



Characteristics and Needs of Long-Term Supports and Services Recipients with ASD or Other IDD Living with a Family Member

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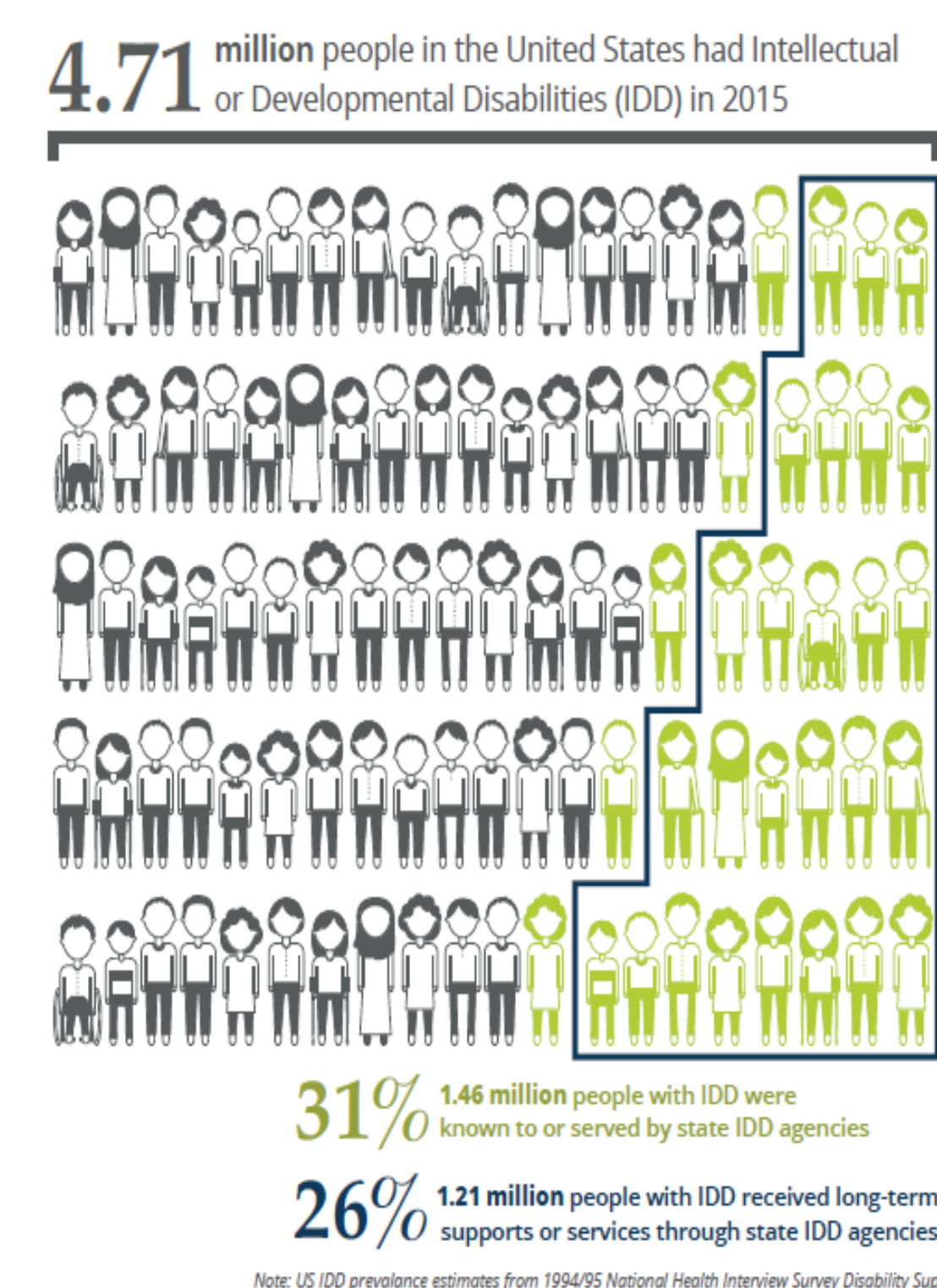
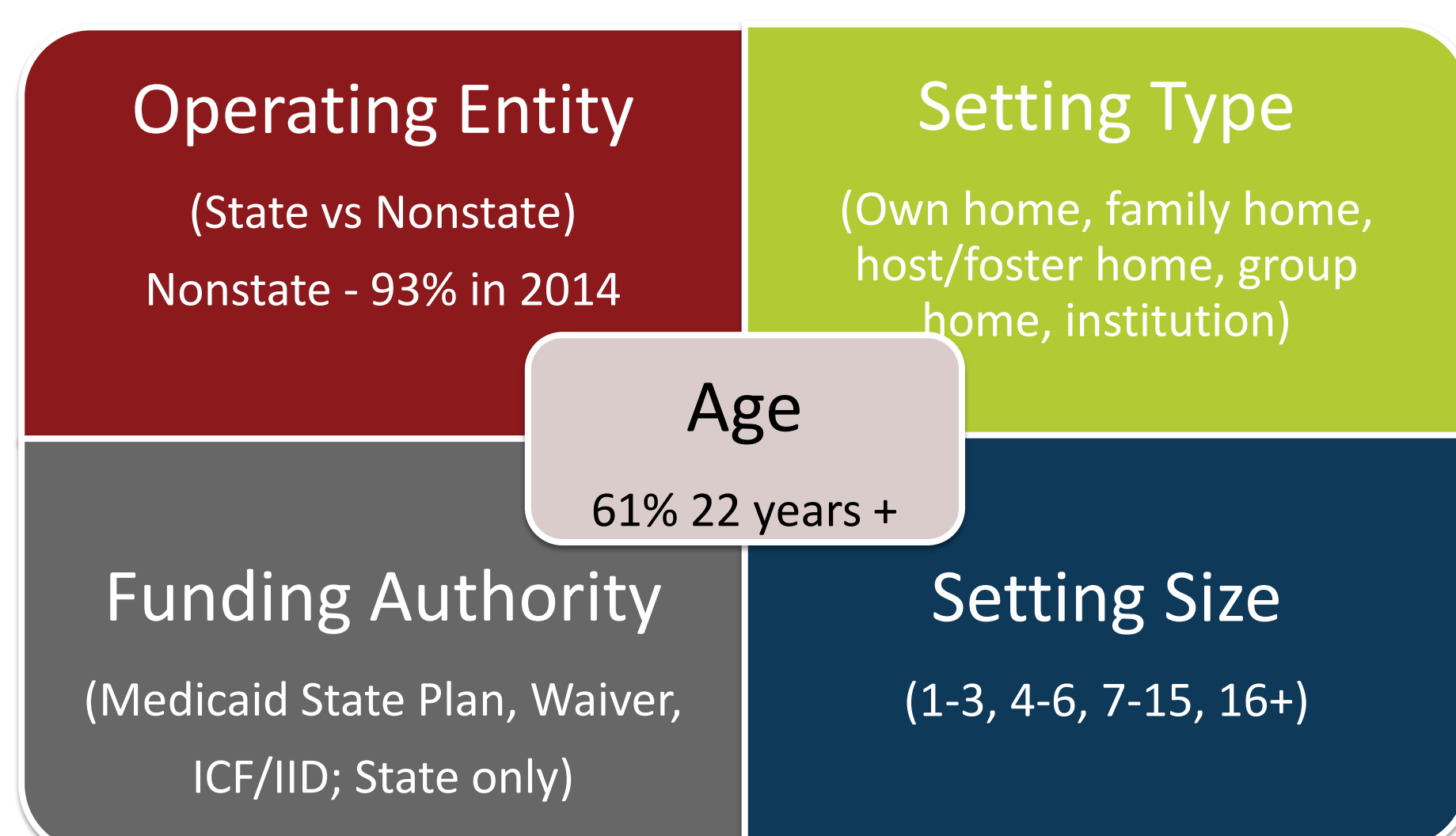
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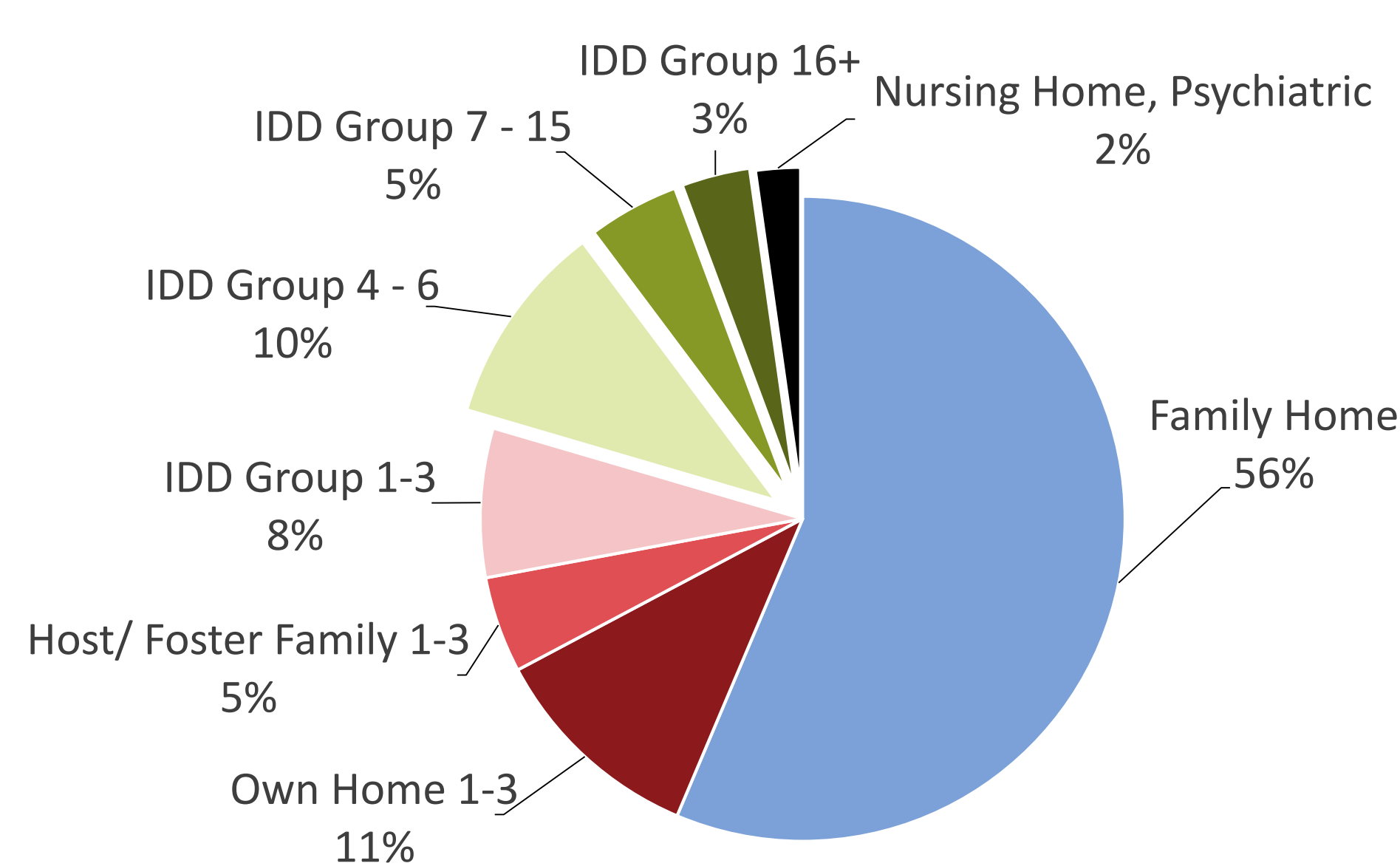
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Residential Information Systems Project

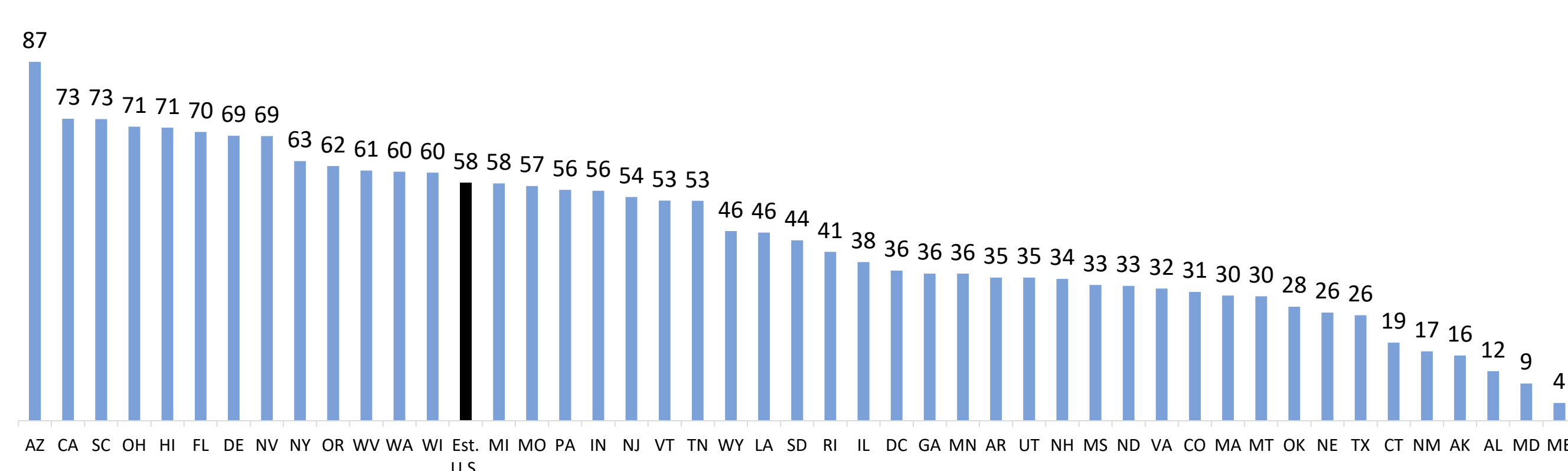
Longitudinal Study of Residential Supports for People with Intellectual or Developmental Disabilities Since 1977



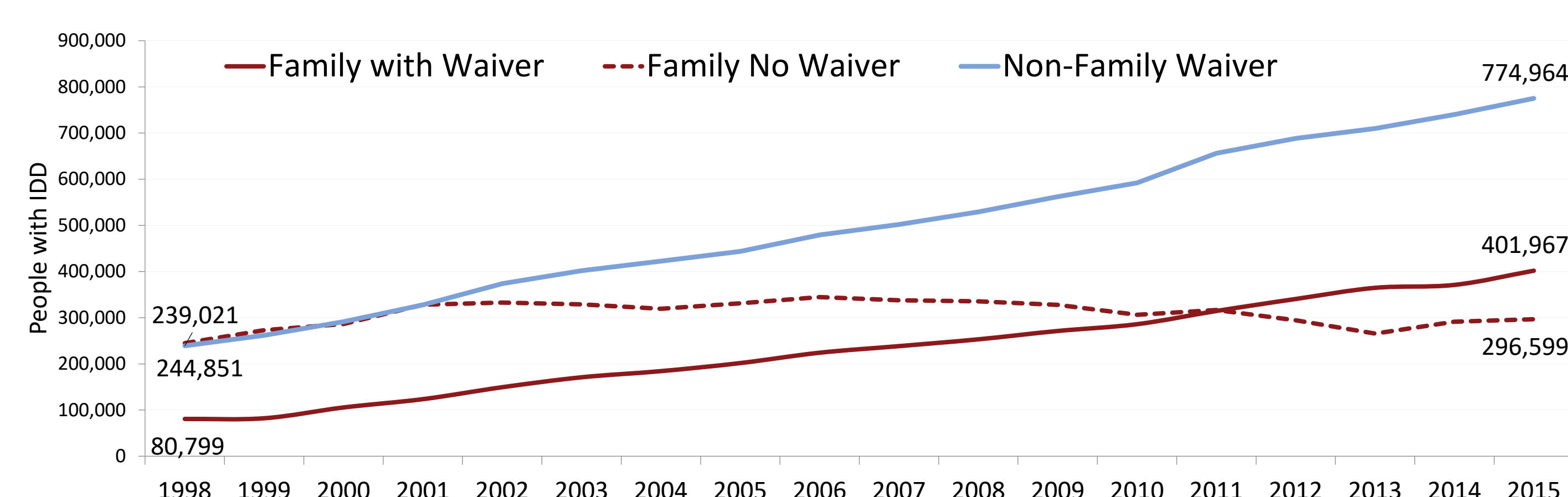
More than half of all LTSS recipients with IDD lived with a family member in 2015



Percent of LTSS Recipients with IDD living with Family Members Varied Dramatically by State in 2015



Medicaid Waiver Recipients in Family Home or Other Settings and People in Family Home who are Not Medicaid Waiver Recipients 1998 to 2015



2013/2014 National Core Indicators - Family Surveys

Surveyed families of 2,019 children and 4,936 adults with IDD in 18 states

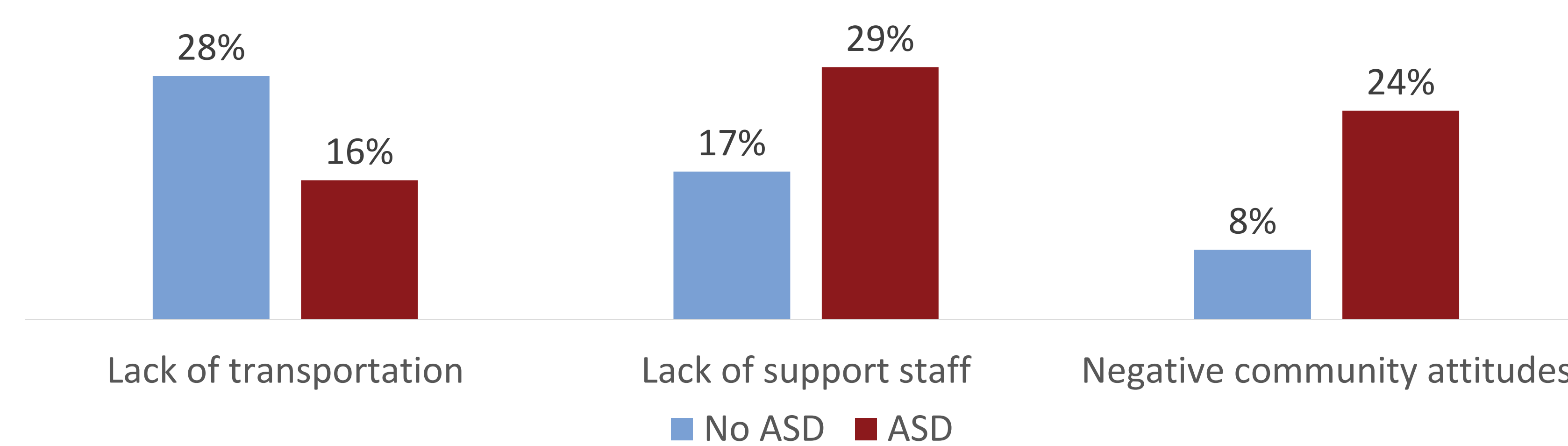
Characteristic of Family	No ASD	Has ASD
Age 18 years or older	80%	54%
Male	54%	74%
Need some or extensive support for behavior	39%	71%
Full or Limited Guardian (adults)	64%	71%
Communicates via speech	70%	66%
Has diagnosed mental illness	31%	36%

2014/2015 NCI Adult Consumer Survey

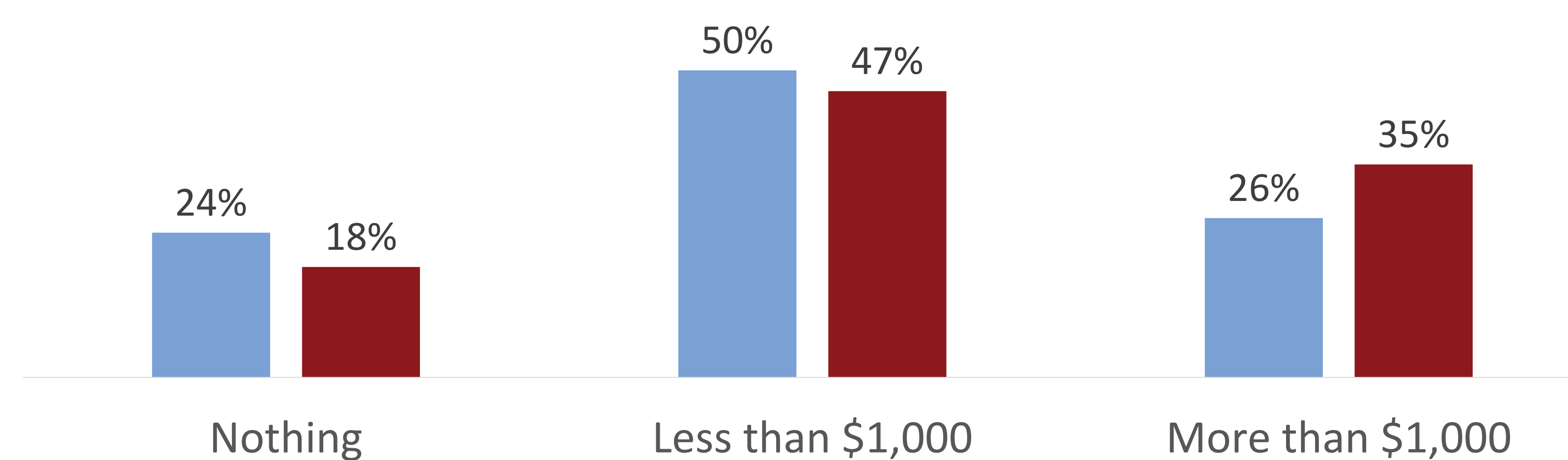
Interviewed 24,104 Adult LTSS Recipients with IDD in 32 states

Characteristic	No ASD	Has ASD
Age 18 to 34 years	34%	63%
Male	54%	76%
Lives with a family member	39%	51%
No intellectual disability	9%	29%
Has limited or full guardian	40%	48%
Mood disorder (e.g., depression, mania)	16%	22%
Anxiety disorder (e.g., panic disorders)	16%	33%
Challenging Behavior (e.g., aggression)	16%	37%
Moves around without mobility aids	75%	94%

Barriers to Community Participation



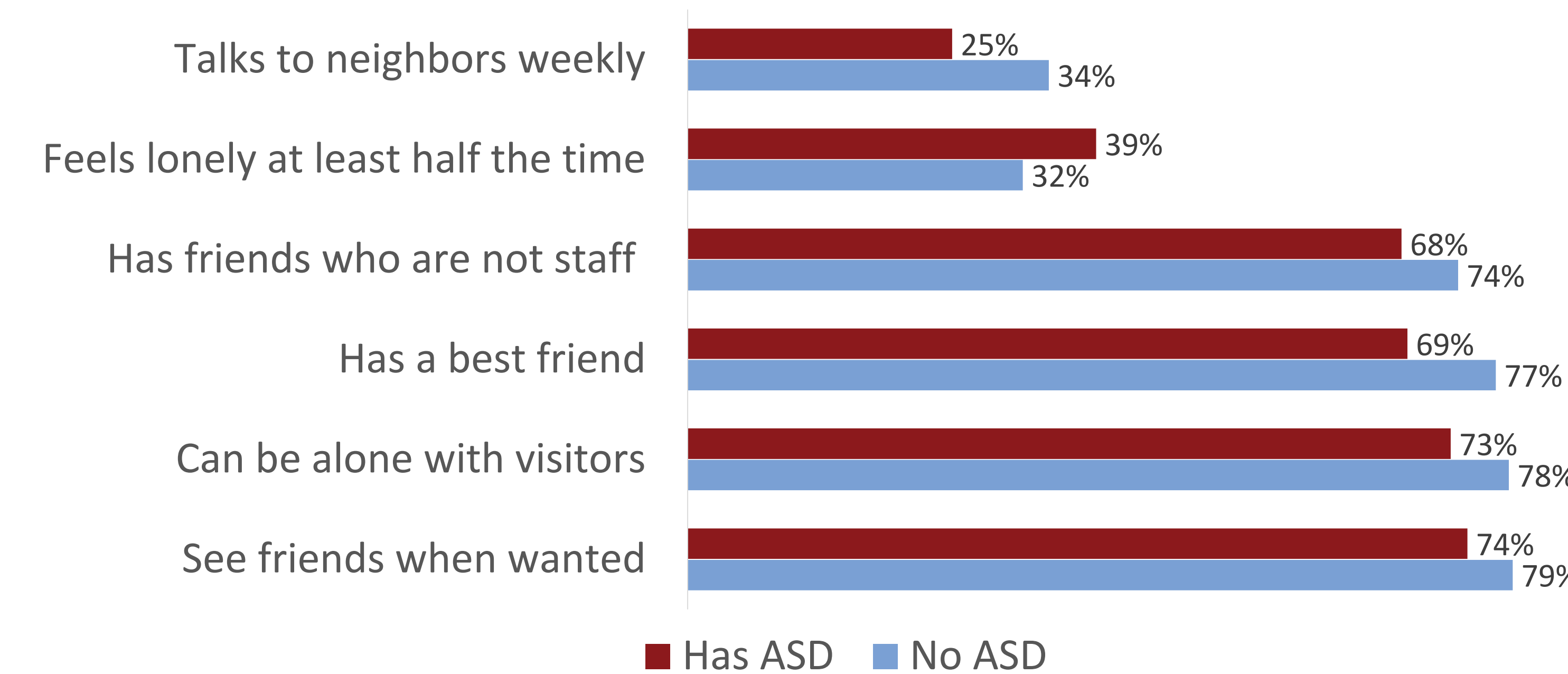
Annual Family Out-of-Pocket \$ for Disability Services and Supplies



Service Quality and Satisfaction

Supports received by person/family	No ASD	ASD
Social Security Benefits	84%	70%
In-home support - paid staff	51%	57%
Out-of-home respite	32%	38%
Quality of supports (scales) (0 never, 4 always)		
Gets information for and participates in planning	3.07	2.99
Needed services in plan and received	3.42	3.26
Services available when needed from trained on-time staff	3.38	3.26
Overall satisfaction with services and supports	3.17	3.01
Crisis or emergency services provided when needed adults	74%	67%

Social Relationships



Services Received

Service	No ASD	Has ASD
Respite/Family Support	46%	54%
Transportation	58%	51%
Social/relationship supports	35%	39%
Education or Training	33%	37%
Communication Technology	7%	10%
Environmental Adaptations	11%	7%

Activities

Activity	No ASD	Has ASD
Volunteer	34%	39%
Unpaid facility based activity	38%	33%
Paid community job (not different)	25%	25%
Likes community job	93%	88%
Paid facility based work	18%	11%
Wants to live elsewhere	20%	23%
Gets needed services	69%	62%

Health and Wellness

Health and Wellness	No ASD	Has ASD
Engages in moderate physical activity	52%	65%
Excellent health	19%	24%