

IACC Services Workshop

**A Seamless System of Quality
Services & Supports Across the
Lifespan**

We Have Built a System on a Foundation of Promises

Formal Promises:

- Developmental Disabilities Assistance and Bill of Rights Act
- Americans with Disabilities Act (ADA) and *Olmstead*
- Individuals with Disabilities Education Act (IDEA),
- The Rehabilitation Act of 1973 as amended
- UN Convention of the Rights of Persons with Disabilities

Tangible Commitments:

- “access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life” [Developmental Disabilities Assistance and Bill of Rights Act]
- “the right of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers and enjoy full inclusion and integration in the economic, political, social, cultural and educational mainstream of American society” [Rehabilitation Act of 1973 as amended]

We Have Created National Goals as Defined in Our Laws, Regulations and Rulings for Persons with Disabilities

- Increasing self-determination and personal control in decisions affecting people with disabilities and their families
- Providing opportunities to people with disabilities to live and participate in their own communities
- Improving quality of life for individuals and families as they define it for themselves
- Supporting families as the most important and permanent unit of development, protection, and lifelong assistance to persons with disabilities
- Investing in each individual's developmental potential and capacity to contribute in age-related roles as productive, respected community members
- Assuring access to sufficient, high-quality health and social supports to protect each person's health, safety, rights, and well-being

(From Keeping the promise: Self-Advocates Defining the Meaning of Community)

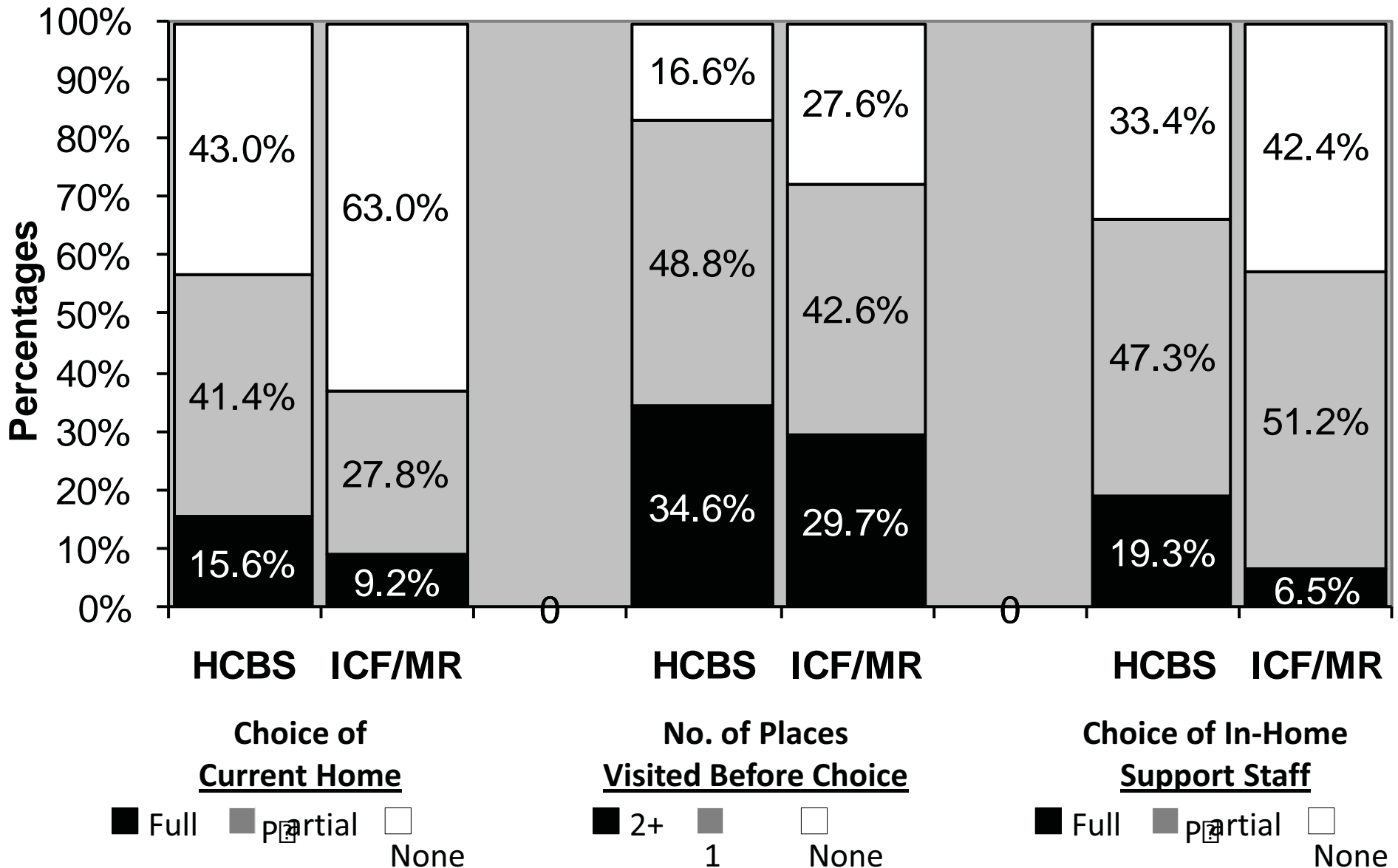
Among the Commitments to Rights are Ones That Challenge Us

- Article 19a of the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) states:
 - *“Persons with disabilities have the opportunity to choose their place of residence and **where and with whom they live** on an equal basis with others and are not obliged to live in a particular living arrangement”.*



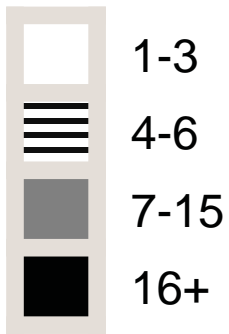
Rights and Dignity of Persons with Disabilities

We Have a Long Way to Go in Opportunities for Choice in Housing (2,950 HCBS and ICF/MR Recipients in Six States)

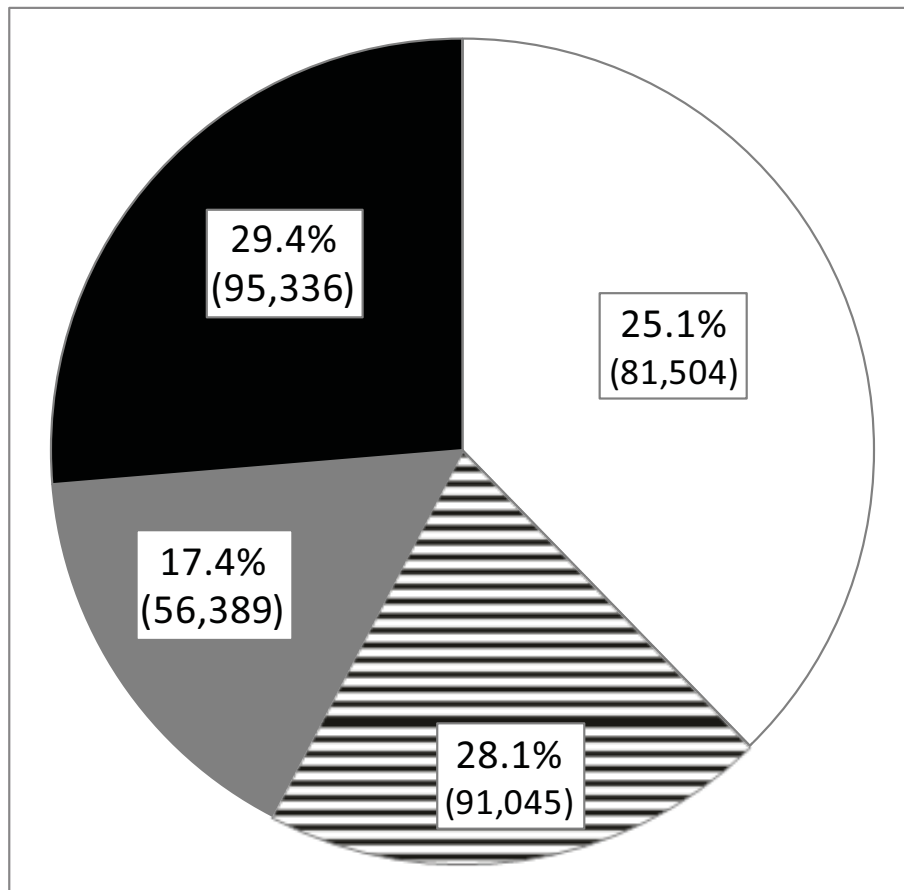


Source: From CMS-funded evaluation of Medicaid HCBS in 6 states using National Core Indicators

But We Have Made Progress Toward More Integrated (or at least smaller) Settings

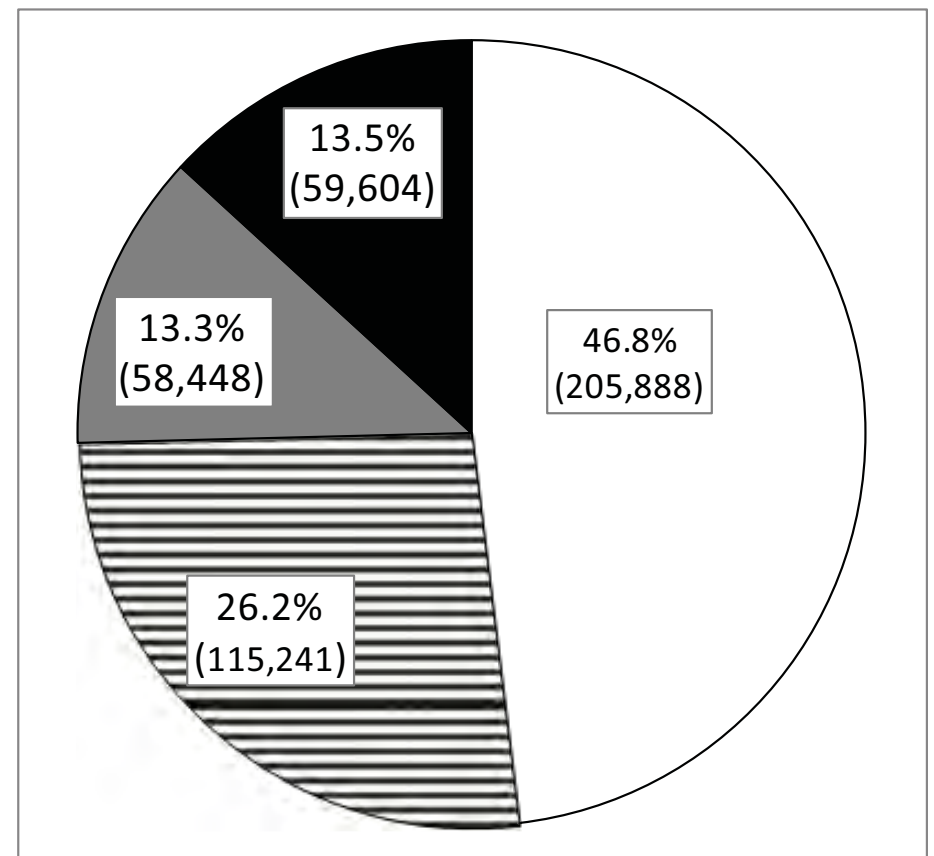


1996



Total = 324,274

2009



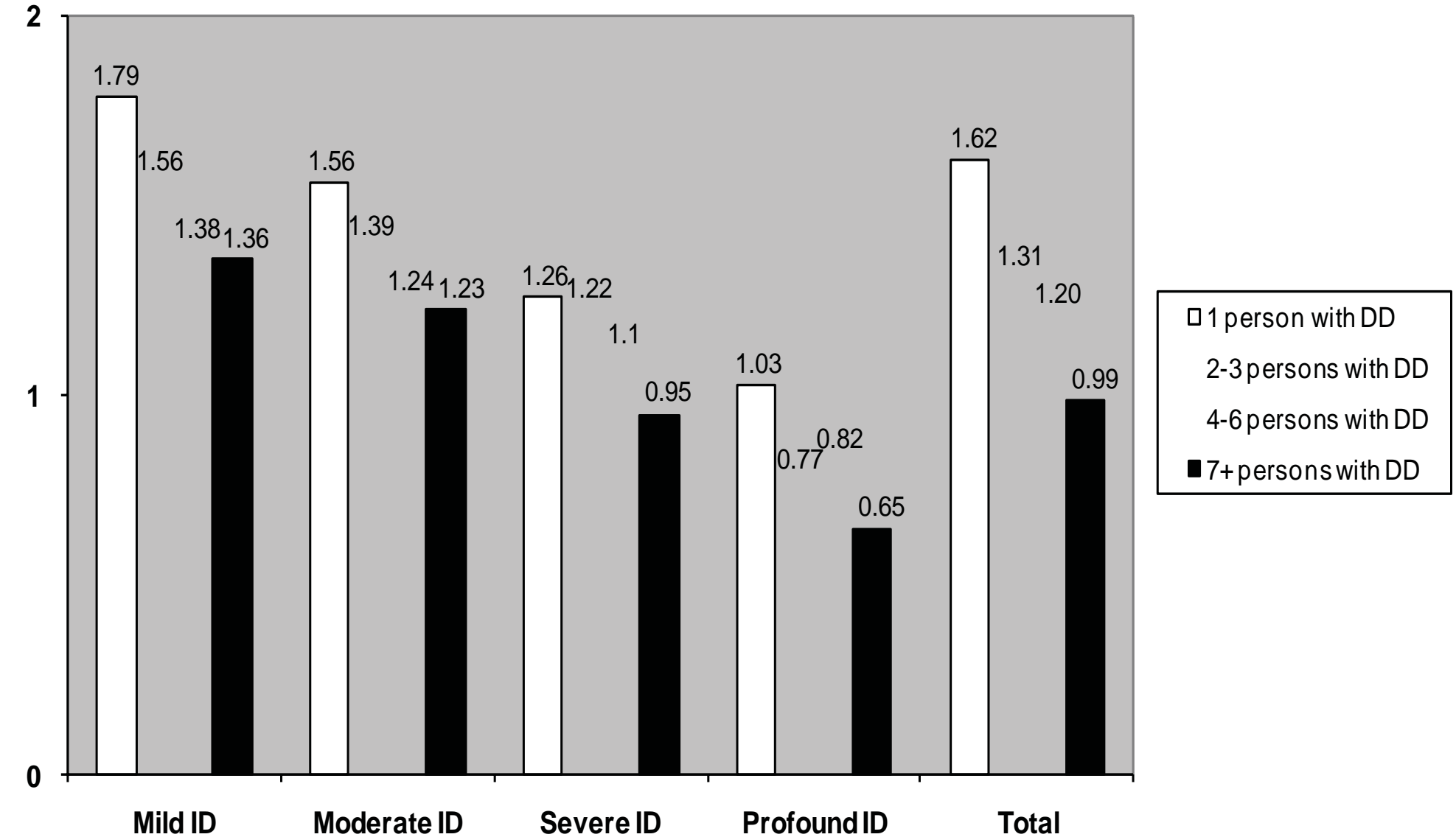
Total = 440,457

National Core Indicators (for people with ID/DD)

- Collaboration between the *National Association of State Directors of Developmental Disabilities Services* (NASDDDS) and the *Human Services Research Institute* (HSRI)
- <http://www.hsri.org/nci/>
- NCI data gathered **annually** with a common instrumentation package
- Outcome data collected on a **random sample** of each state's service users (minimum 400).
- The current set of NCI performance indicators includes approximately 100 consumer, family, systemic, cost, and health and safety outcomes.
- Sources of information include:
 - **consumer survey** (e.g., well being, empowerment and choice issues),
 - family surveys (e.g., satisfaction with supports),
 - provider survey (e.g., staff turnover),
 - state systems data (e.g., expenditures, mortality, etc.).

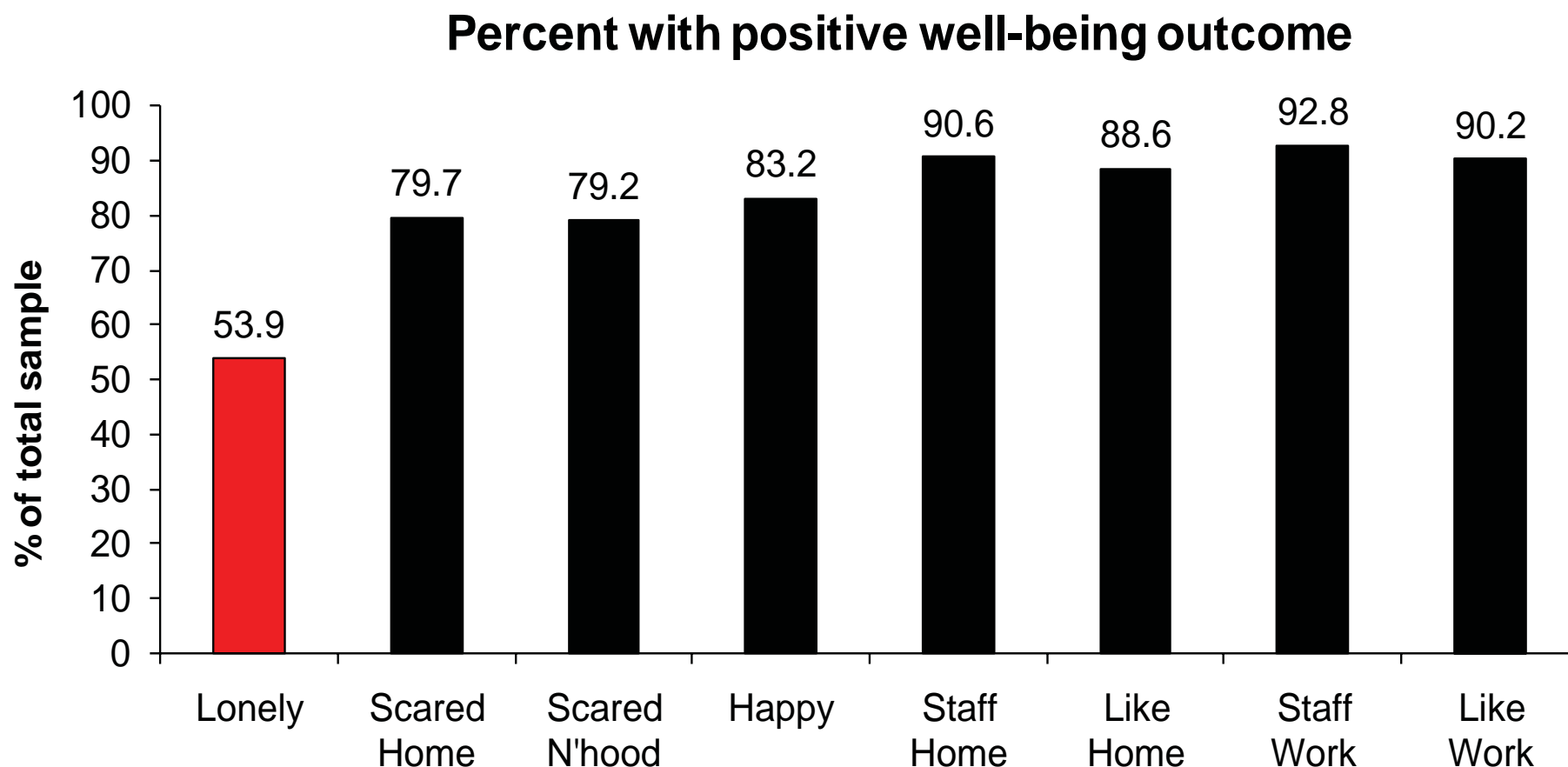


These Changes Have Increased Everyday Choice as Choice is Related to Residential Setting Size



Choice in daily schedule, use of free time, use of money, scored as
2 = complete, 1 = partial, 0 = none

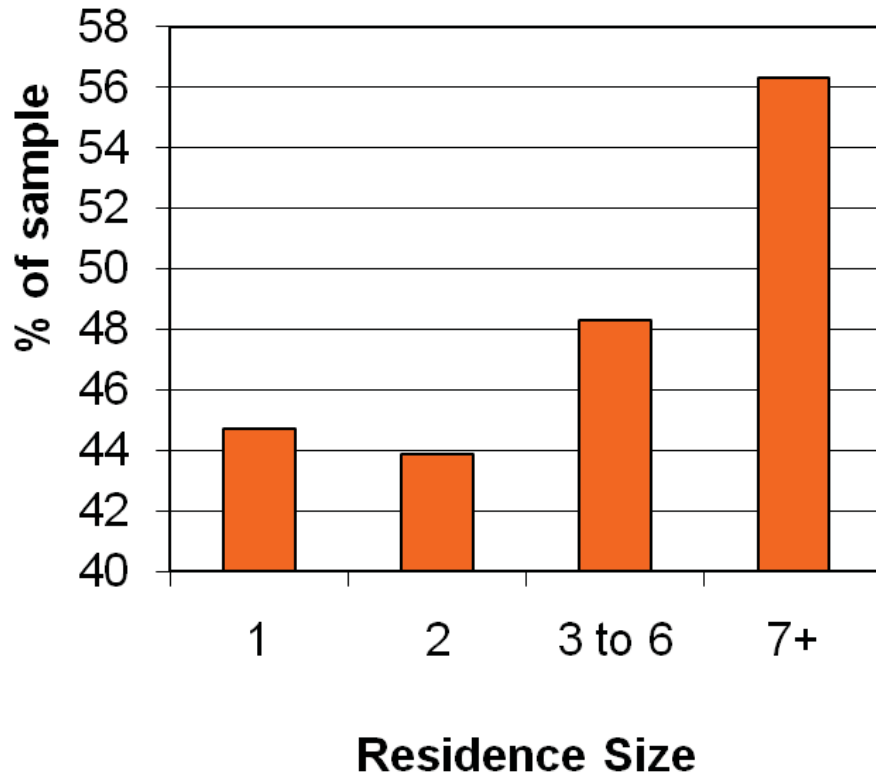
We've Found That People with ID/DD Are Generally Positive About Their Well-Being in Places of 15 or Fewer Residents; Loneliness is the Most Widespread Problem



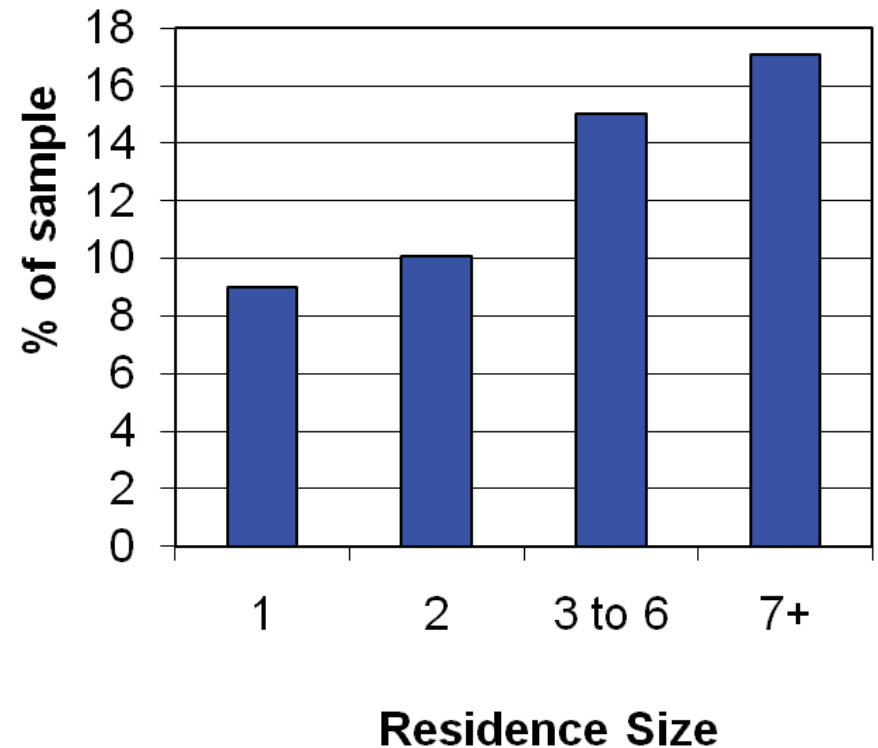
Source: National Core Indicators

We've Learned That Home Size Affects Perceptions of Well-Being

% Lonely Sometimes or Often

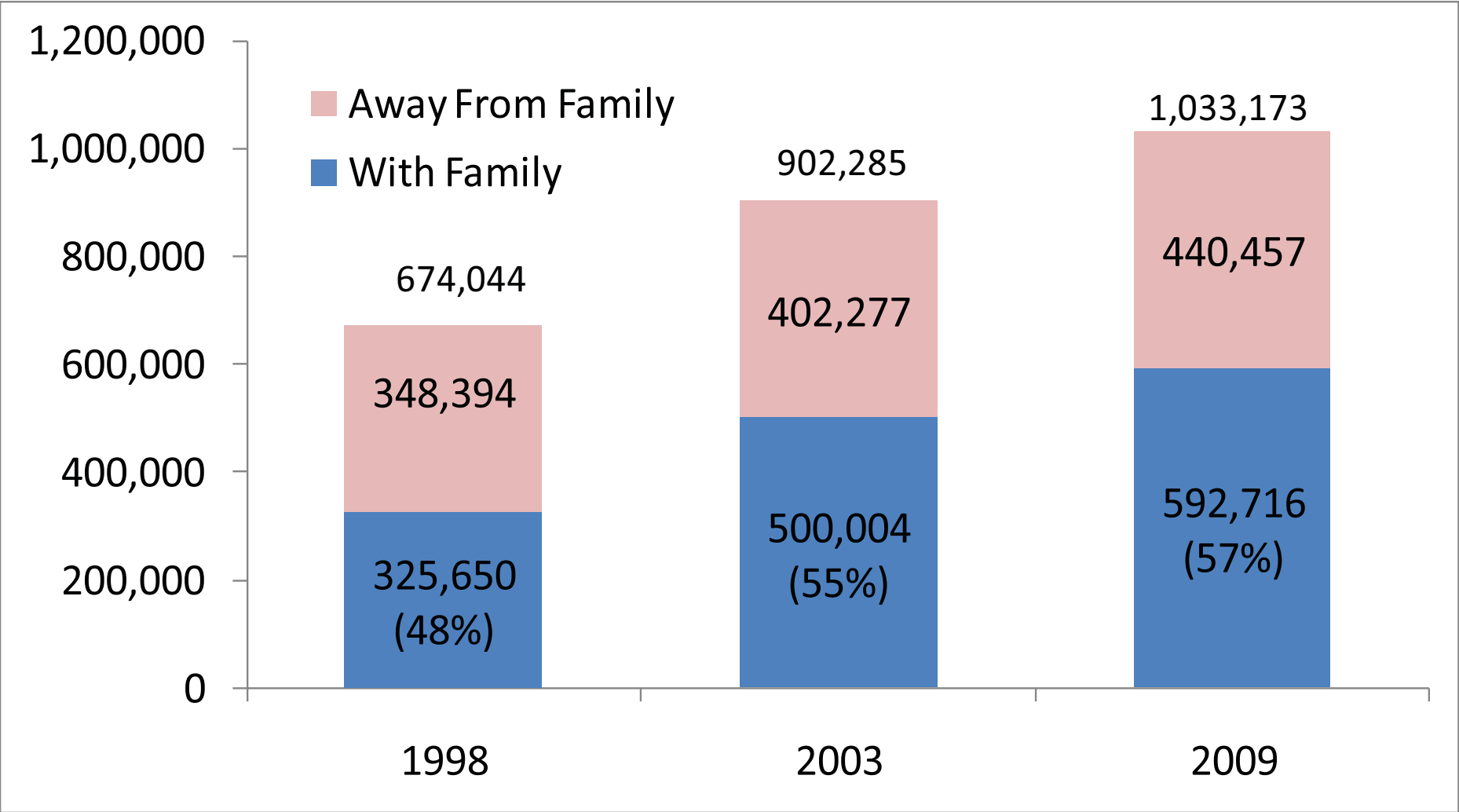


% Like Home? No or In-Between



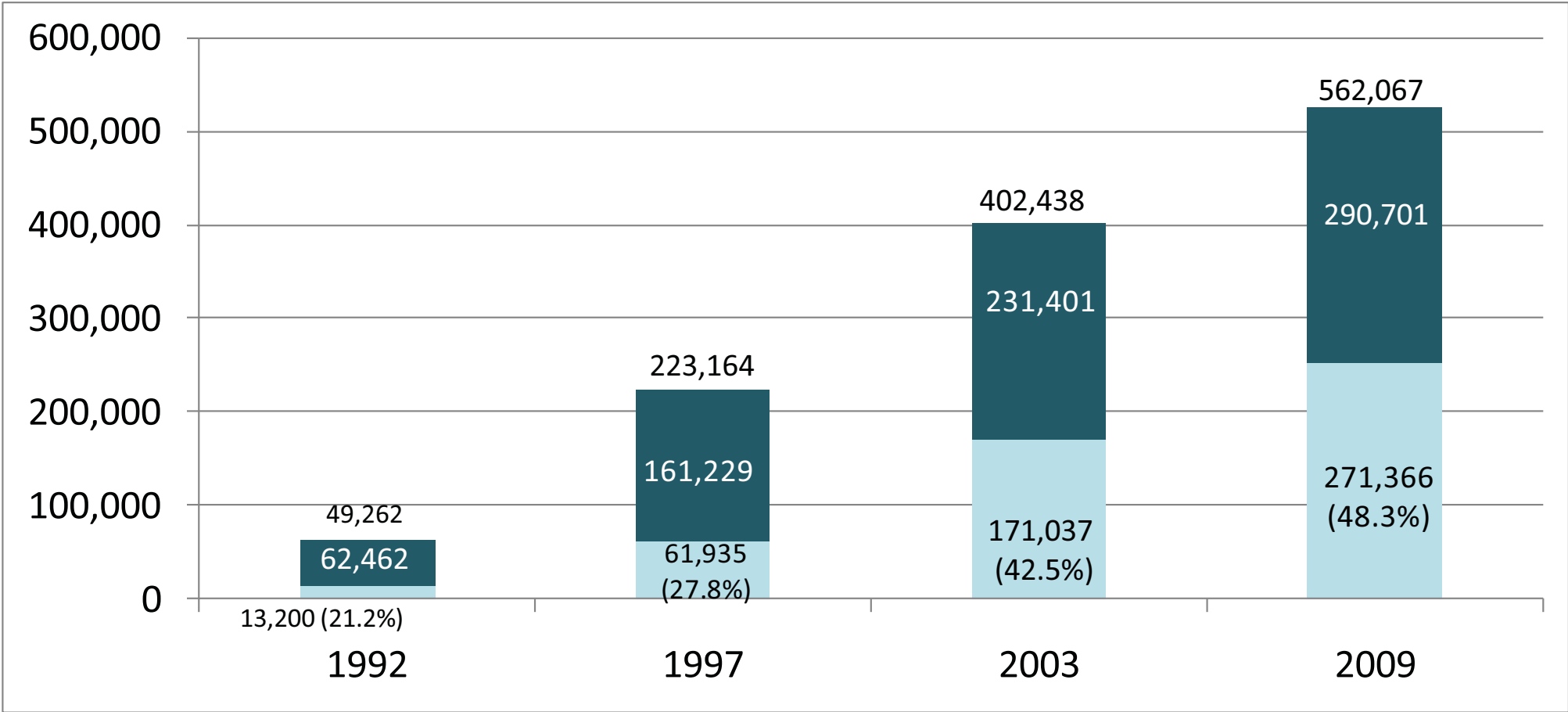
Source: National Core Indicators

In the Past Decade We Have Increased the Number of People Receiving ID/DD Services and Supports While Living with Family Members



And Within Medicaid Supported Services Rapidly Growing Numbers and Proportions of HCBS Recipients Are Living with Family Members

■ Away From Family ■ With Family

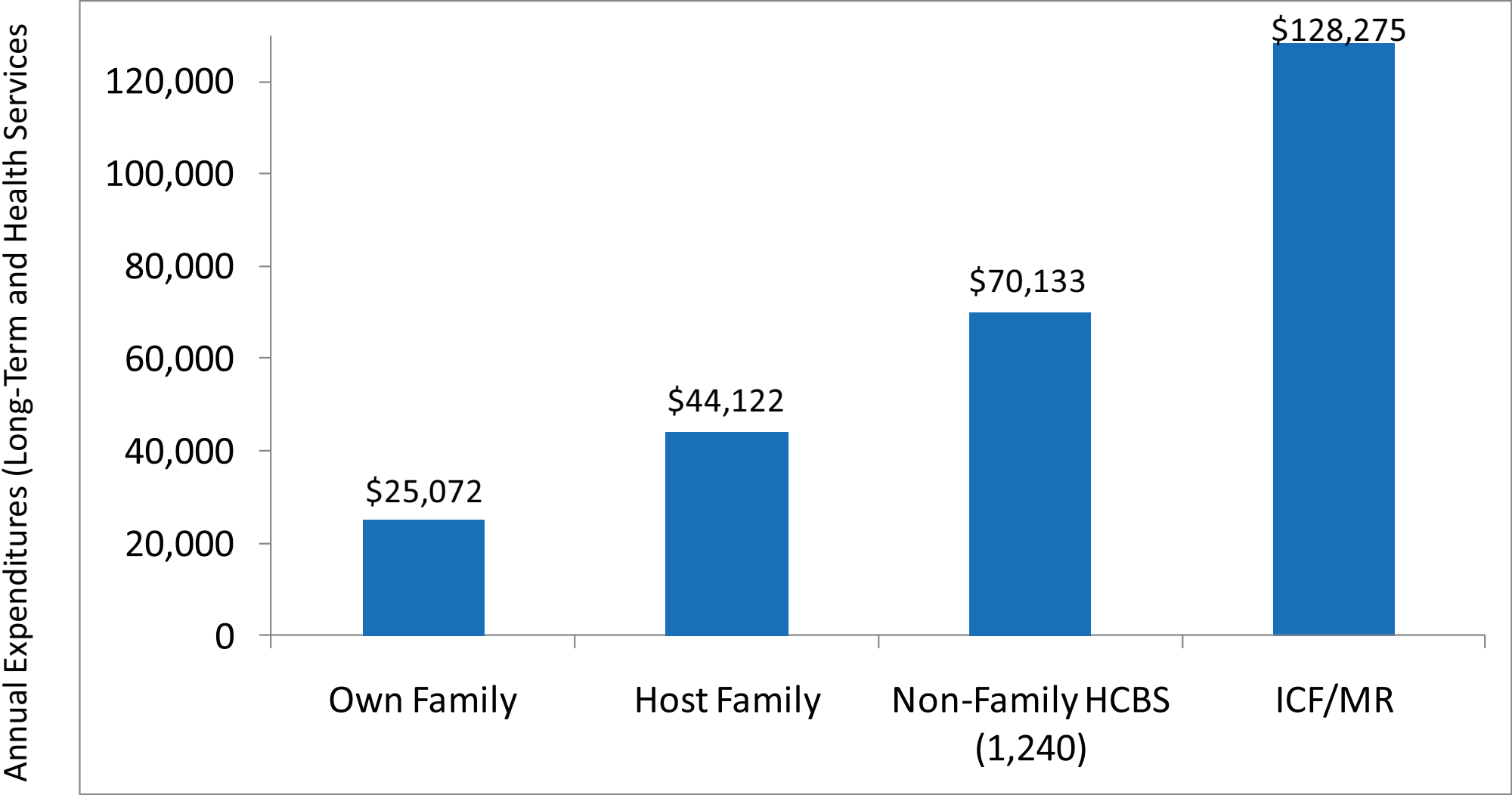


We've Seen That Adults Report Good Quality of Life Outcomes While Living with Family Members

- No difference on:
 - Feeling afraid in your neighborhood
- Better results for those NOT living with family on:
 - Home staff nice & polite
- Better results for those living with family on:
 - Loneliness
 - Feeling afraid at home
 - Feeling happy
 - Liking home

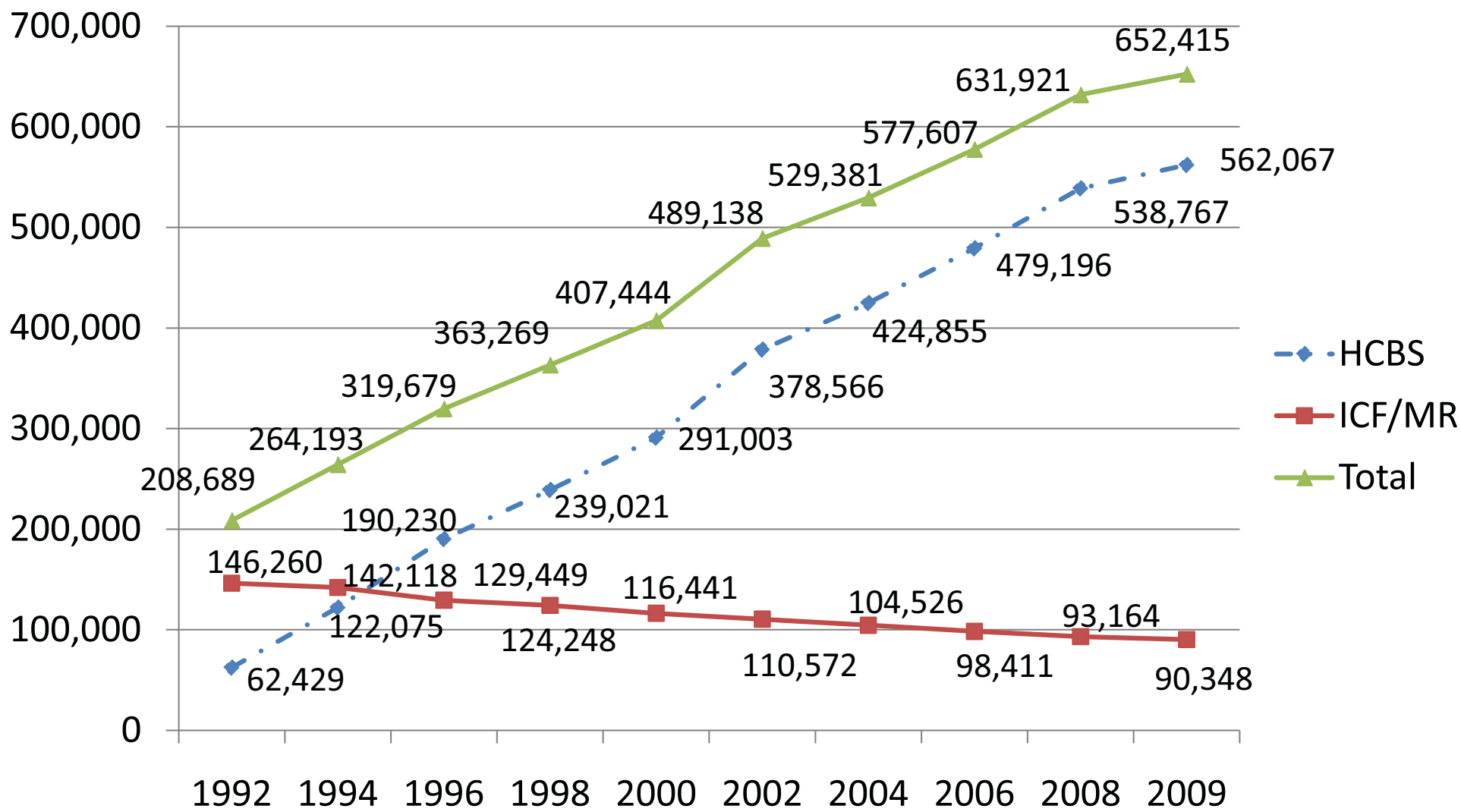
Source: National Core Indicators

Family-Based Services Are Growing in Large Part Because Expenditures Are Much Lower on Average for Adults in Family-Based Settings



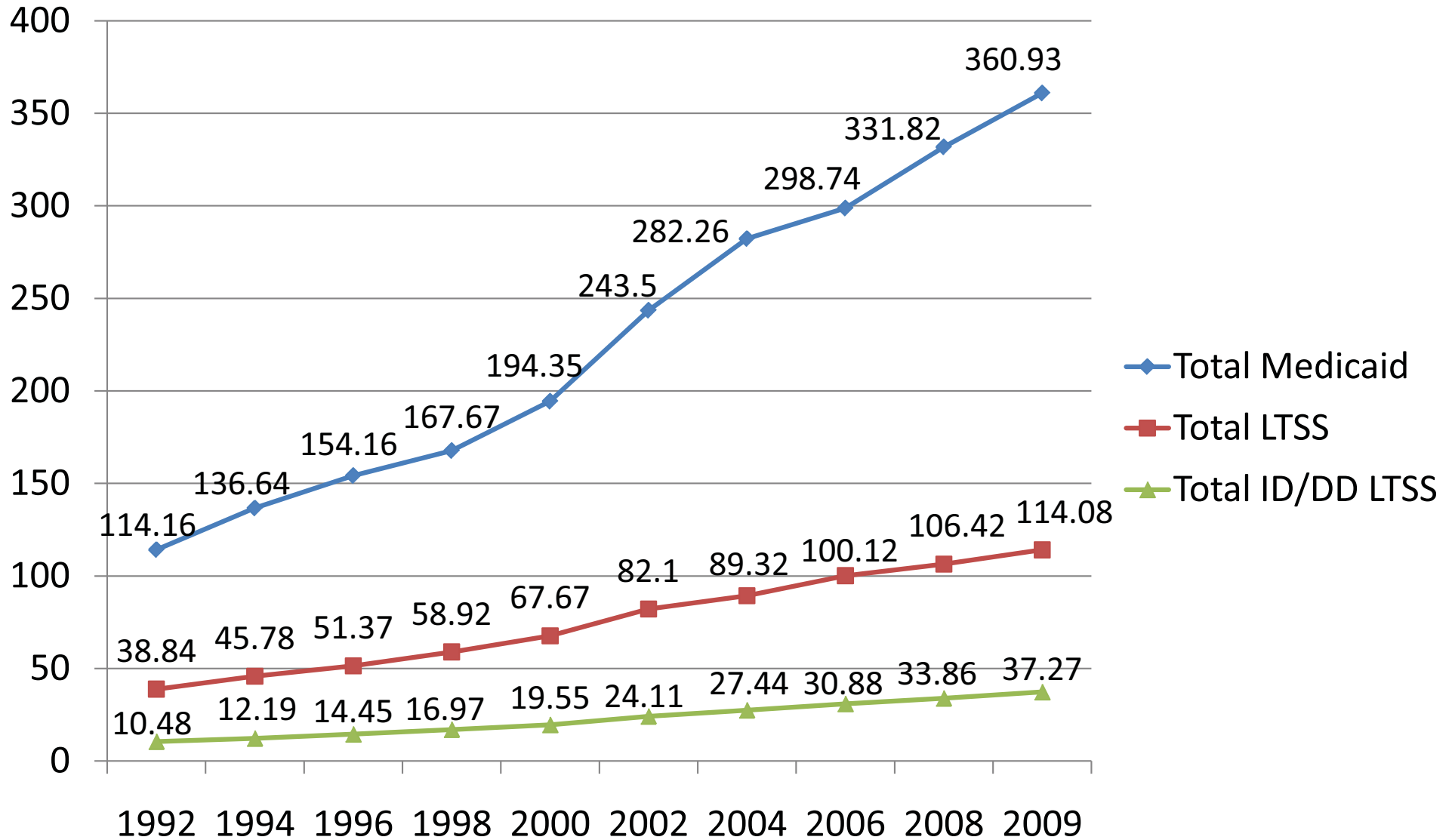
Source: MSIS and NCI data from 4 states (1,240 Individuals)

Medicaid Is the Principal Support for Long-Term Services for Persons with ID/DD and We Have Greatly Expanded the Number of Medicaid ICF/MR and HCBS Recipients (1992-2009)



Source: Residential Information System Program, 2010

We Have Rapidly Expanded Medicaid Expenditures for People with ID/DD, but Not More Than Other Medicaid Expenditures Total, All Long-Term Services and Supports (LTSS), LTSS for Persons with DD



So Where Do People with Autism Fit In: In Most States Eligibility for Long-Term Supports Comes Through Medicaid ICF/MR and Home Community Based Services

State	Autism as Related Condition	Autism Waiver for Children	Autism Waiver for Adults
AL			
AK	X		
AZ	X		
AR	X		
CA	X		
CO	X	X	
CT			
DE	X		
FL	X		
GA	X		
HI			
ID	X		
IL	X		
IN	X	X	X
IA			
KS	X	X	
KY	X		
LA	X		
ME	X		

State	Autism as Related Condition	Autism Waiver for Children	Autism Waiver for Adults
MD	X	X	
MA		X	
MI			
MN	X		
MS	X		
MO	X	X	
MT	X	X	
NE	X		
NV	X		
NH	X		
NJ	X		
NM	X		
NY	X		
NC	X		
ND	?		
OH			
OK			
OR	X		

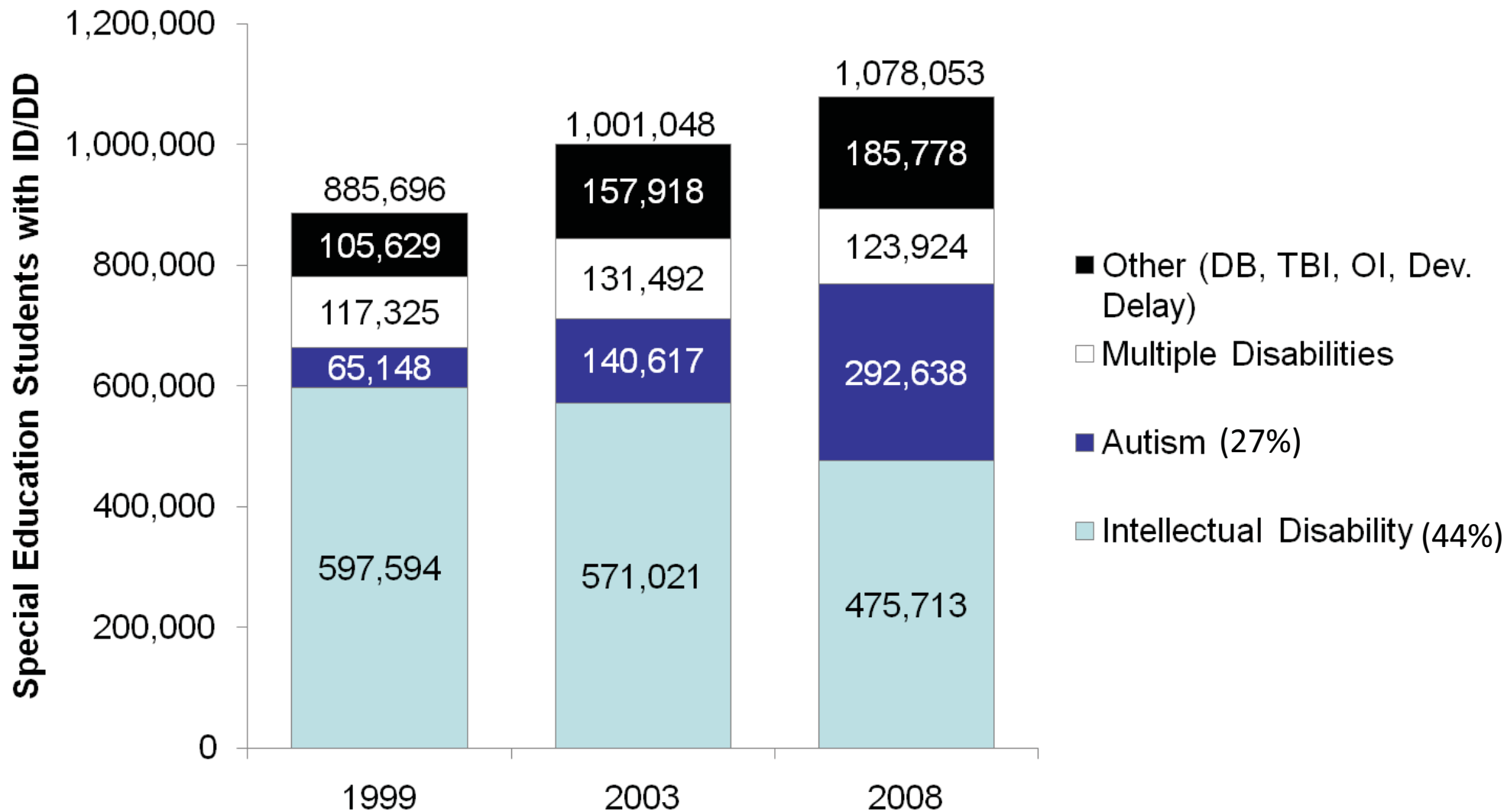
State	Autism as Related Condition	Autism Waiver for Children	Autism Waiver for Adults
PA	X	X	X
RI	X		
SC	X	X	
SD	X		
TN	DD		
TX	X		
UT	X		
VT	X		
VA	SW		
WA	X		
WV	X		
WI	X	X	
WY	X		

CT – qualify with ID diagnosis, but small program for persons with autism who do not

DD – no specific reference to autism, but recognizes the “DD” definition

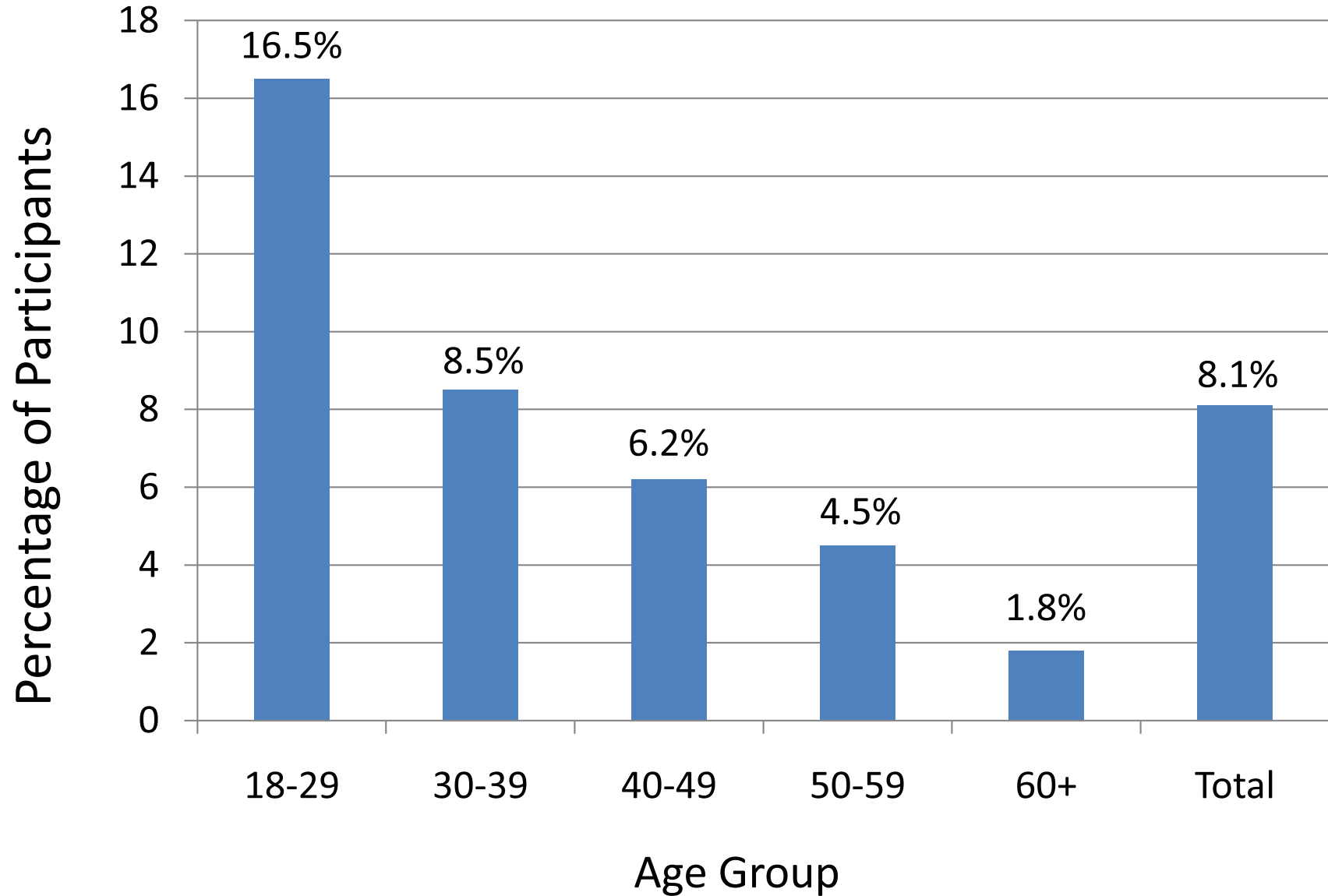
SW – Individual and Family Support waiver for people without ID, but similar support needs

There will Be Growing Pressure to Focus on Autism, But There Are Challenges in Overall Numbers of Children and Youth (6-21) Identified with Conditions Associated with ID/DD Services (+22%)



Source: Department of Education, 2010 Report to Congress

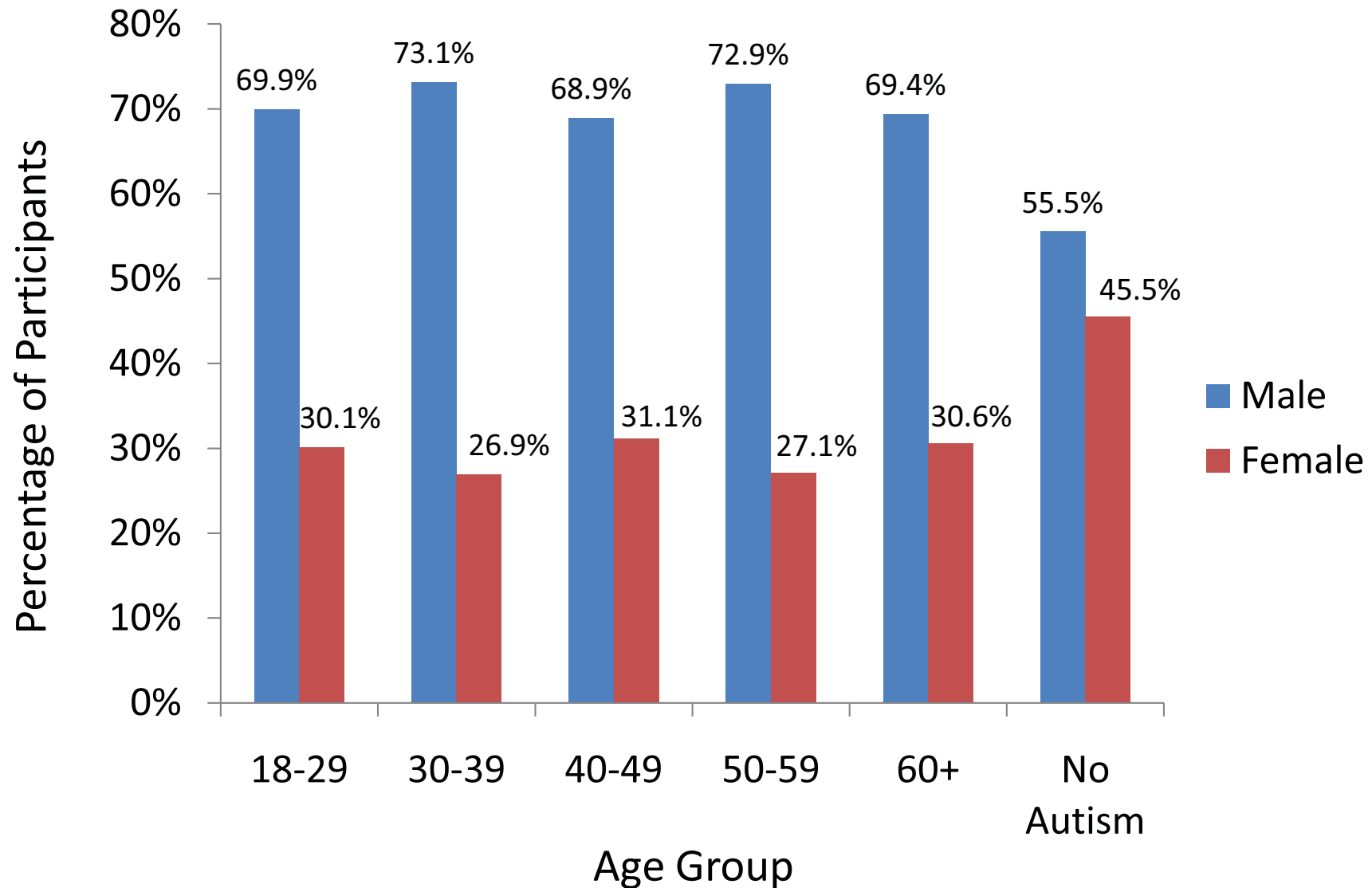
Most Individuals Identified With Autism in State “DD” Systems Are Young Adults



N=12,382 (2007-2008)

Number with Autism Dx= 1,002

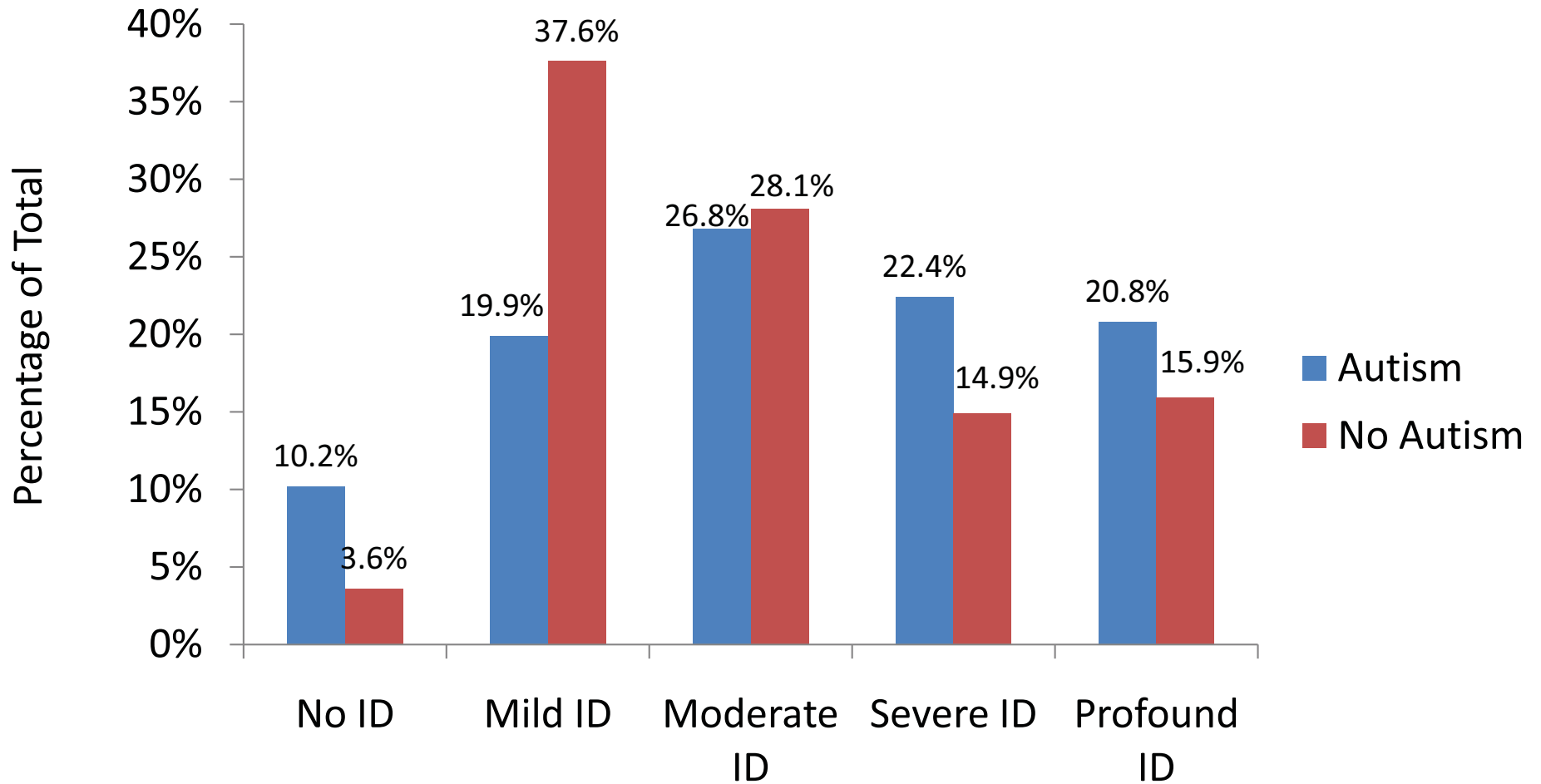
Males Are Disproportionally Among Persons with Autism in Each Age Group



N= 12,382

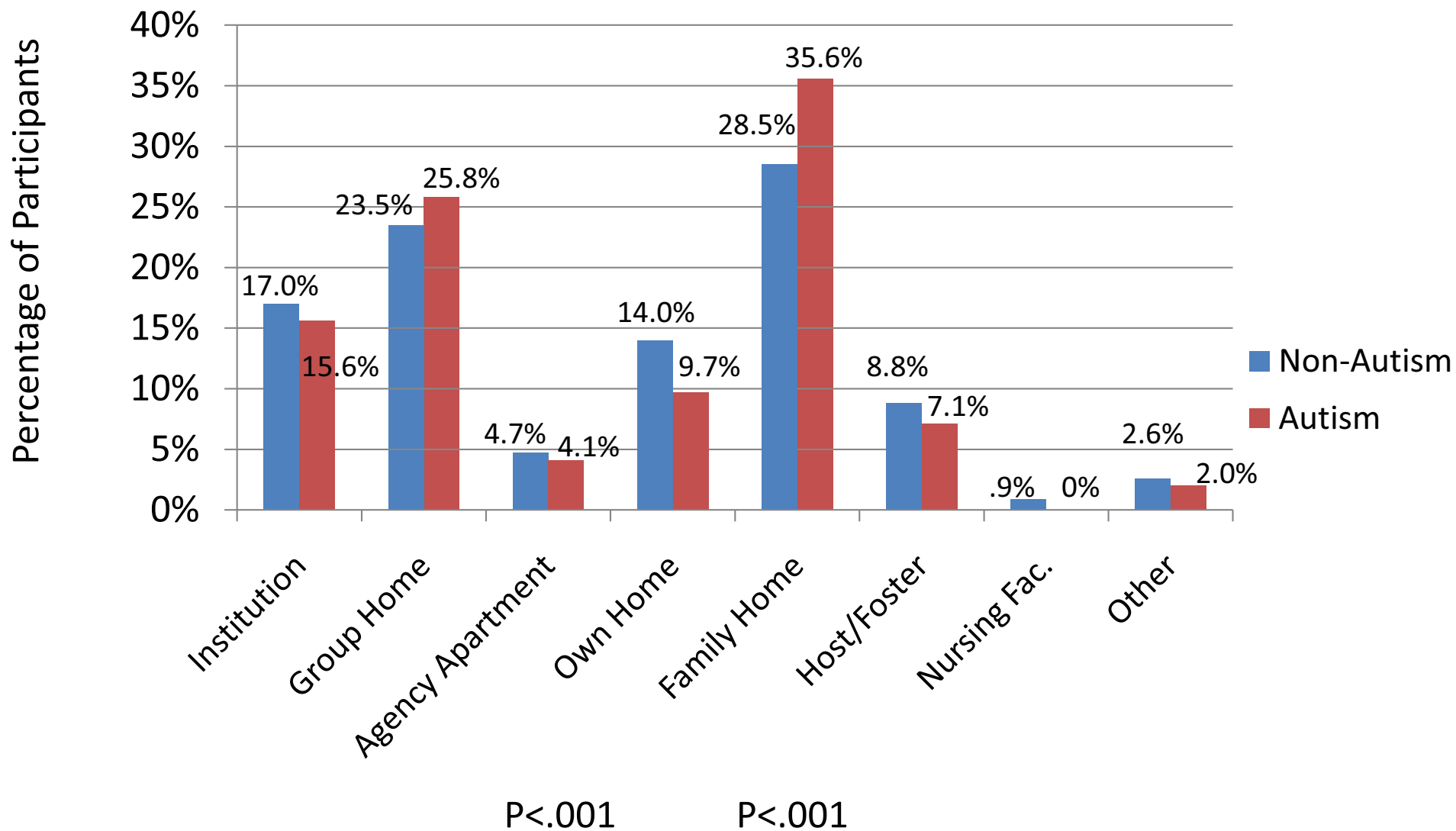
Number with Autism Dx= 1,002

There is a Bi-modal Distribution by Level of Intellectual Disability Among Adults with Autism in Developmental Disability Service Systems in 24 States, 2007-2008, N= 11,949

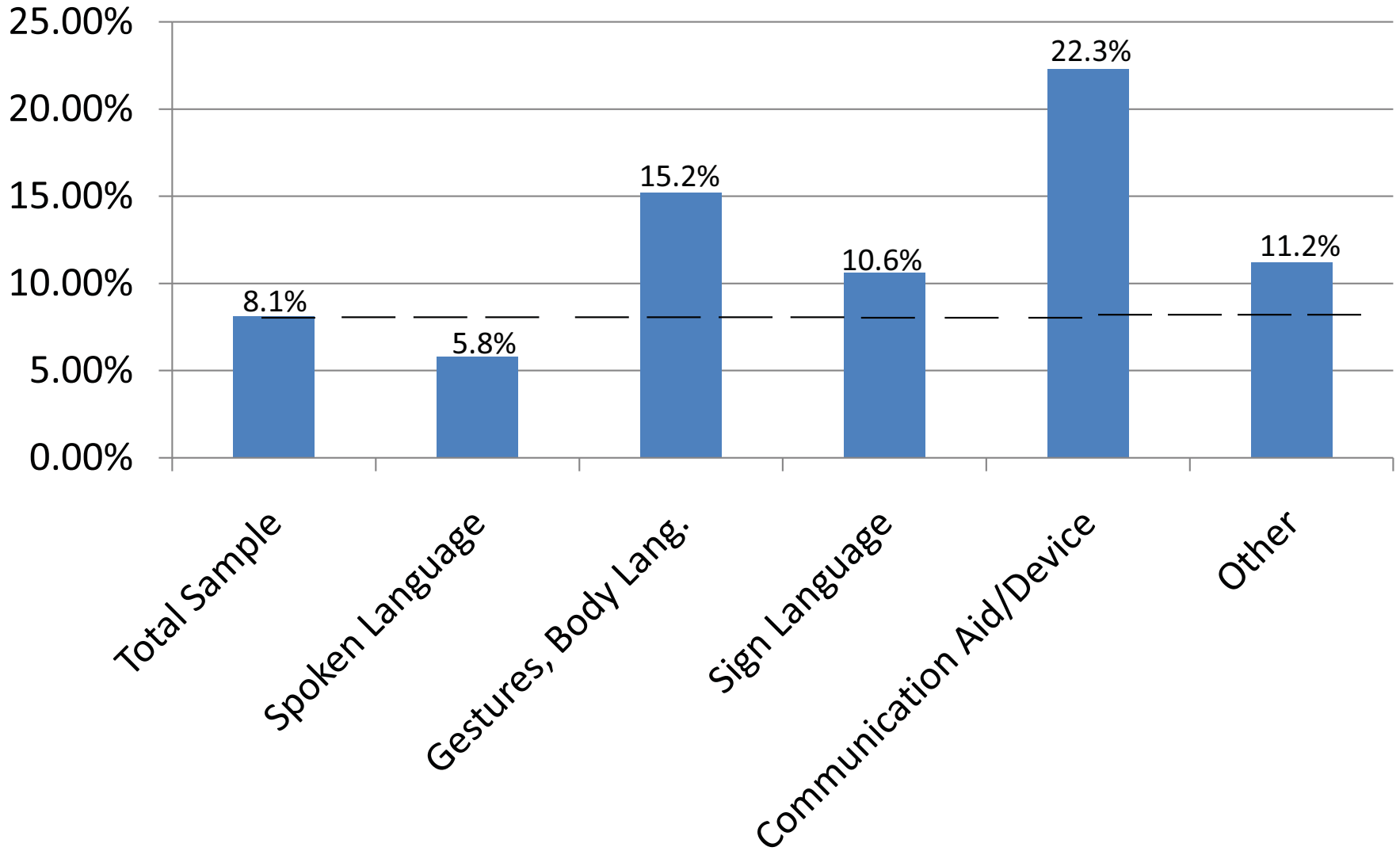


Note: 8.1% of Adult DD Service Recipients, 20% of those without ID

Adults With Autism Are More Likely to Receive Services Systems While Living with Family Members

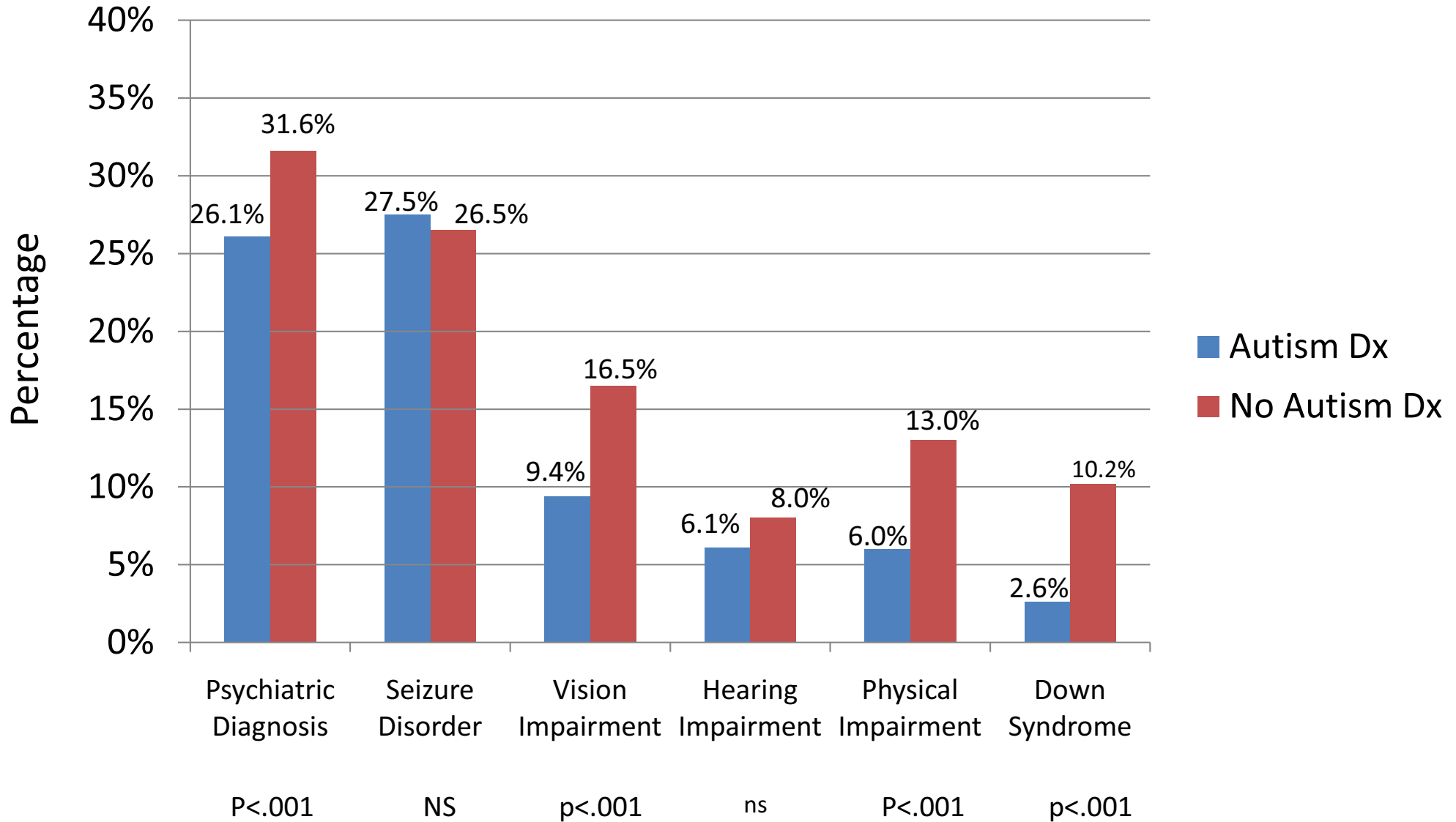


Adults with Autism Appear to Receive Accommodations Related to Their Primary Means of Expression

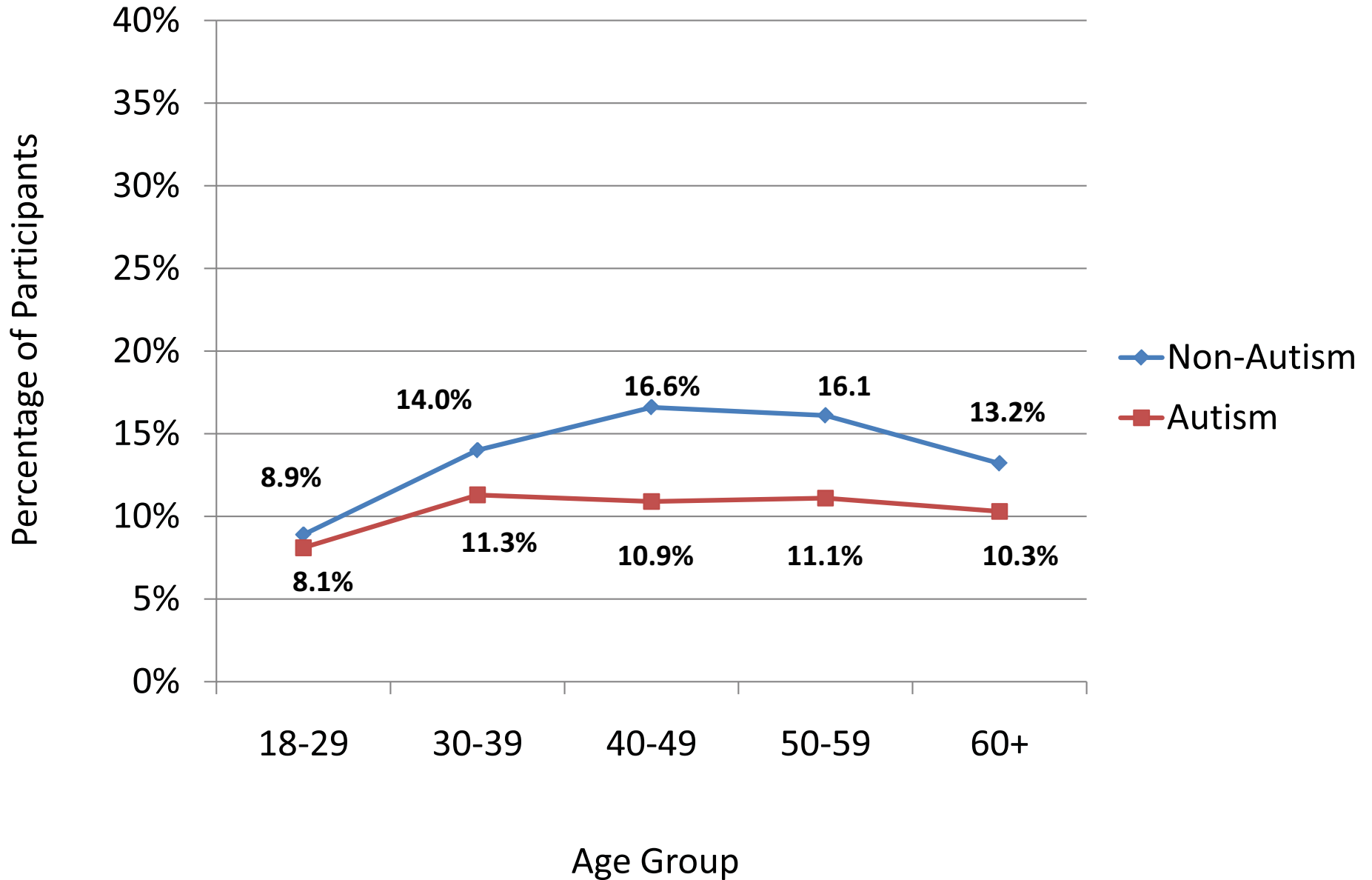


Proportion of

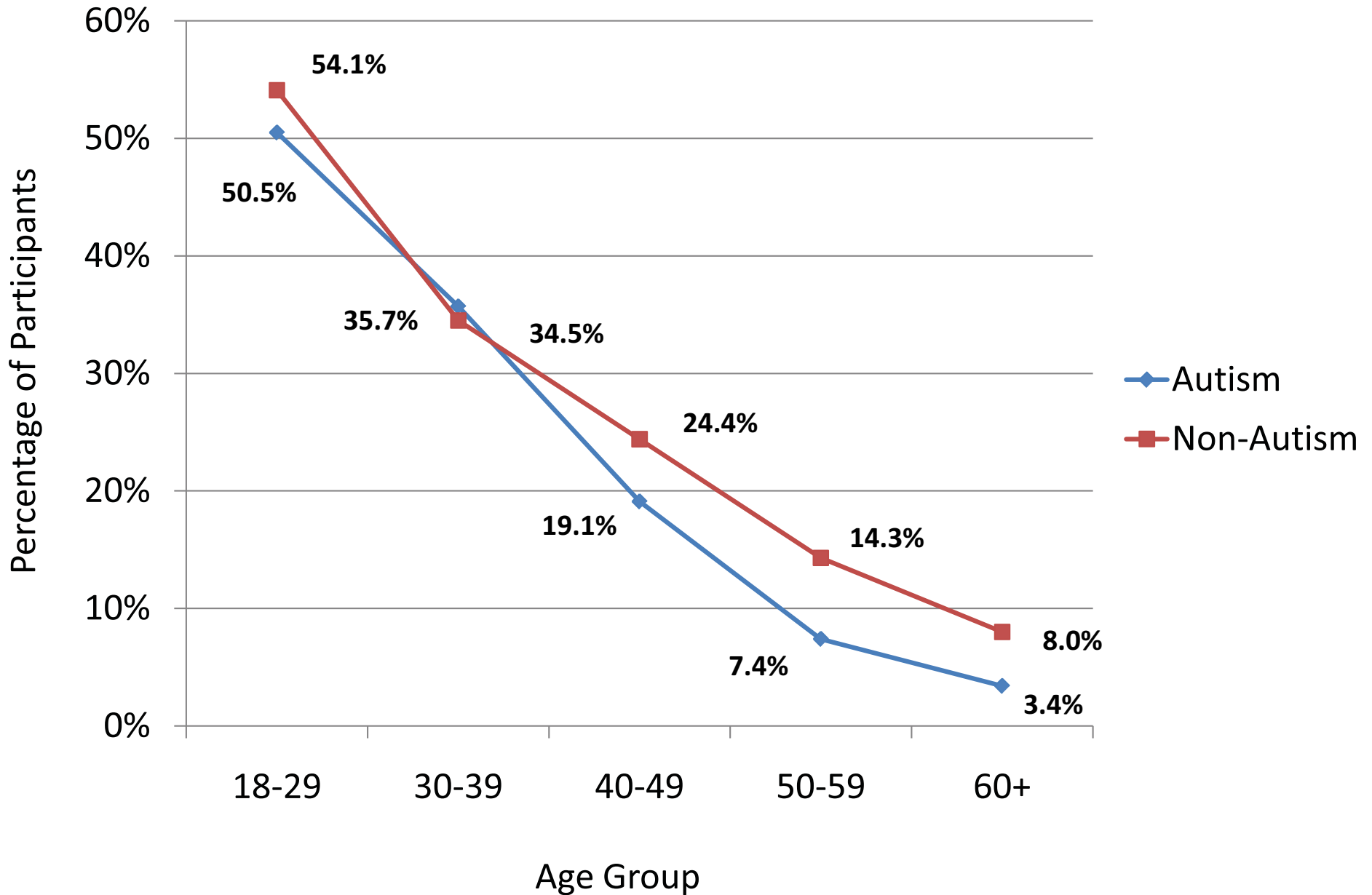
Related Conditions of Adults With Autism Are Different Than Others in “DD” Services Systems (24 States)



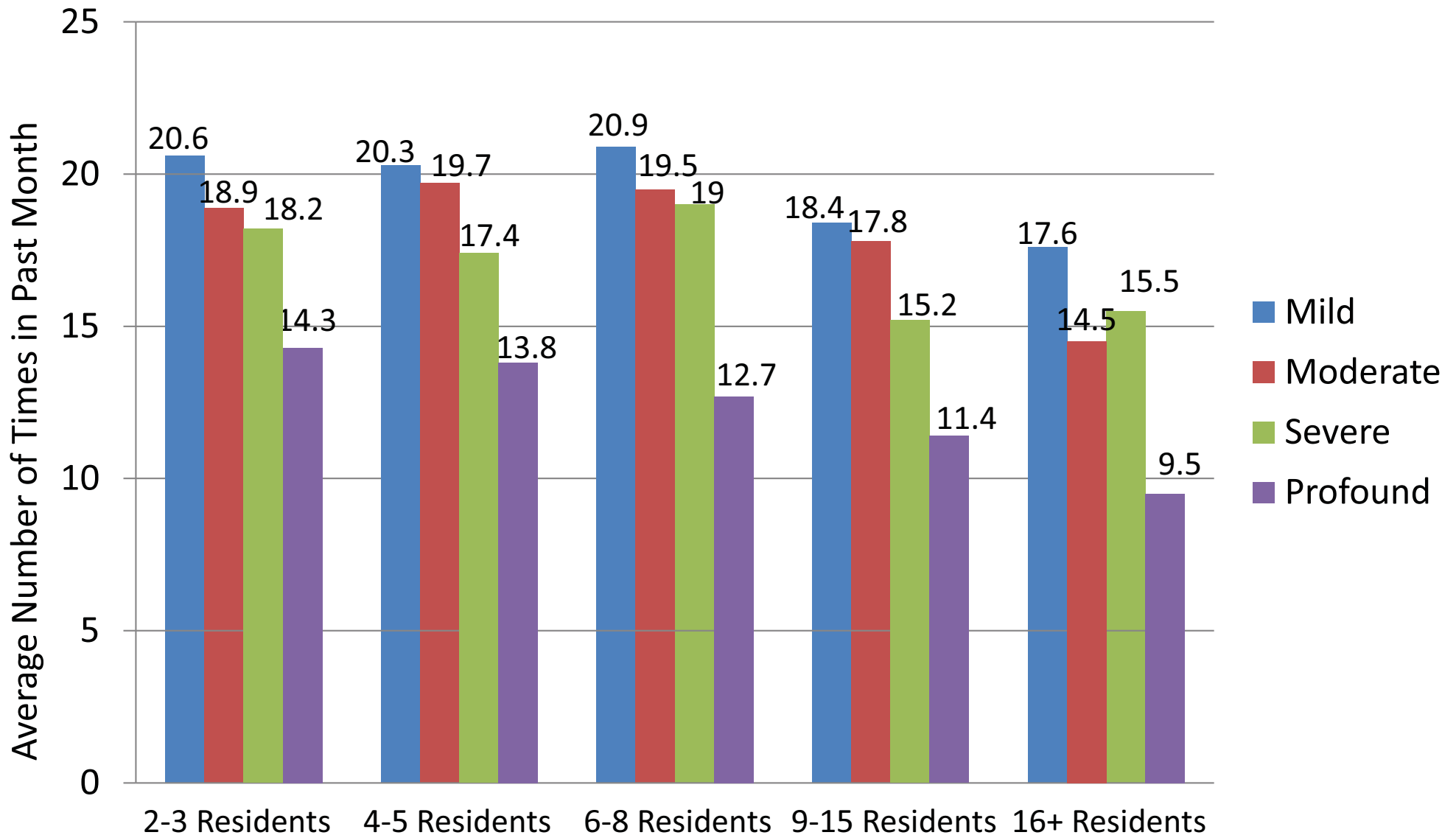
In Middle Age Higher Proportions of Adults Without Autism Live in Homes of Their Own (N=13,312)



In General the Patterns for Adults With and Without Autism Living With Family Members by Age Are Similar Until Middle Age

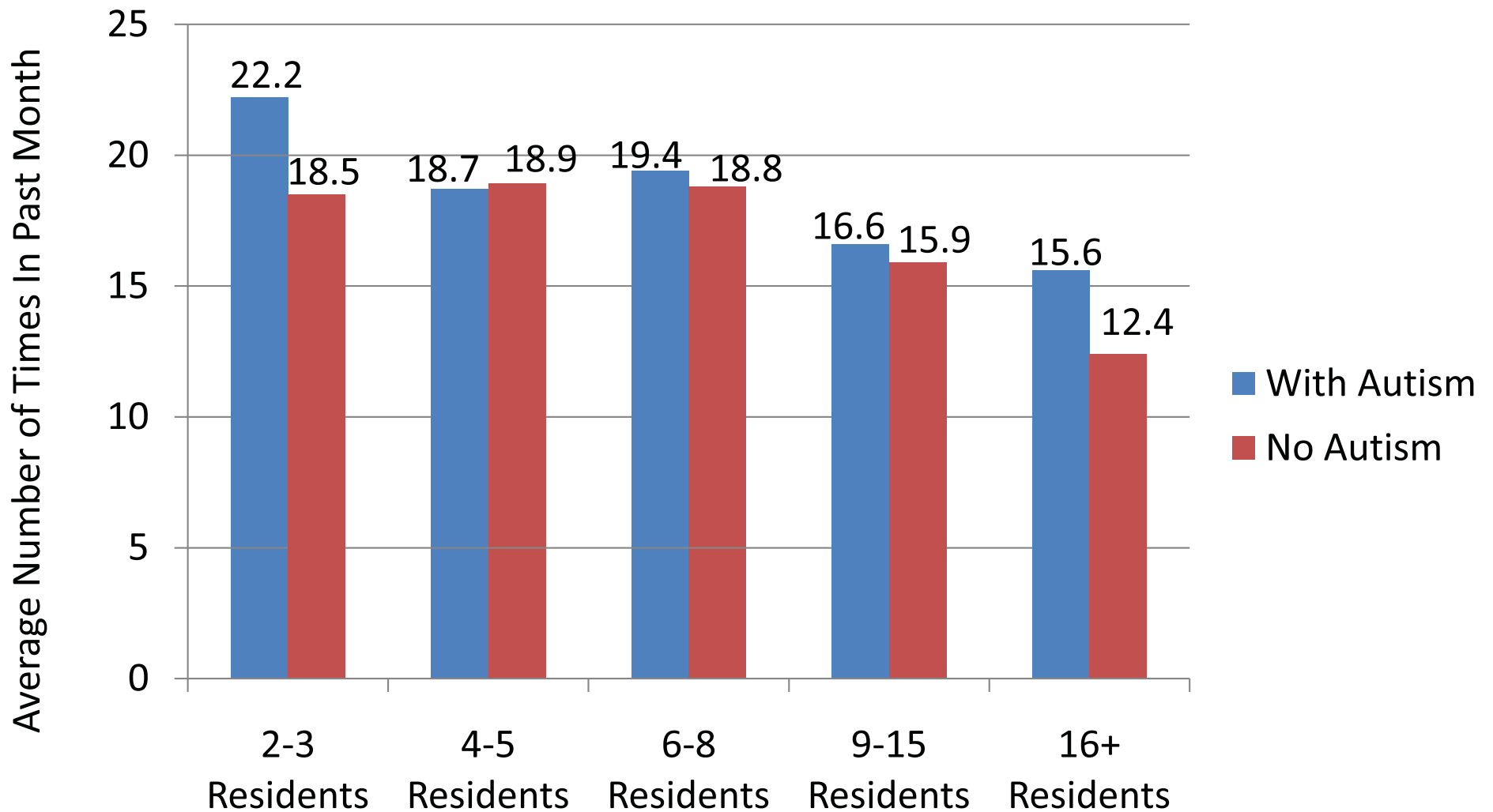


People Living in Smaller, Agency-Operated Settings Participate More Actively in Their Communities Than People in Larger Ones



Community participation is a count of the number of times people participate in the previous month in 7 areas of community activities (recreation, religious, shopping, going out to eat/drinks, running errands, social outings/entertainment, vacation).

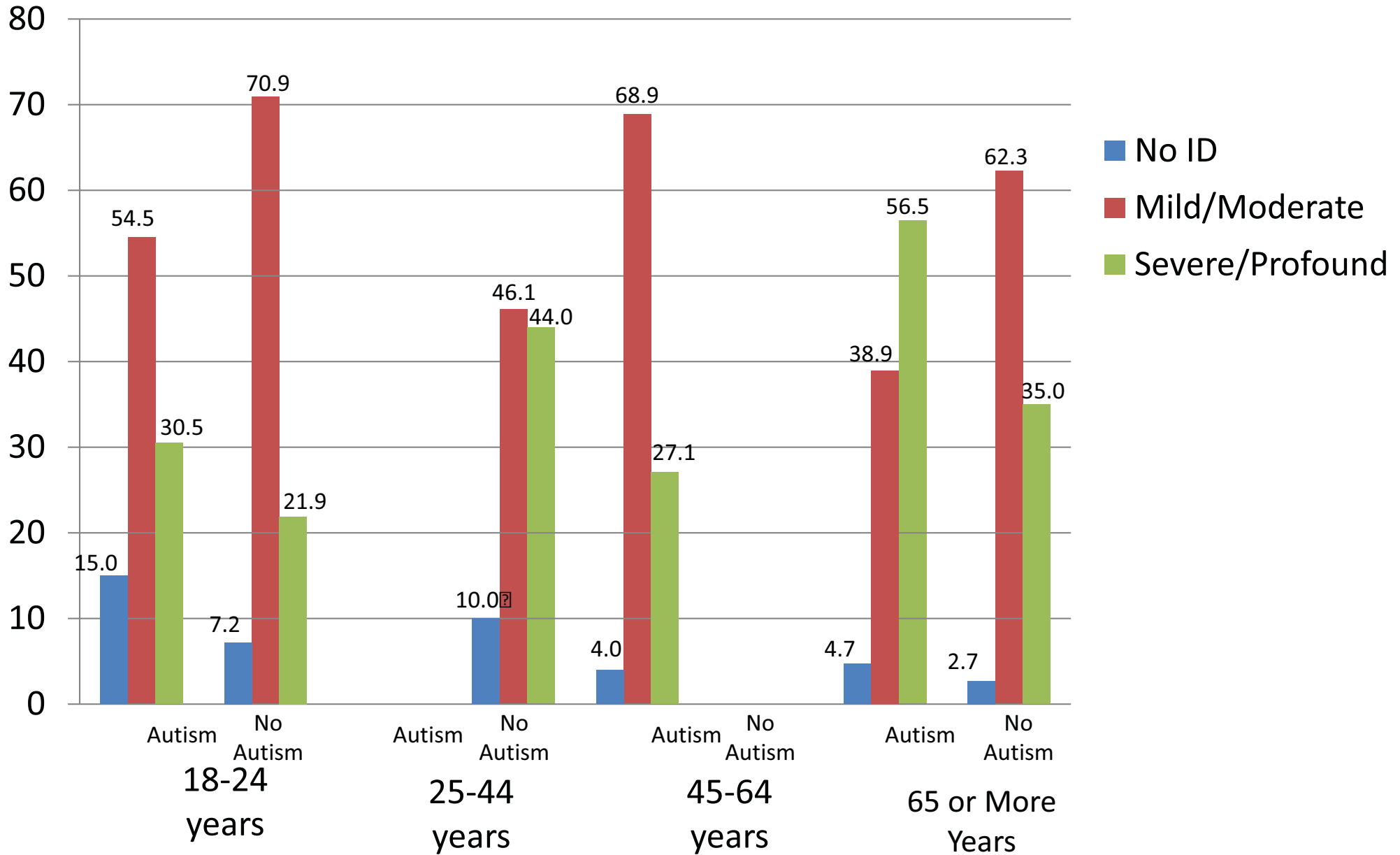
Community Participation of People With and Without Autism Living in Agency-Operated Settings of Different Sizes



Community participation is a count of the number of times people participated in the previous month in 7 areas of community activity (recreation/sports, religious, shopping, going out to eat/drink, running errands, entertainment/social, vacation)

Size $F = 8.21$ ($p < .001$), Autism, $F = 4.53$ ($p < .05$)

Level of Intellectual Disability of Persons With and Without Autism by Age Grouping



Source: National Core Indicators (26 states)

Looking Toward the Future: Competition for Resources an Aging Society

Politics as allocation of “scarce” resources

- Amount of resources (\$\$, DSPs...)
- Number of people who want/need them
- US facing unprecedented growth in demand for LTSS

We've Been in a Long, Difficult Recession, But It Will End.

Two Perspectives on the Future:

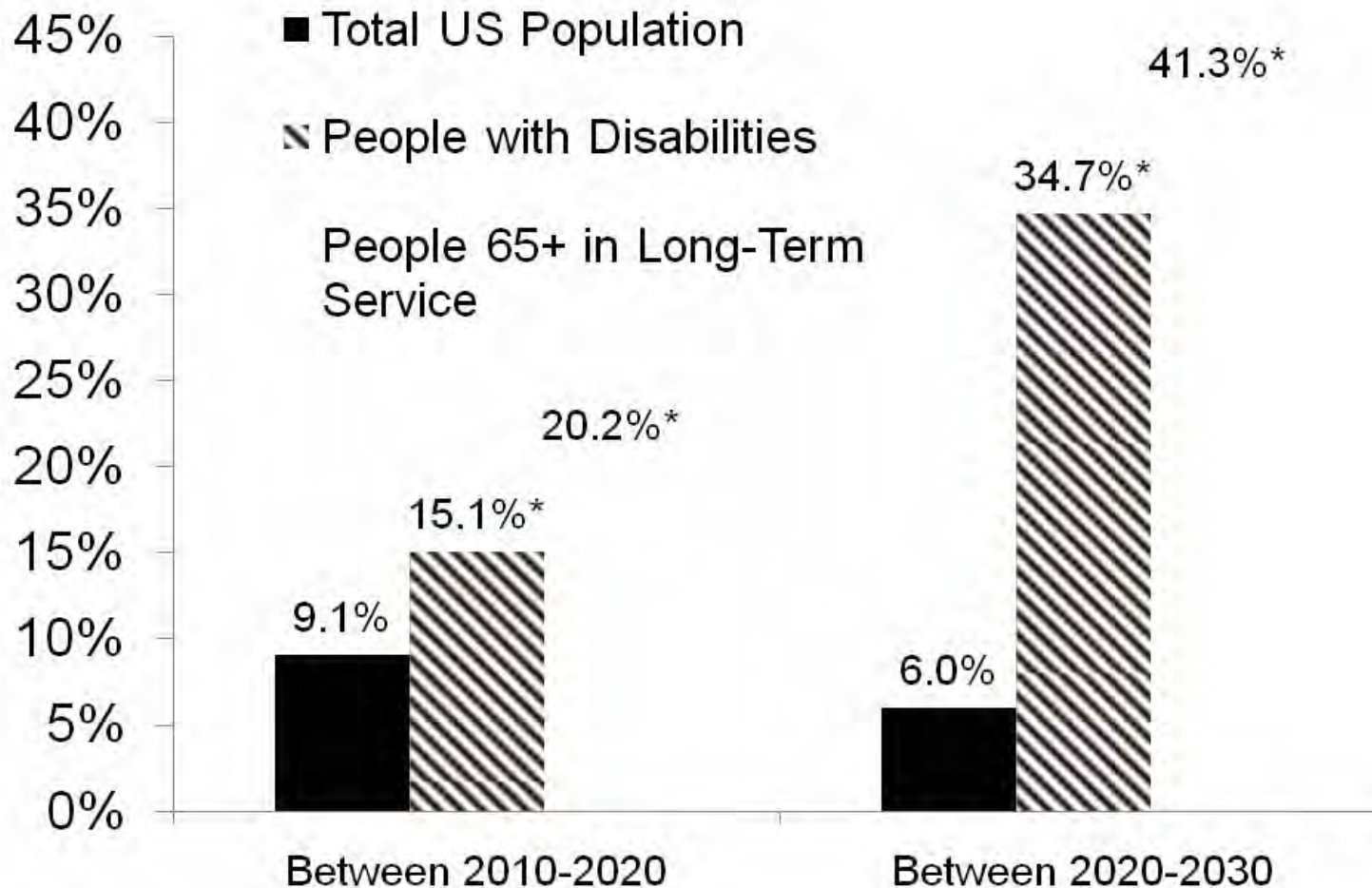
“The future will be better tomorrow.”

Dan Quayle

“The future ain't what it used to be.”

Yogi Berra

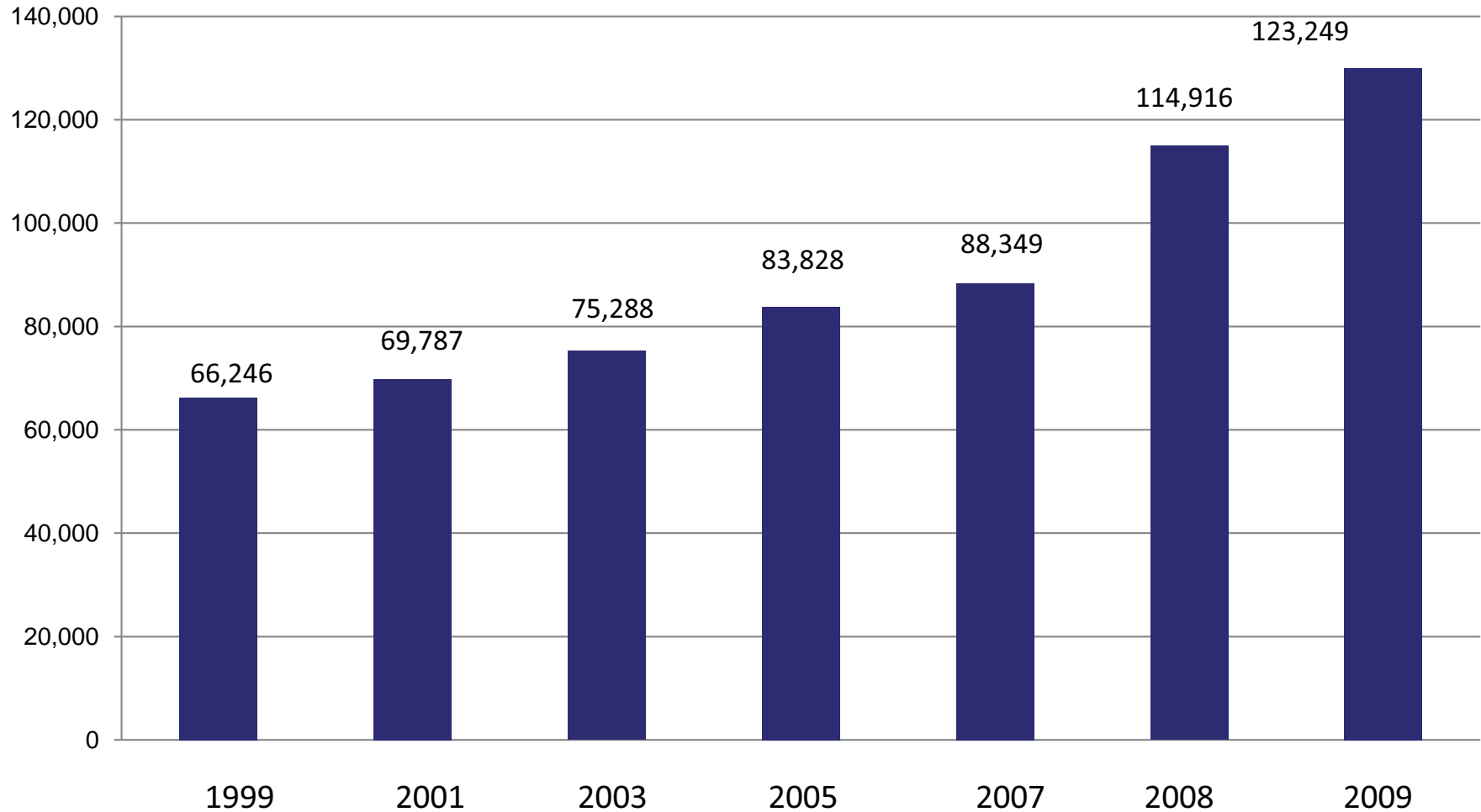
Population with Disabilities Will Grow at an Increasing Rate



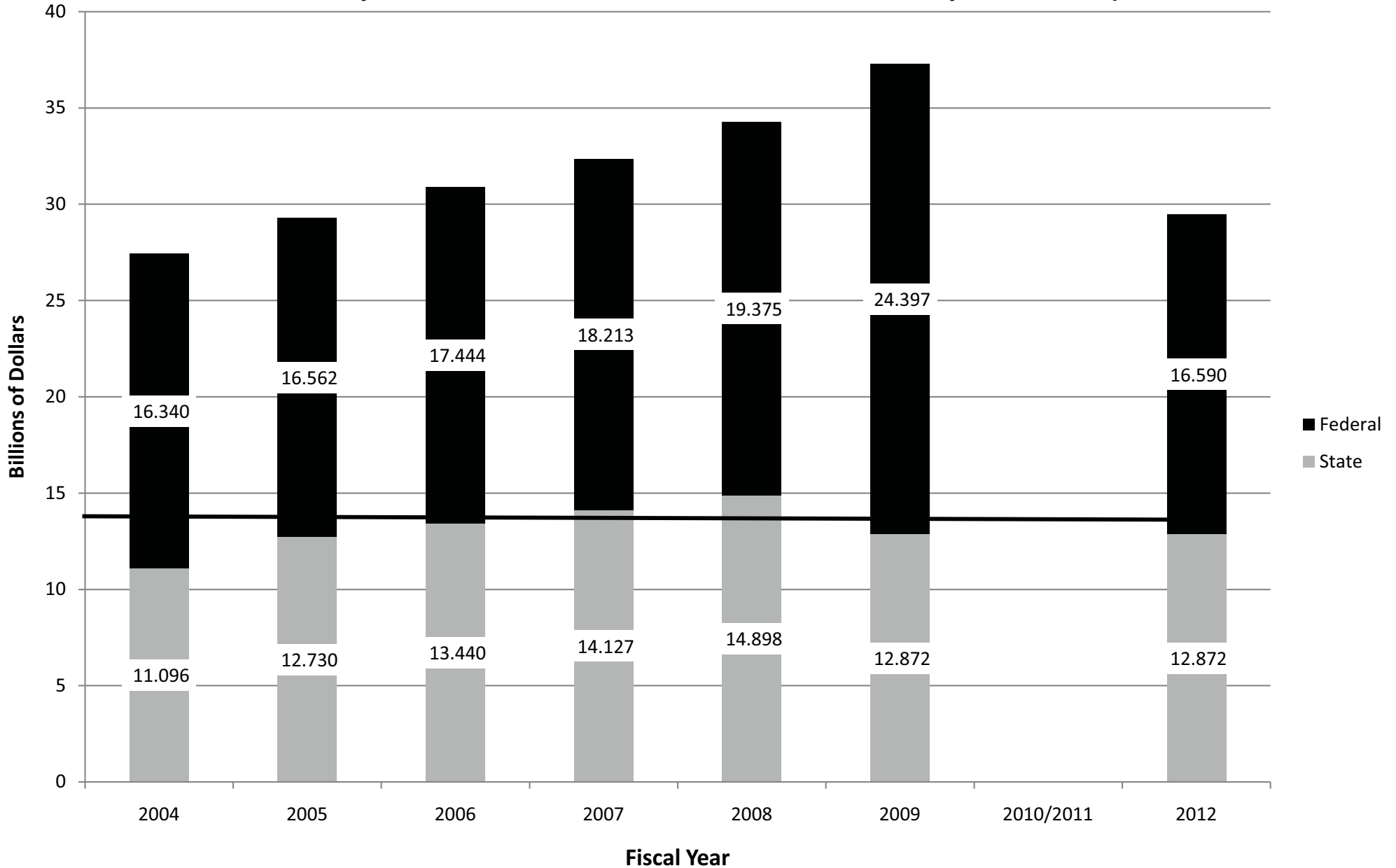
American Community Survey, 2006,

*Assume rates of disability and institutionalization remain the same as 2006

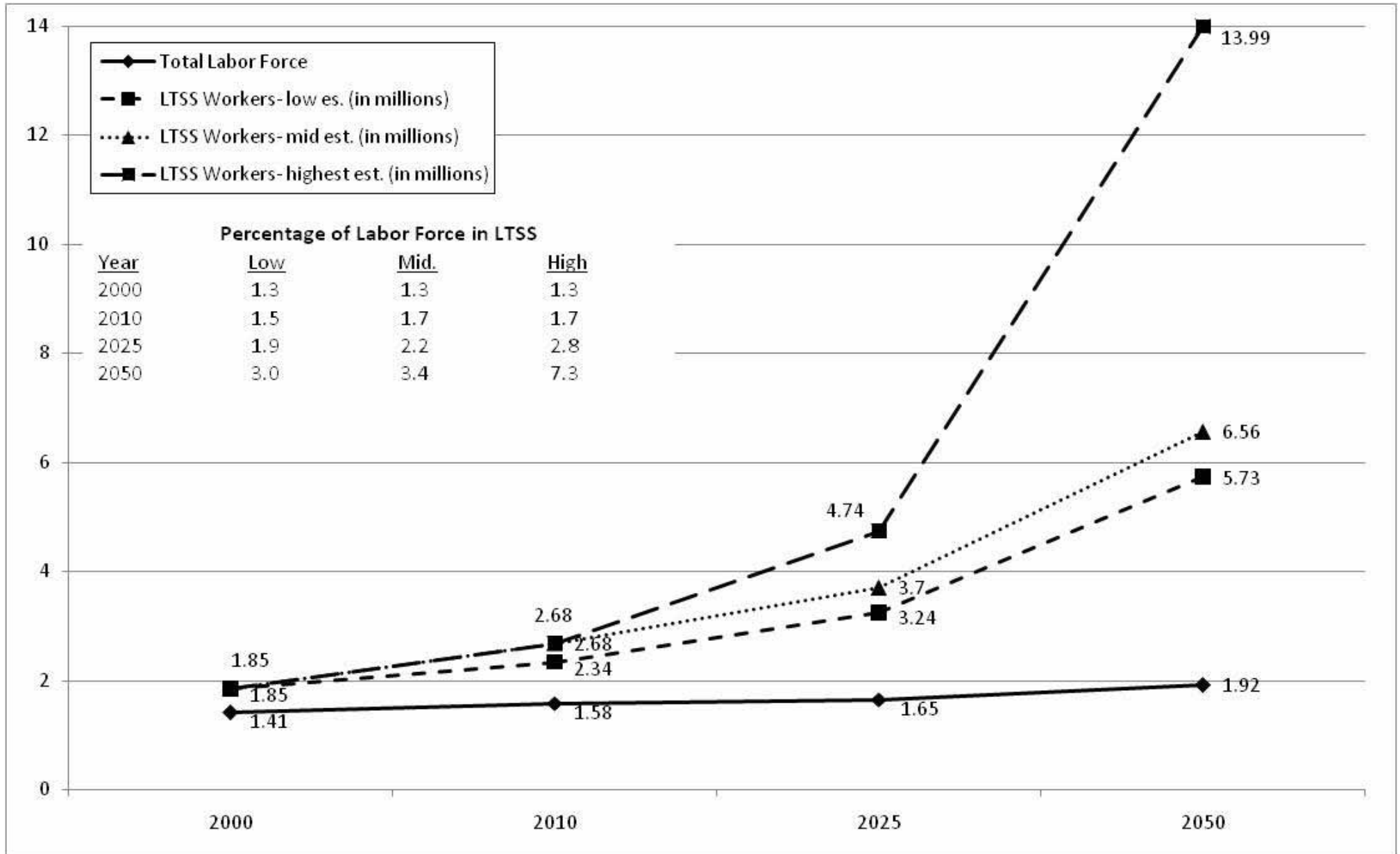
And More and More People Are Waiting for Services...People Reported By States to Need Residential Services Now or Within Next 12 Months, 1999-2009



Changes in Federal and State Medicaid ICF-MR and HCBS Expenditures for Persons with ID/DD, FY 2004 to FY 2009 with Projections for FY 2012 (Assuming State Expenditures for ICF-MR and ID/DD Waiver equal FY 2009)

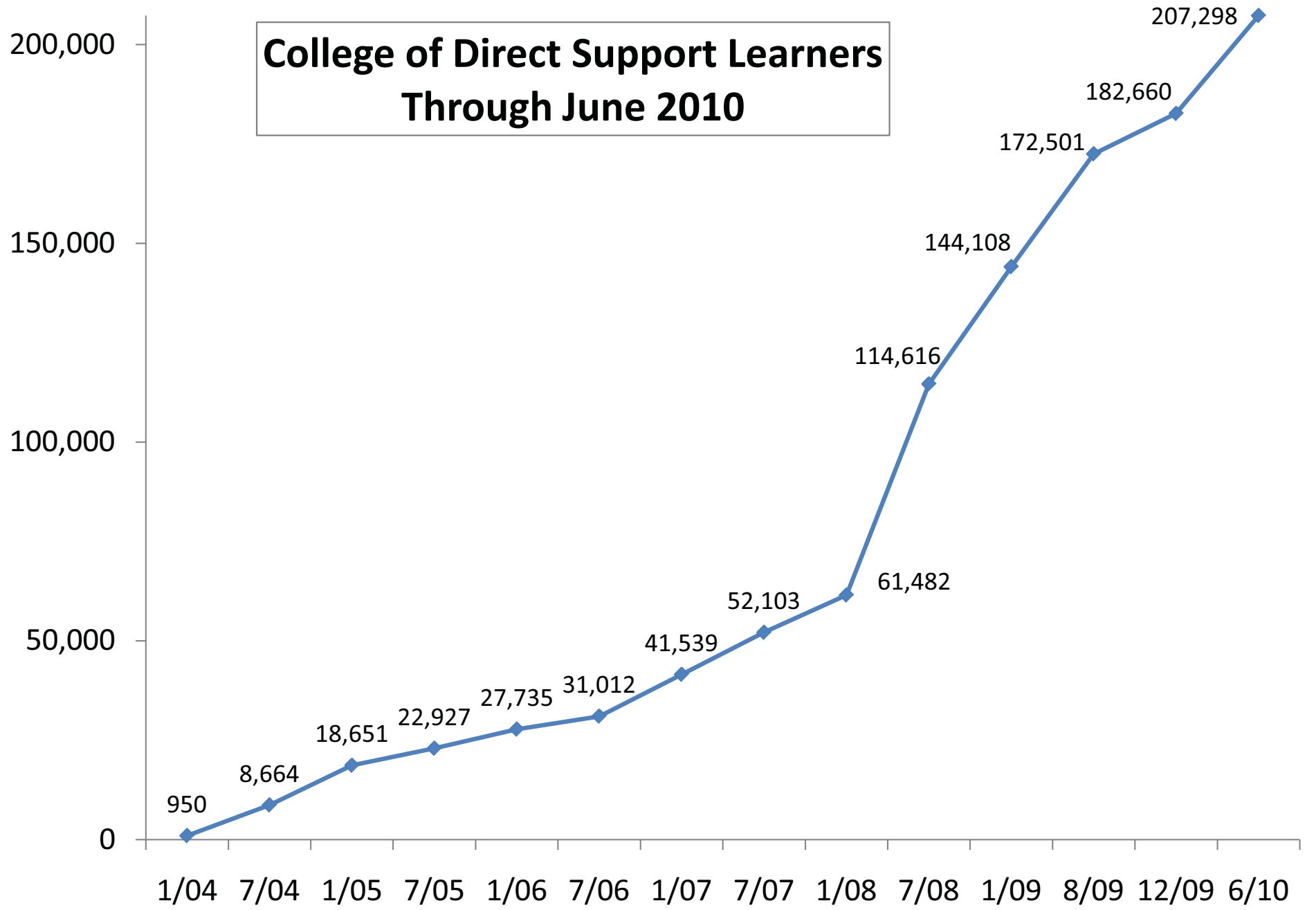


Future Growth in U.S. Labor Force (in hundred millions) Will Be Much Slower Than the Needed Growth For Persons Providing Long-Term Services (in millions)



College of Direct Support Learners Through June 2010

Learners



So If the Struggles of the Last 2-3 Years Are The New Normal, What Can We Expect and Advocate?

- How will expectations for families change?
 - Prolonged living in families?
 - Increased roles for families in out-of-family living?
 - Increased supports/opportunities for family-directed creativity?
- How will expectations for cost containment change?
 - Intolerance of costly models (institutions, high staff ratios)?
 - Increased focus on outcomes and cost-benefits
 - Trading rules for reduced cost?
 - Uniform individual budgeting/allocations based on characteristics
- What Possibilities Are We Willing to Entertain?
 - No one gets more than needed until all get minimum needed?
 - That compared with others with disabilities this is a rich system?
 - That continuing in ways we know may pose danger?
 - That others deserve access and support?