

Non-Elderly People Needing Long-Term Services & Supports: Who are they? What services do they get? What do they need?

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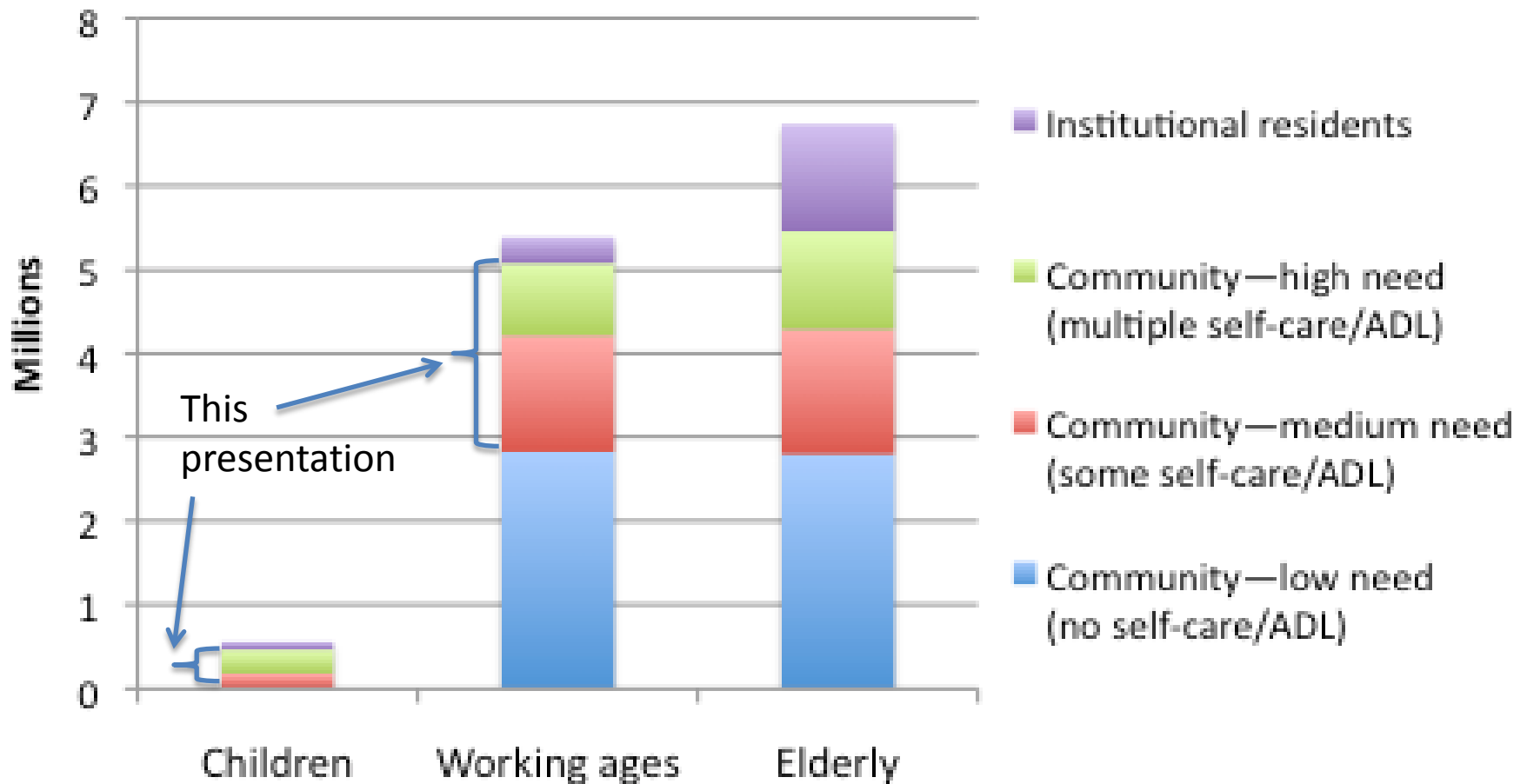
Research funded by National Institute on
Disability & Rehabilitation Research



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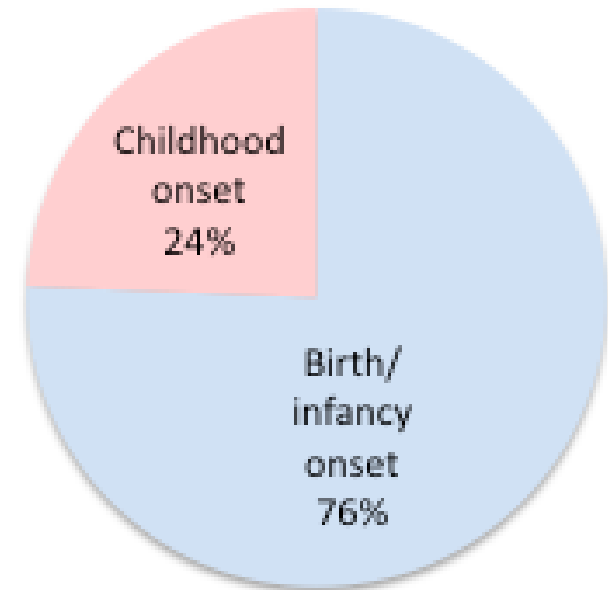
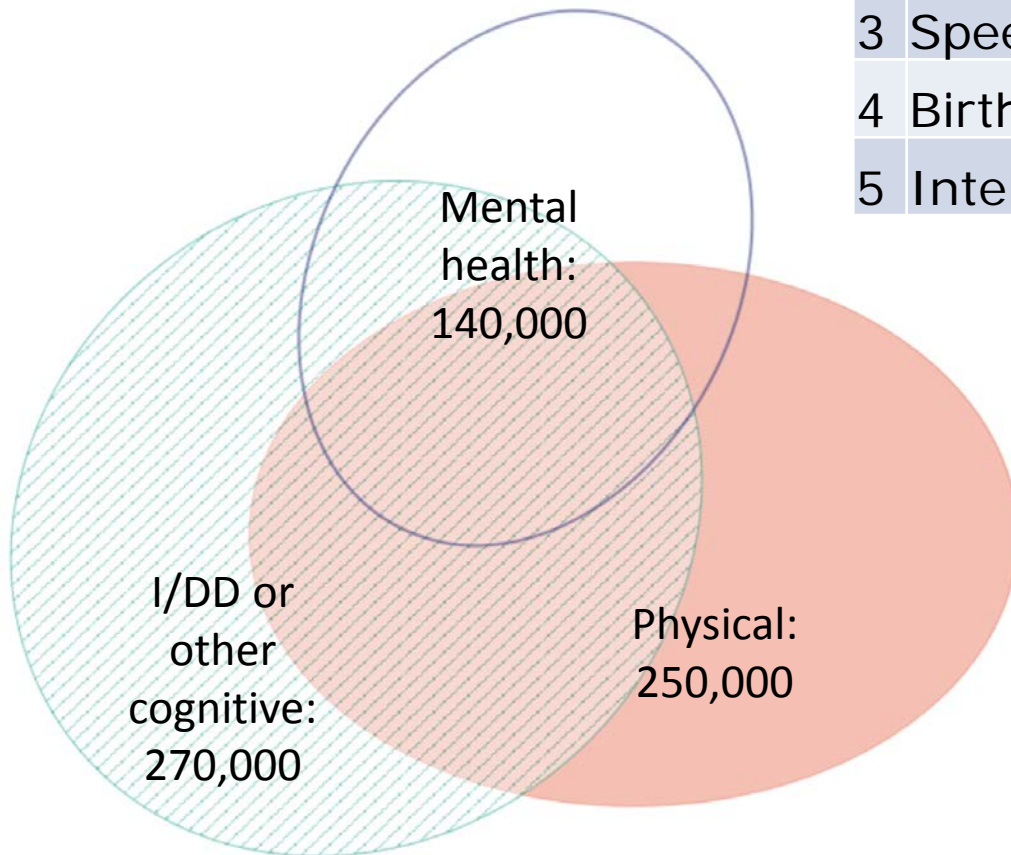
Non-elderly are nearly half of 12 million Americans needing LTSS

Population needing LTSS, by age, level of need, and setting



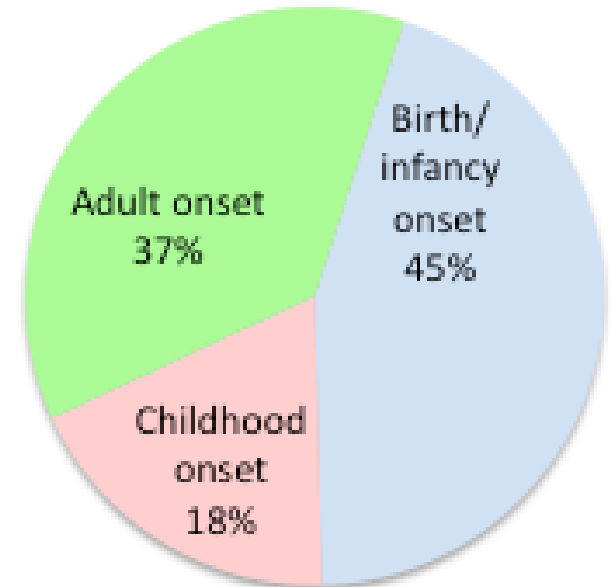
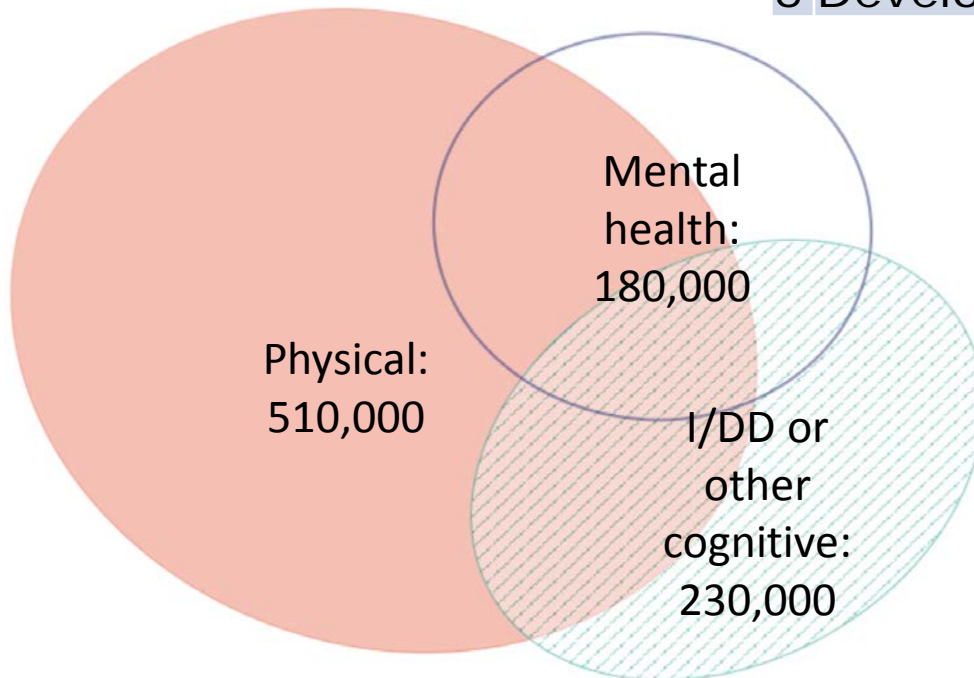
Disabilities among children needing LTSS

Top-ranked causes	
1	Mental health condition
2	Developmental disability
3	Speech impairment
4	Birth defect
5	Intellectual disability



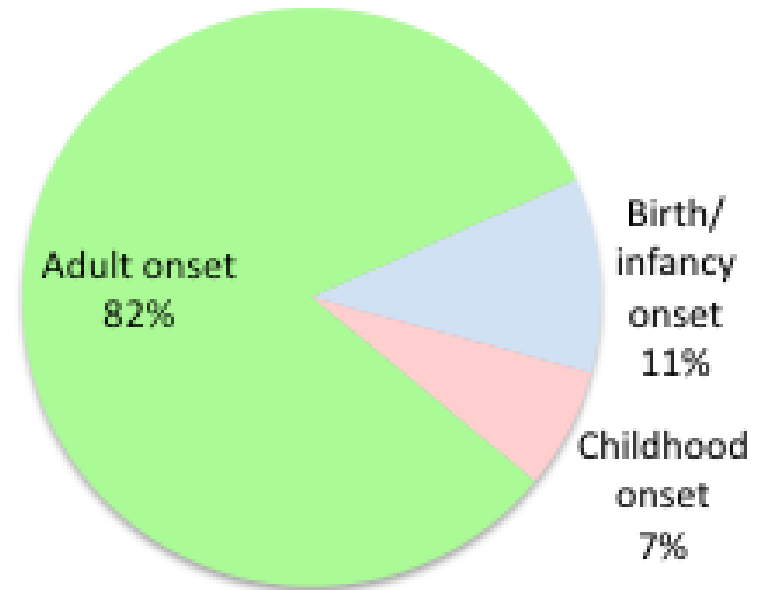
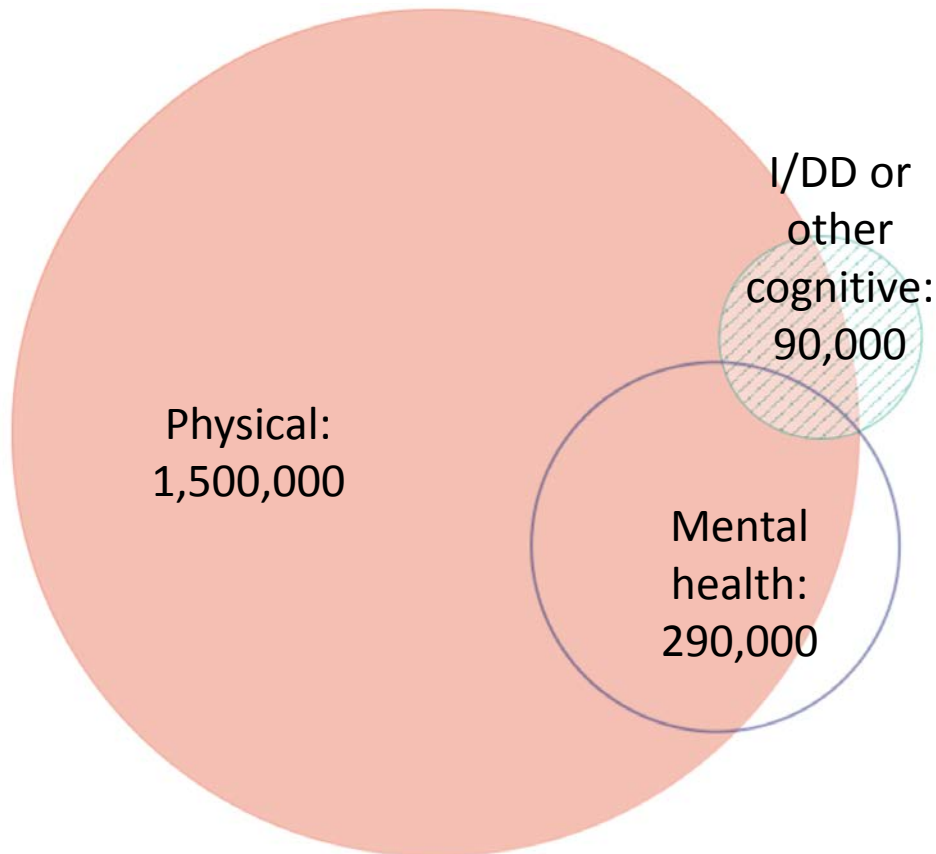
Disabilities among adults 18–44 needing LTSS

Top-ranked causes	
1	Intellectual disability
2	Paralysis & nervous system
3	Back problem
4	Mental health condition
5	Developmental disability



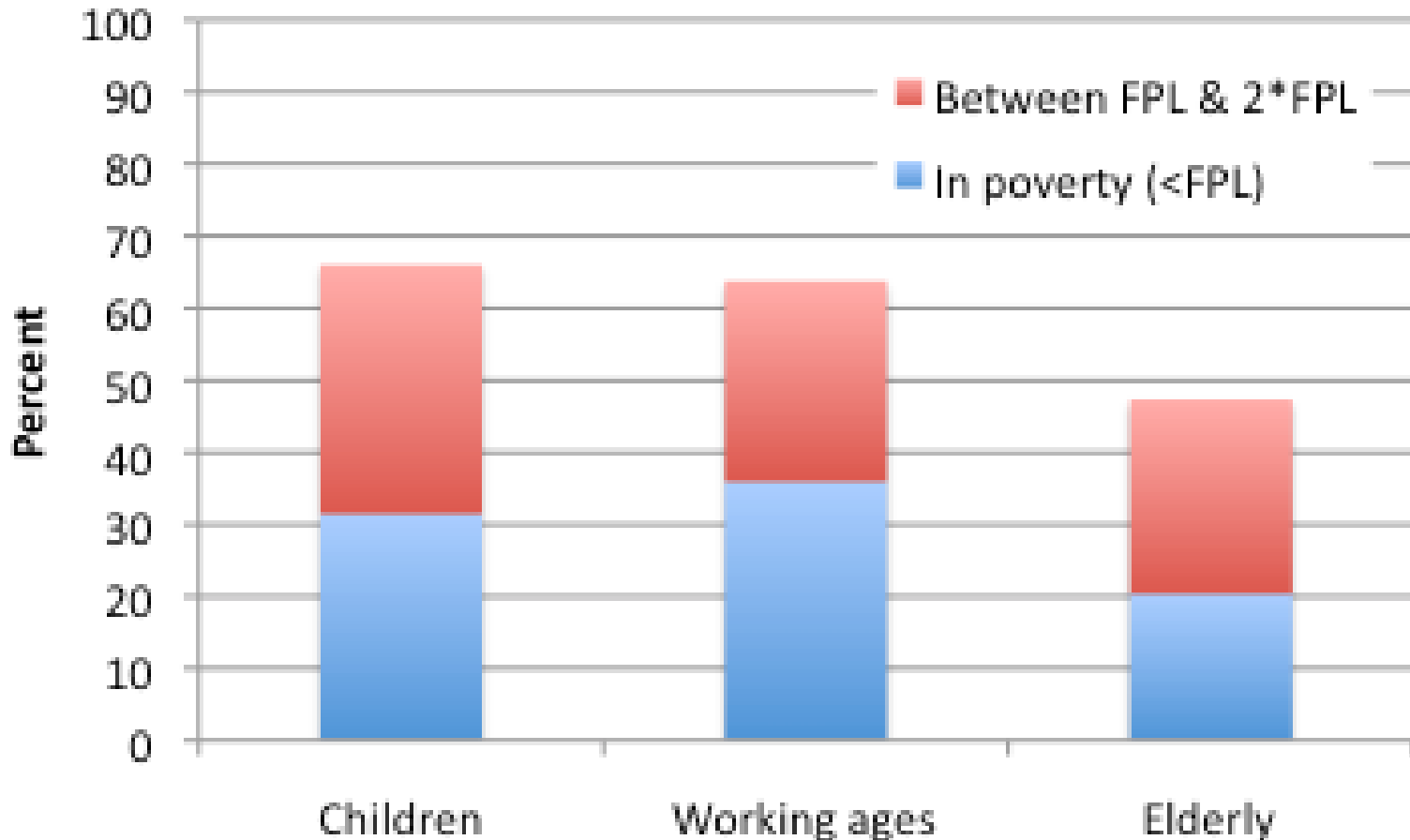
Disabilities among adults 45-64 needing LTSS

Top-ranked causes	
1	Back problem
2	Arthritis
3	Diabetes
4	Paralysis & nervous system
5	Asthma, breathing, lung



Many LTSS consumers live in or near poverty

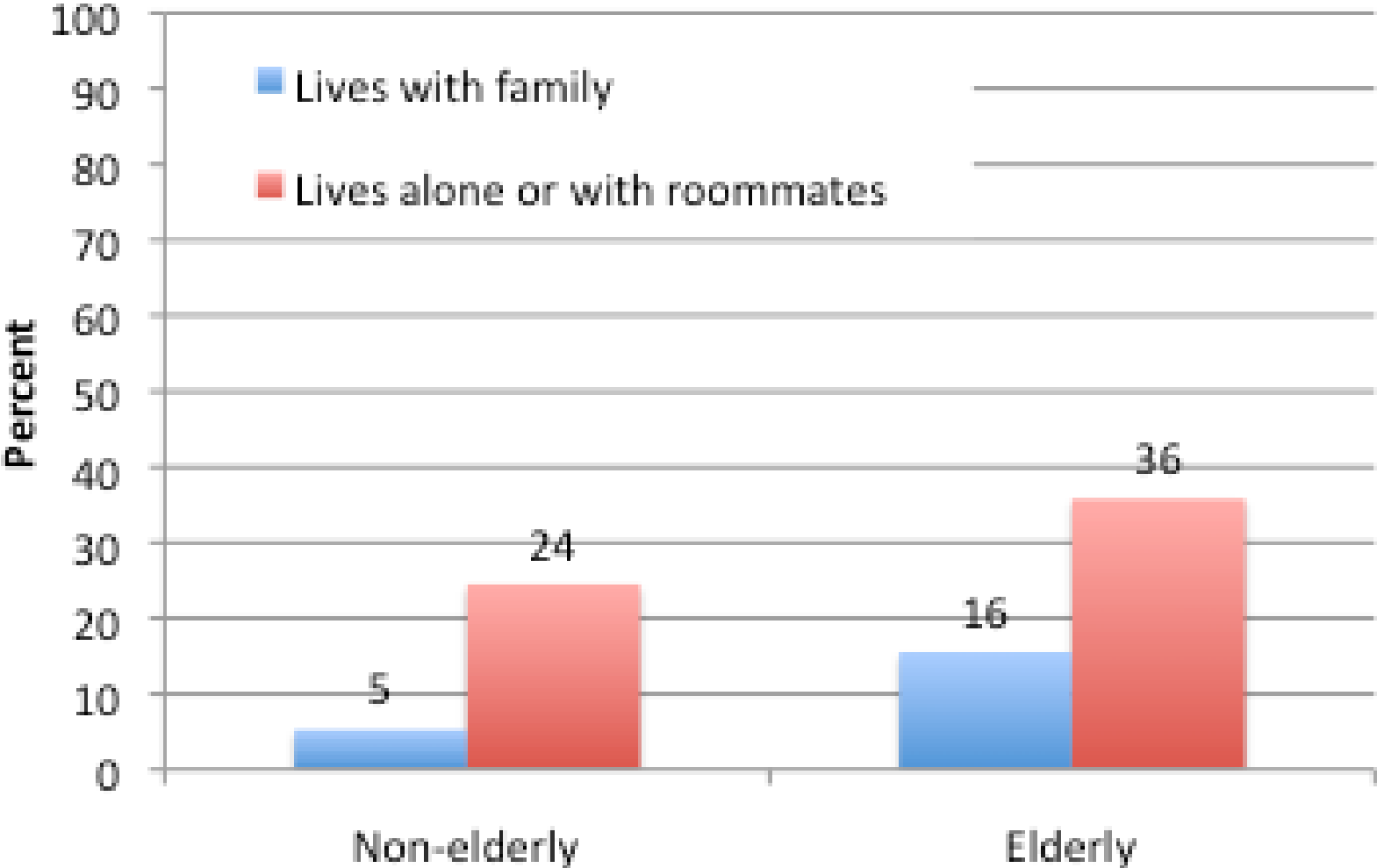
Family income compared to poverty level among people needing LTSS, by age, 2012



2010 Federal Poverty Level = \$11,170 for single, \$23,050 for family of 4

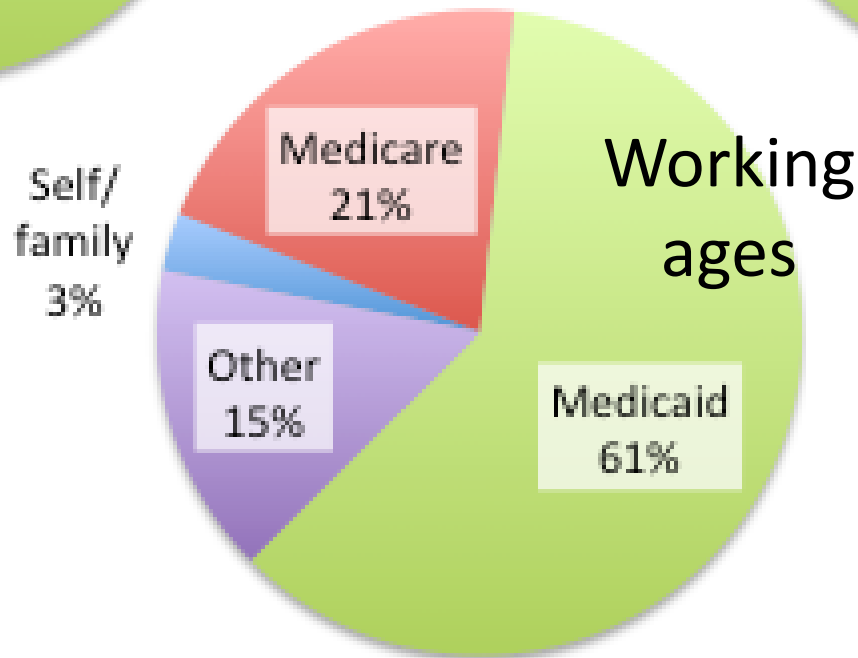
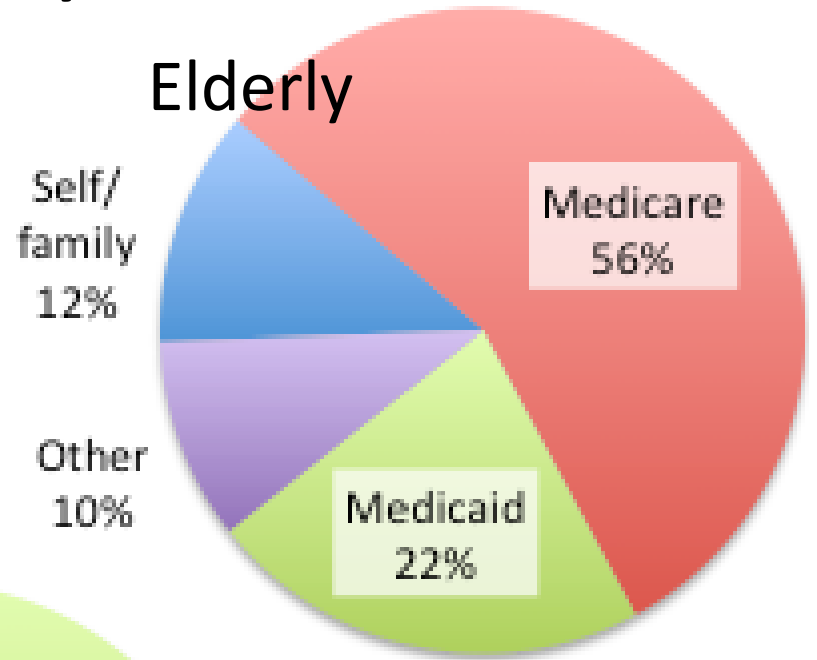
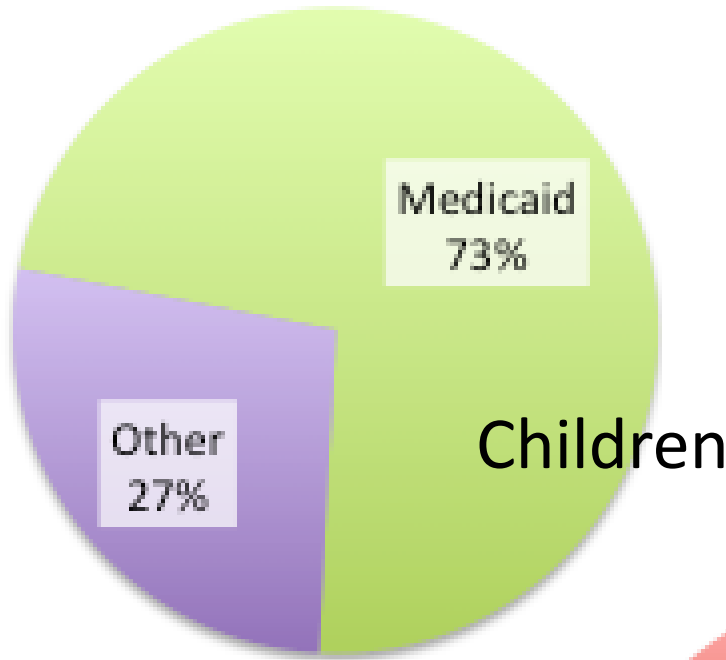
Only a small minority use paid help

Use of paid help among adults needing LTSS



Source: Author's analysis of 2010 data from the Survey of Income and Program Participation

Primary payer



Medicaid Home- and Community-Based Services Programs (HCBS)

HCBS Waivers

Intensive services for specific high-need groups (288 programs in all states)

For working-age adults

"Aged/ disabled"(71)		TBI (22)
Physical disability (39)		HIV (14)
I/DD (128)	Mental illness (12)	Medically fragile (17)

For children



Personal Care Services

Help with daily activities for a broad population (32 states)

Home Health

Healthcare services often including help with activities (all states)

Managed LTSS

Integrates acute care & LTSS, Medicaid only or duals demo (30 states active/proposed)

New HCBS Options

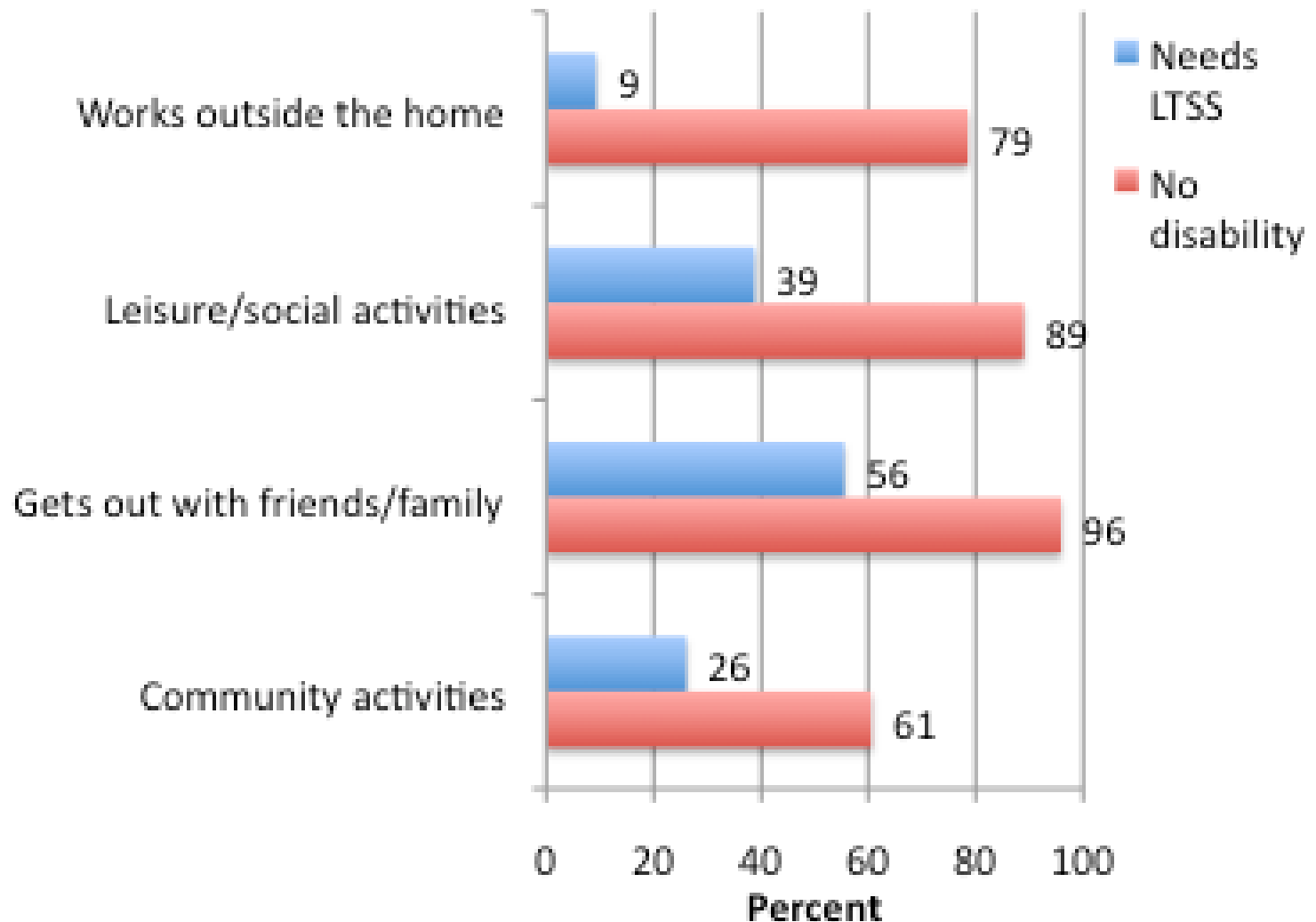
Under ACA (a few states)

Problems with Medicaid HCBS

- Fragmentation:
 - Confusion, inefficiency
 - Gaps in services, inequity across disabilities & ages
 - Most programs optional—huge variation across states
- Rationing results in unmet need for services:
 - **½ million** people on waiting lists for Waivers
 - PCS programs place caps on hours and/or expenditures
- Program may not provide all needed services:
 - E.g., technology, home modifications, family supports
- Only some programs offer consumer direction

Goal is not just survival, but integration

Participation among working-age adults needing LTSS



Source: Author's analysis of data from the 2011 National Health Interview Survey

Policy needs of non-elderly LTSS consumers

- Policy must foster, not hinder, participation
 - Working shouldn't jeopardize LTSS: asset, income limits
 - Must meet people's LTSS needs, not shortchange them
- Laggard states must rebalance to increase HCBS
 - “Institutional bias” must be overcome
 - Rebalancing does not increase expenditures
- Fragmented programs should be streamlined
 - But concerns over too-rapid shift to managed LTSS
- Must support those who don't qualify for Medicaid
 - Don't know how to get support, find quality workers
 - Need family supports
 - Many can't afford private-pay