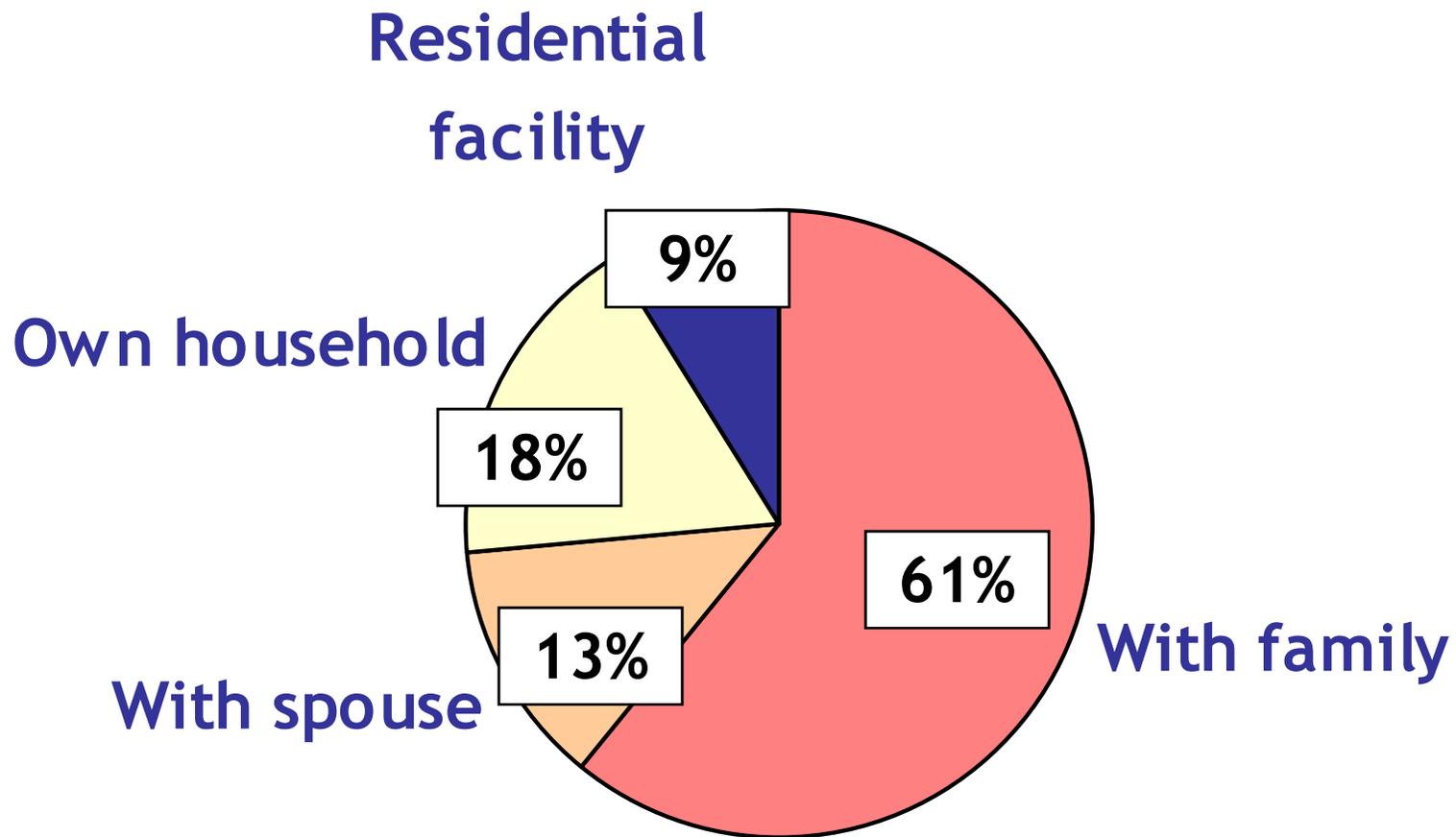
- Have community parents work closely with institutional parents
- Extensive transition planning to support individuals as they move
- Family support & consumer direction determination
- Facilitate job training for affected institutional staff
- Have staff transition with residents to work in community settings
- Moratoriums on respite & new admissions
- Minimize public announcements



The End of Caregiving Transition

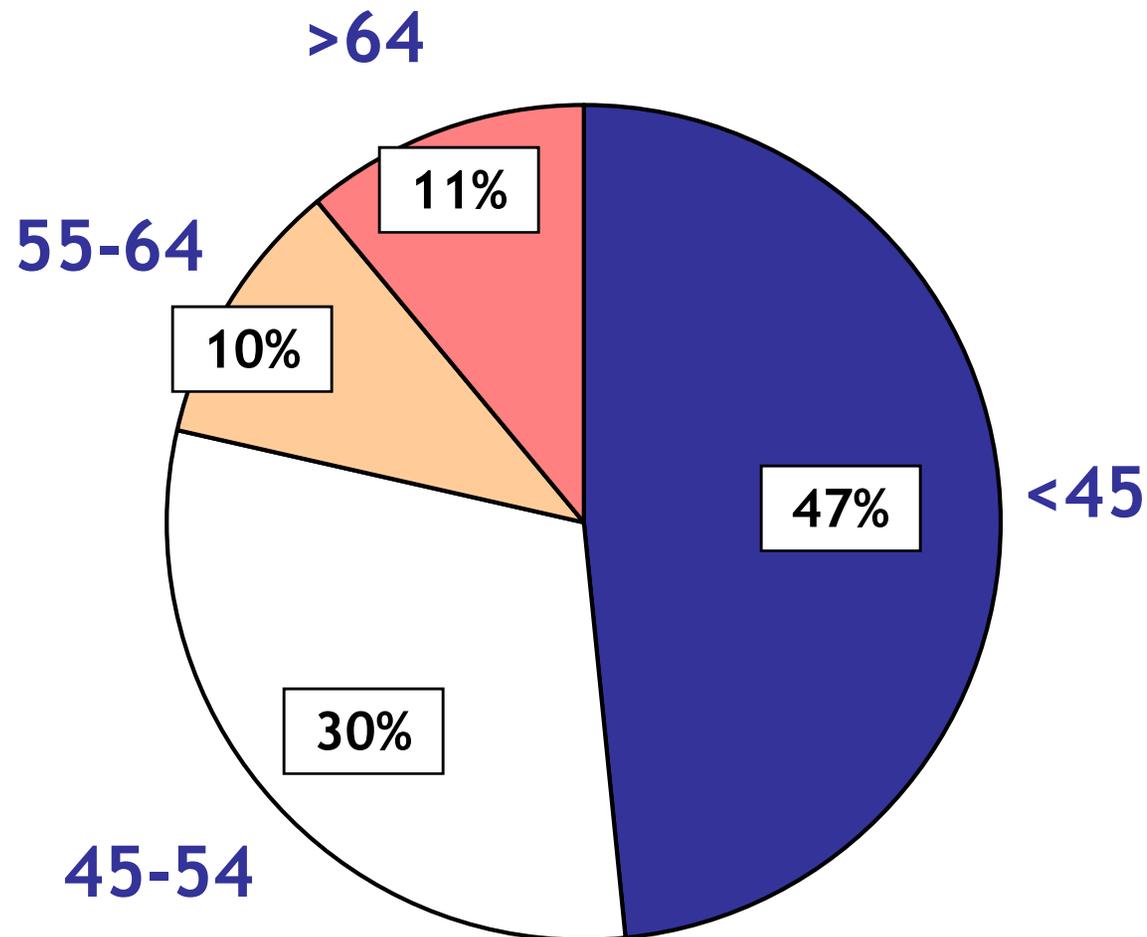


Where People with DD live in the US



Source: Parish (2008) unpublished data from 2001 Survey of Income & Program Participation

People with DD Living at Home, by Age of Family Caregivers, US



Source: Parish (2008) unpublished data from 2001 Survey of Income & Program Participation

Demographic changes

- People with DD beginning to outlive their parent caregivers in large numbers
 - Technological advances have extended lifespan
- Women's increased employment, greater family mobility, and declining fertility means that fewer family members are available to care for the family member with DD

Source: Parish & Lutwick (2005)



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Vestiges of the Past

- Elderly parent caregivers may believe long-term care services still resemble the institutions of decades ago
- Elderly parents may be exceptionally fearful of what will become of their aging adult child with developmental disabilities when they die or become too frail to continue caring



Parents' Current Mistrust of the LTC System Built on Early Experiences

- State hospitals or institutions were only long-term care options
- Conditions were often horrendous, overcrowded, unsanitary, abusive
- Parents were told to place their child at birth or upon diagnosis



Promising Practice: Planning

- Define how care will be provided as parents cope with their own age-related concerns or the parent can no longer provide care
- Ease the transition and minimize the trauma that the person with DD will experience
- Ensure that caregivers' and care recipients' wishes are understood before crisis occurs
- Assure the financial, residential & legal stability and security of the person with DD

Source: Factor (1997); Heller et al (2007)



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Most parents don't plan

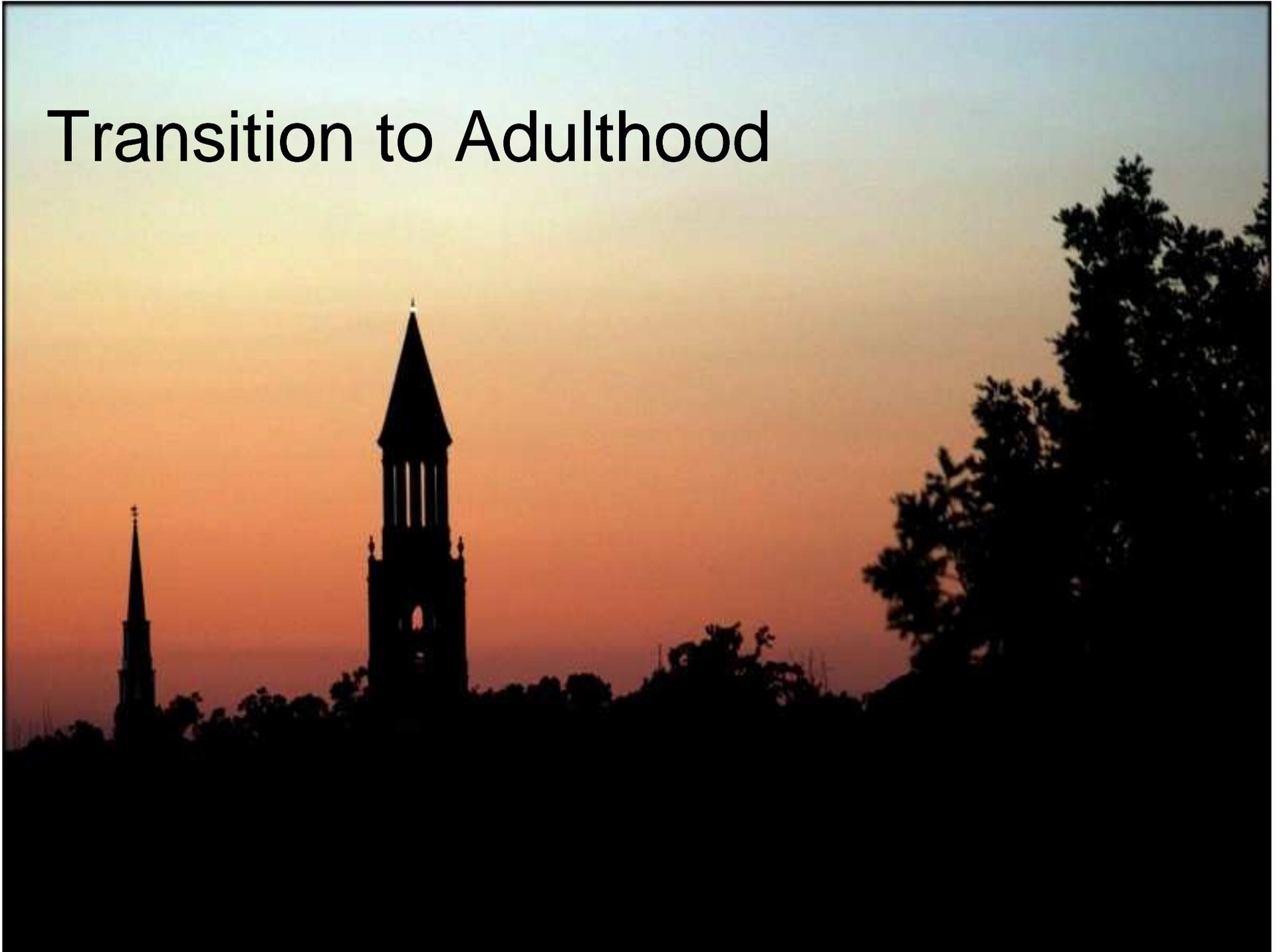
- Overwhelming, emotionally charged process
 - Forces parents to confront their own mortality
 - Forces parents to relinquish care of their (adult) children
- Parents are fearful of residential (long-term care) services

Source: Heller et al (2007)



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Transition to Adulthood



Transition Planning

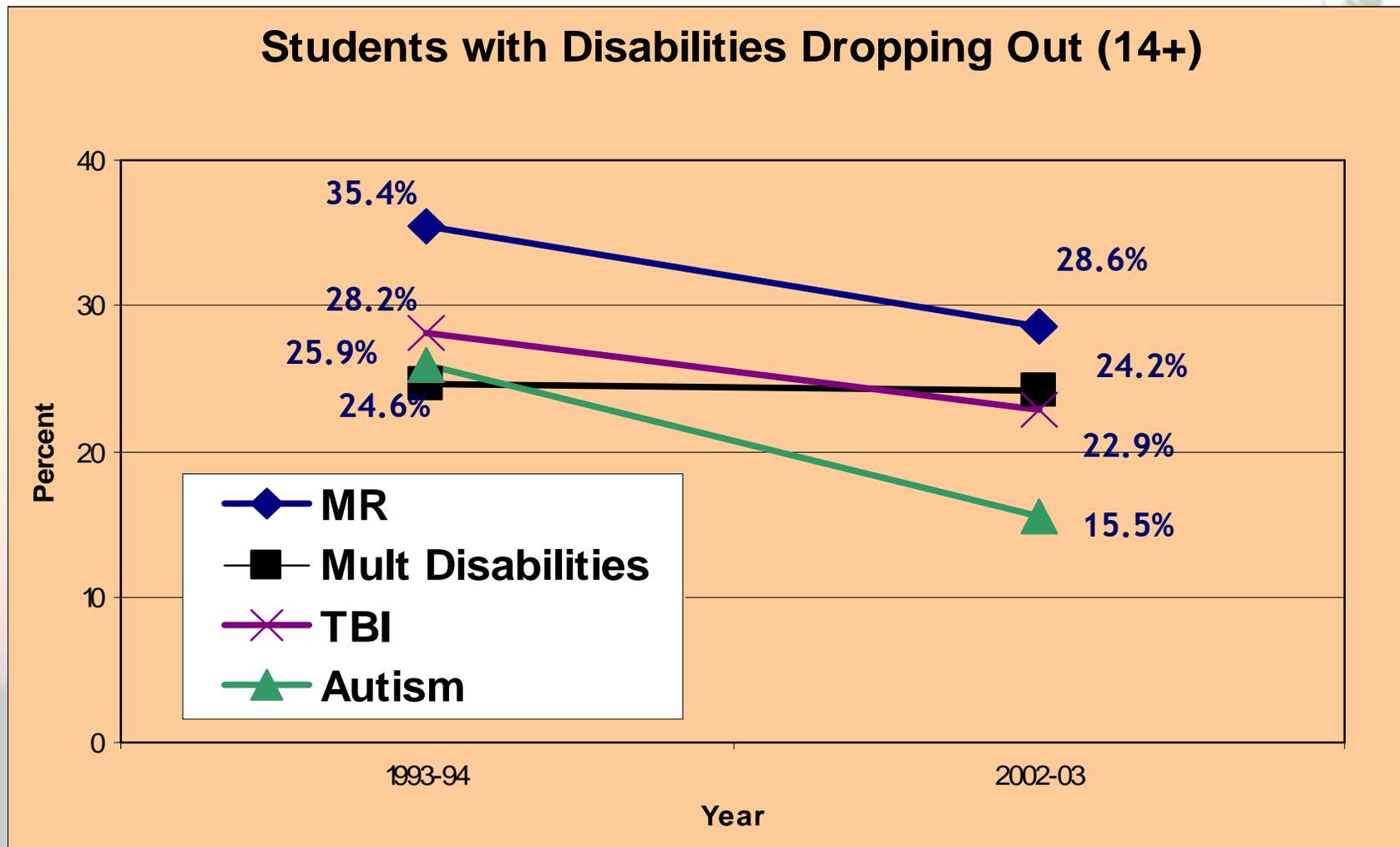
- Goals of transition planning: Employment, independence, full community participation & civic engagement
- IDEA requires transition planning in the Individualized Education Plans of all special education students beginning at age 14
- Existing evidence suggests great variability in the implementation of transition plans

Source: National Center for Special Education Research (2008)



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US Drop Out Trend, Youth with DD



Source: US Department of Education; Annual Report to Congress on Implementation of IDEA (2005)



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Post-High School Outcomes

- Employment rates are exceptionally low for young adults with developmental disabilities
 - Supported employment receives very little funding across the US
- Low employment has enormous implications
 - Young adults cannot leave their parents' homes
 - Young adults have low rates of community participation & civic engagement
 - Poverty is significant



Promising Strategy: SSI Work Incentives

- All students receiving SSI benefits are eligible to participate in SSI work incentive programs
- Work incentives include:
 - Earned Income Exclusion (EIE); Student Earned Income Exclusion (SEIE); Impairment-related Work Expense (IRWE); Plan for Achieving Self-Support (PASS); Blind Work Expenses (BEW)
- < 50% of transition-aged students eligible for SSI benefits are participating

*Source: Work Incentives Transition Network
(2000)*



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Point of Intervention? School Personnel & Work Incentives

- Identify students who may be eligible for SSI benefits & assist with application
- Inform students & parents about SSI
- Incorporate SSI work incentives into IEP/transition planning process
- Work collaboratively with local SSA staff
- Link SSI work incentives to the transition curriculum

Source: Work Incentives Transition Network (2000)



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Summary

- Funding of the system is biased toward supporting people in residential care
- Family support spending is inadequate across the US
- Demand for LTC far exceeds supply
 - In other states, parents are seeking court intervention to obtain community services
- States' ability to expand system is seriously constrained





Thank you!

For further information:

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