

Characteristics and Needs of Long-Term Services & Supports Users

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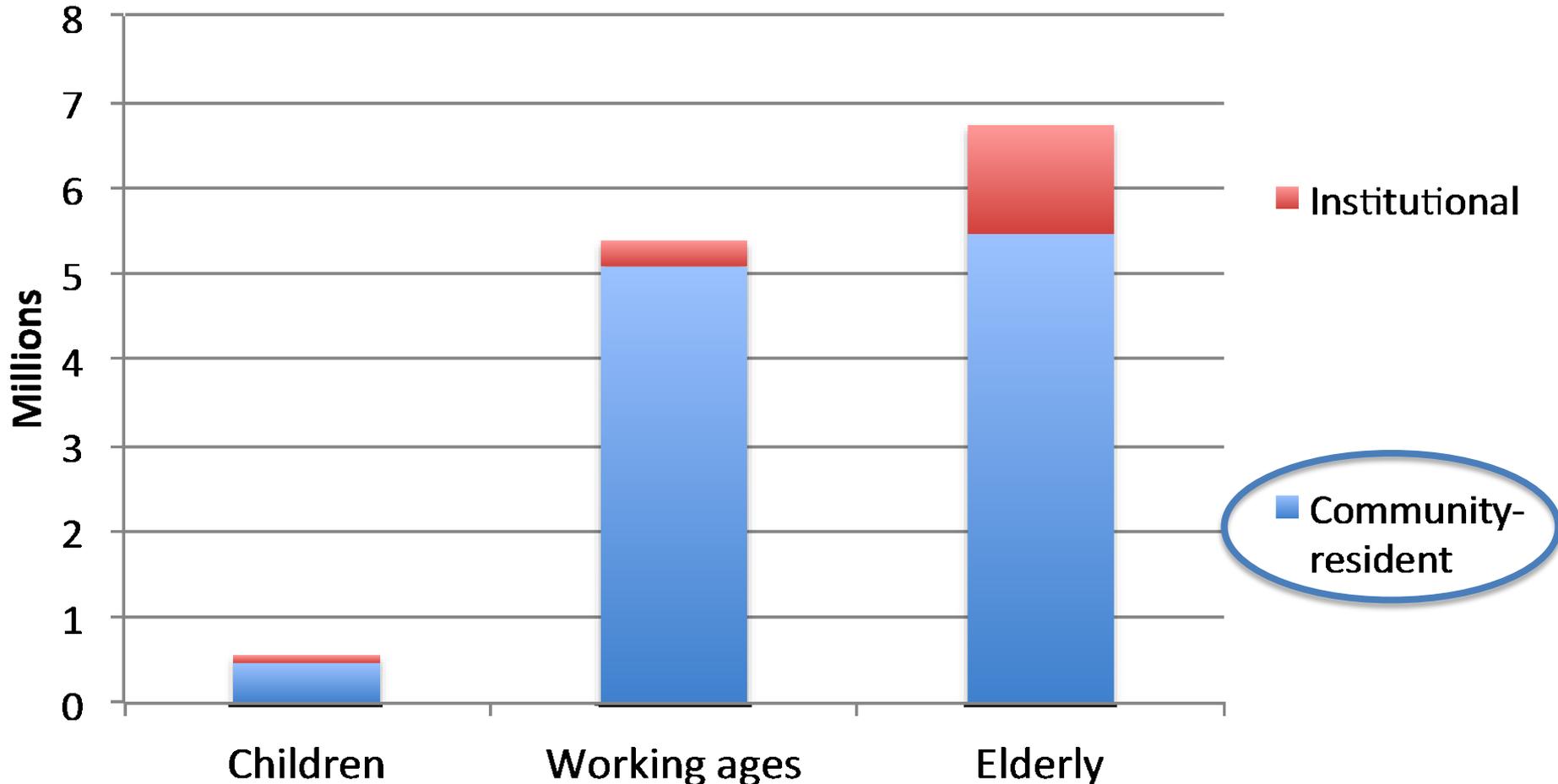
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The need for LTSS

Population needing LTSS, by age, and setting



Source: Author's analysis of data from the 2012 National Health Interview Survey & 2010 Census

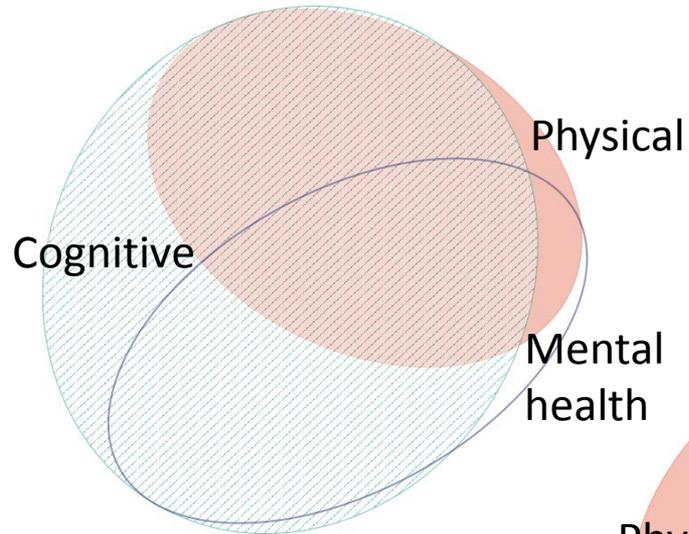
Top-ranked primary causes of disability among LTSS population

	Children	Working ages	Elderly
1	Developmental disability	Back/spine problem	Arthritis
2	Intellectual disability	Intellectual disability	Back/spine problem
3	ADD/Learning disability	Arthritis	Heart condition
4	Mental health	Mental health	Dementia
5	Visual impairment	Heart condition	Diabetes

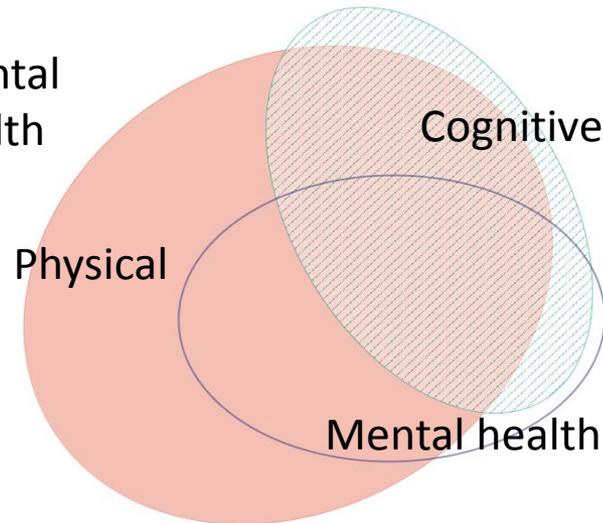
Source: Author's analysis of 2010 data from the Survey of Income and Program Participation

Functional limitations among LTSS users

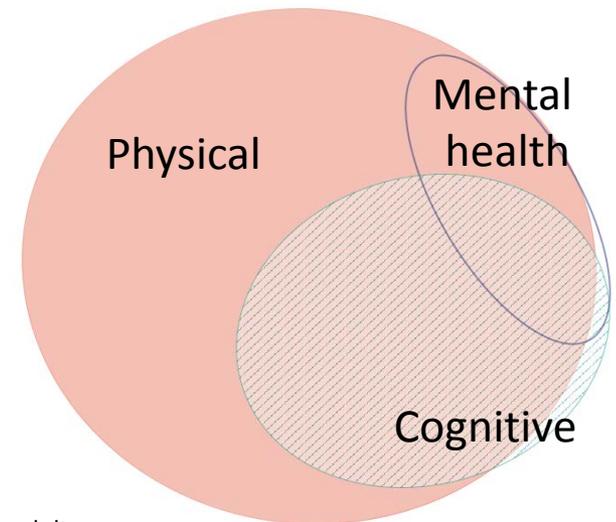
Children



Working ages



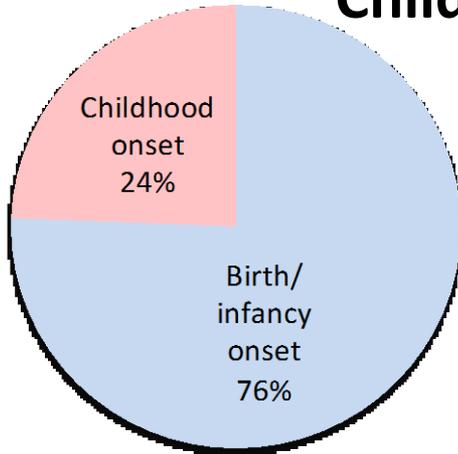
Elderly



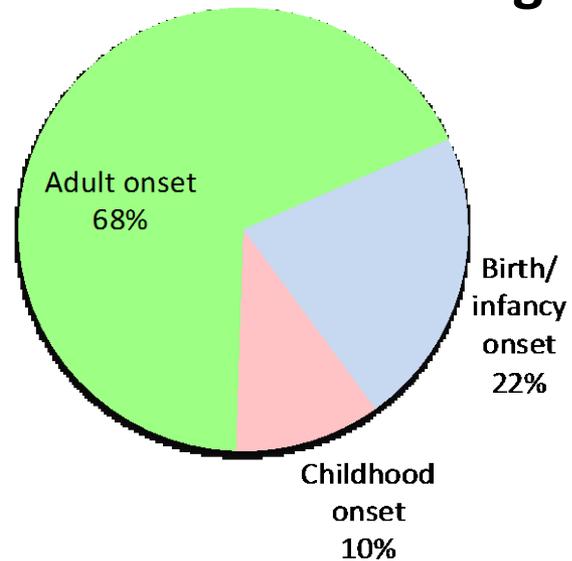
Note: Measures of functional limitations and LTSS needs are different for children than those used for adults.
Source: Author's analysis of data from the 2013 National Health Interview Survey

Age of disability onset

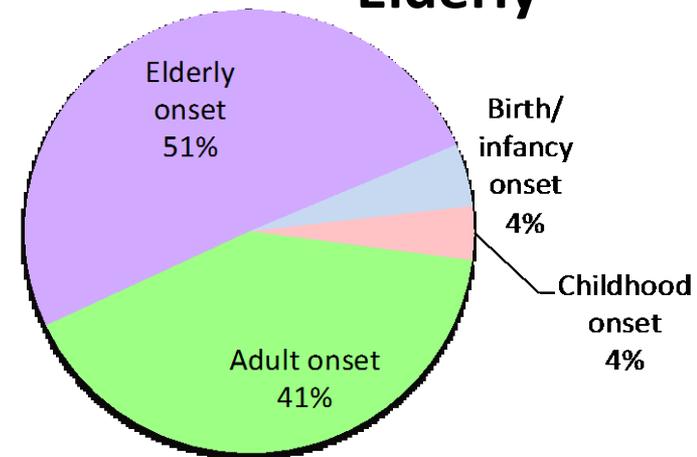
Children



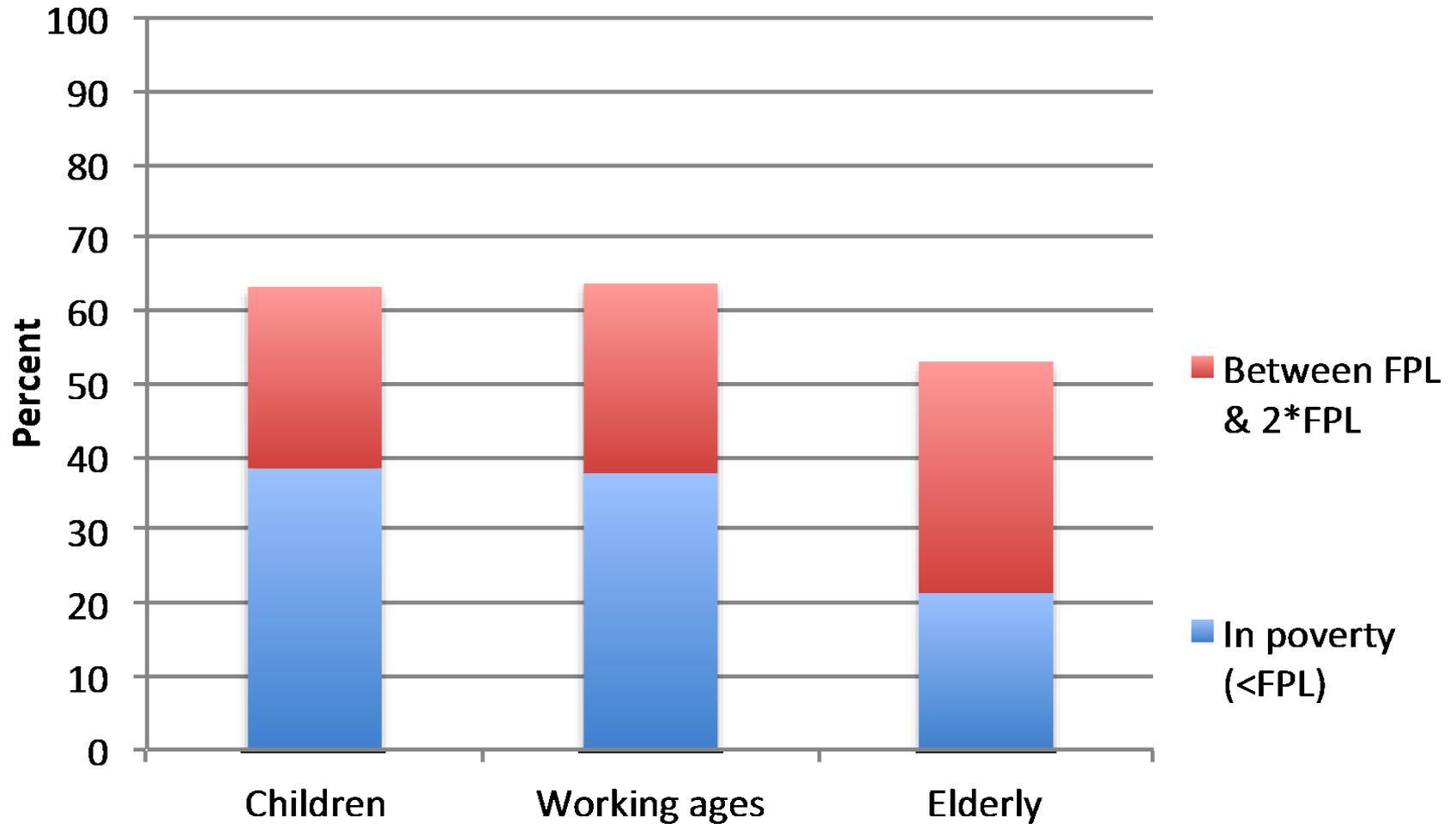
Working ages



Elderly



Poverty & near-poverty



Source: Author's analysis of data from the 2013 National Health Interview Survey

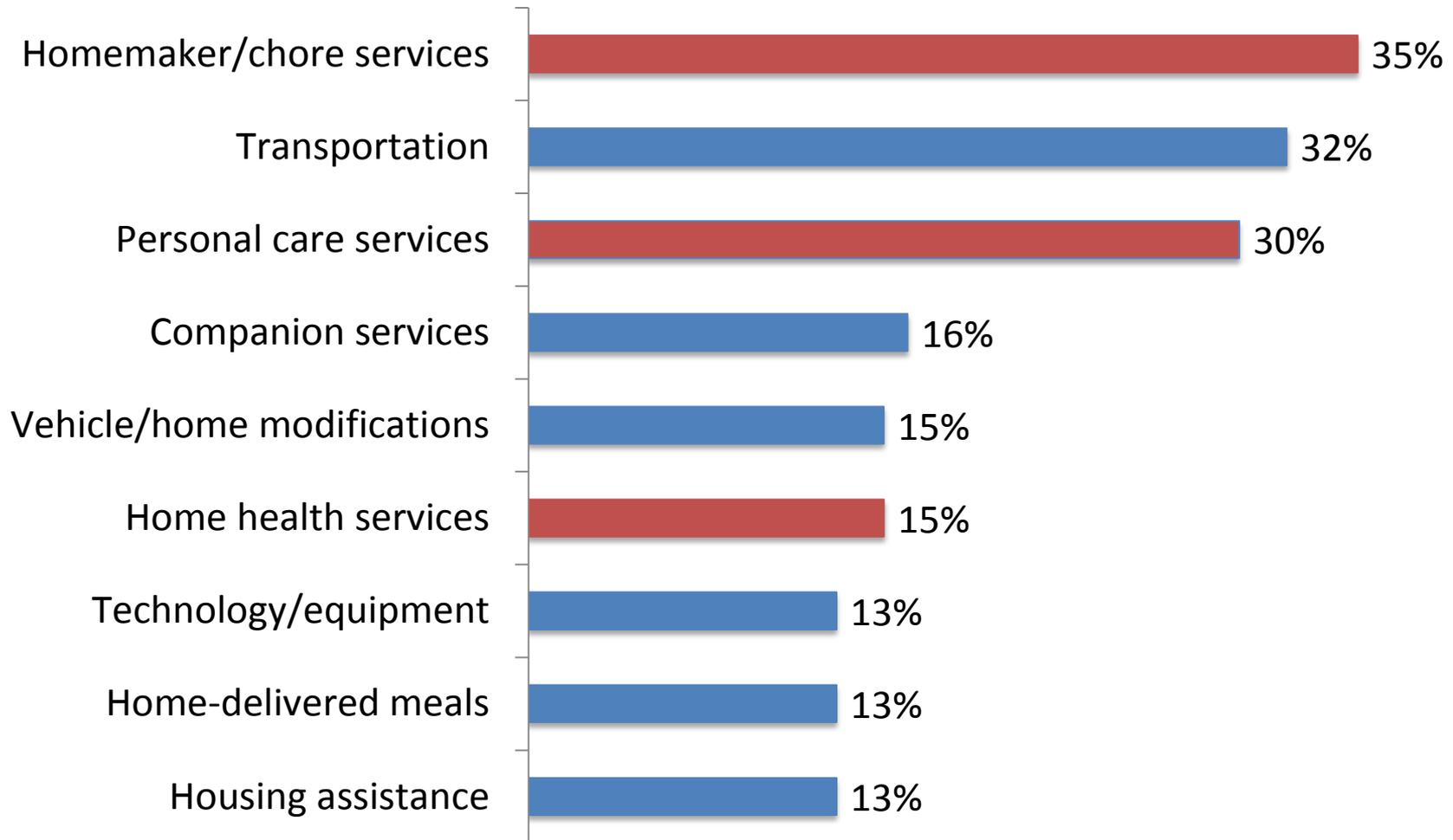
Help needed & received

Level (# of activities)	Typically need help with:	Pop. (millions)	Gets <u>unpaid</u> help	Gets <u>paid</u> help
Low (1–2)	Getting out (+ housework)	6.6	93%	8%
Medium (3–5)	+ preparing meals (+ managing meds + managing money)	3.0	92%	14%
High (6–8)	+ bathing + dressing (+ transferring)	1.4	91%	20%
Very high (9–10)	+ eating + toileting	1.1	89%	22%

Many needs are unmet

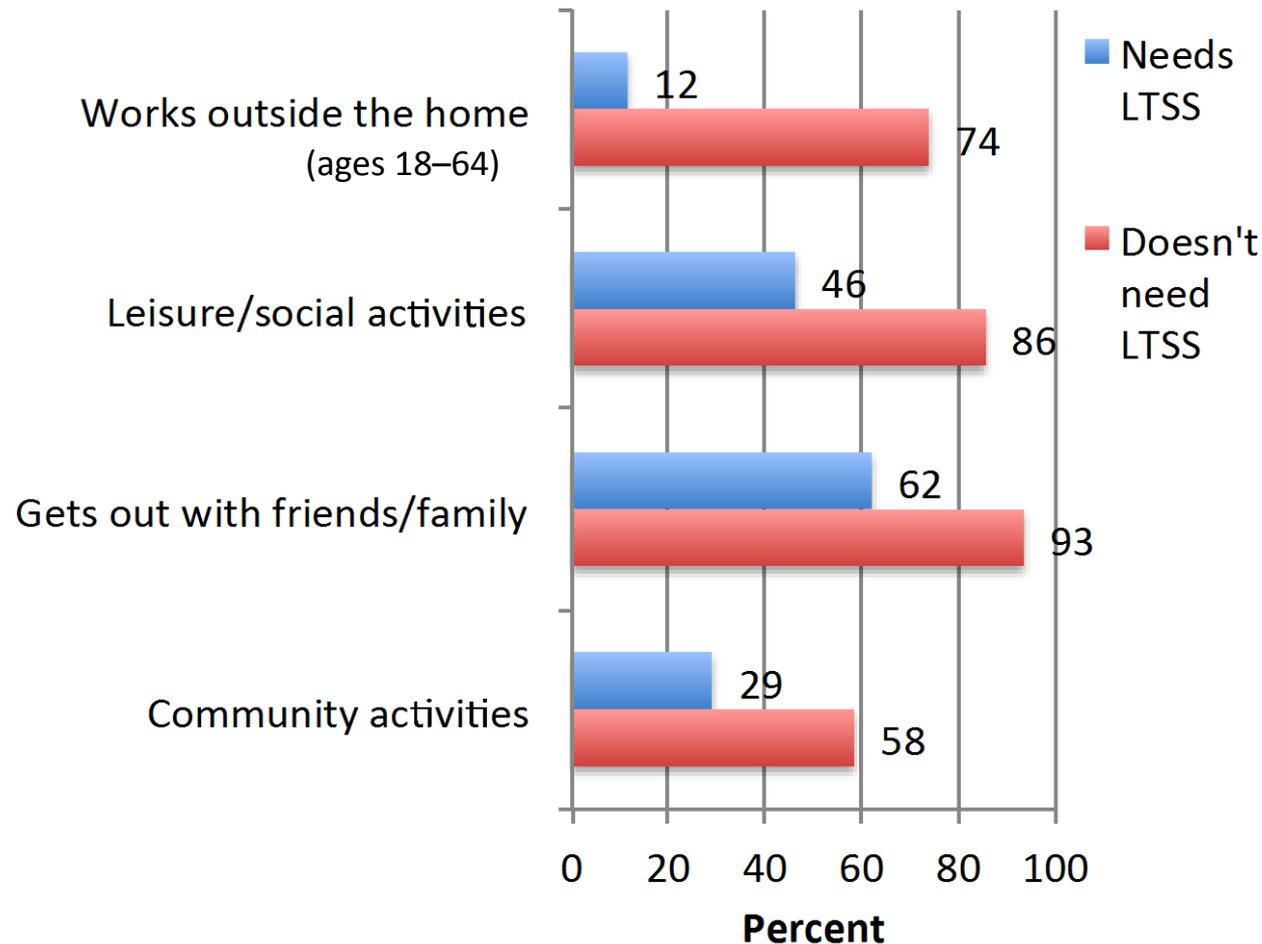
- LTSS users in the general population:
 - Typically 20–30% report unmet need
 - As high as 70% (MA 2007 survey)
- LTSS program participants
 - HCBS participants in 3 states: 34–58%
 - CA IHSS participants: 39%
 - HCBS participants in 6 states: 38% say services don't always meet their needs and goals
 - Of those...

What do they need?



Community participation

Participation among adults needing LTSS



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

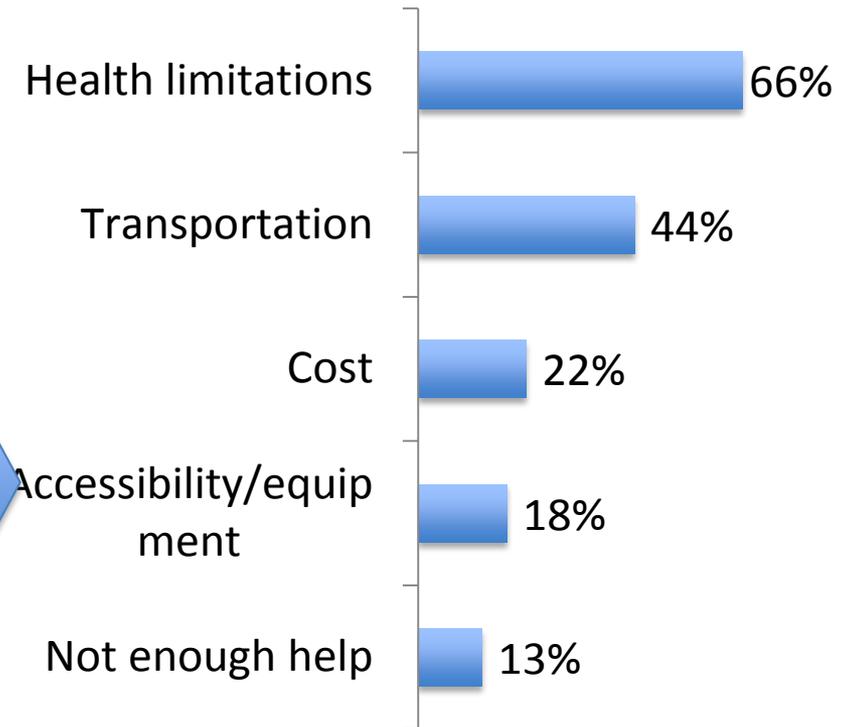
Unmet needs related to community participation



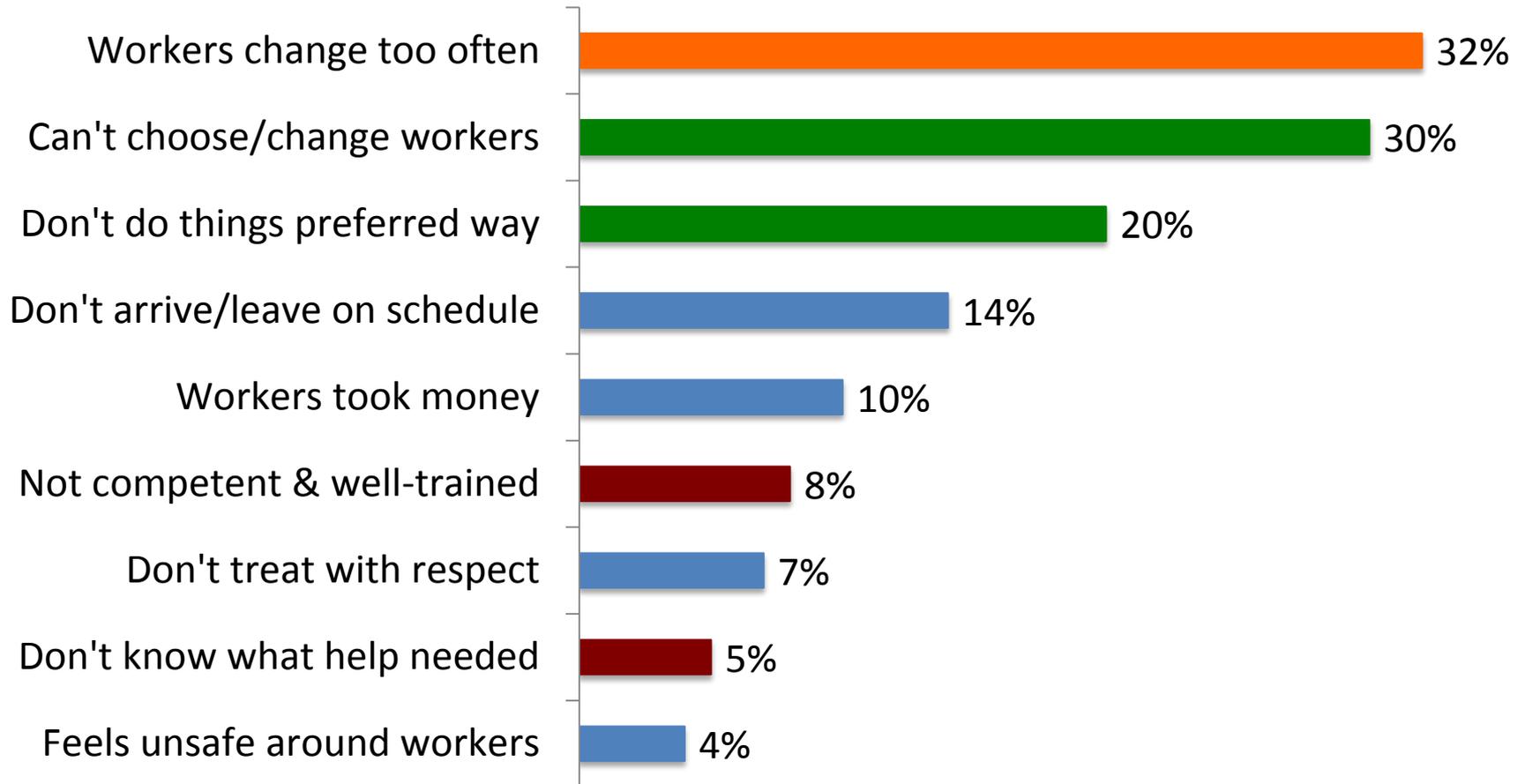
- HCBS participants in 10 states:
 - 71% need more help from paid staff to do things in community
- HCBS participants in 6 states:
 - 38% can't always do things they enjoy outside their homes when & with whom they want



Barriers to doing things outside the home



Consumer-reported difficulties with help received



Disability paradigms

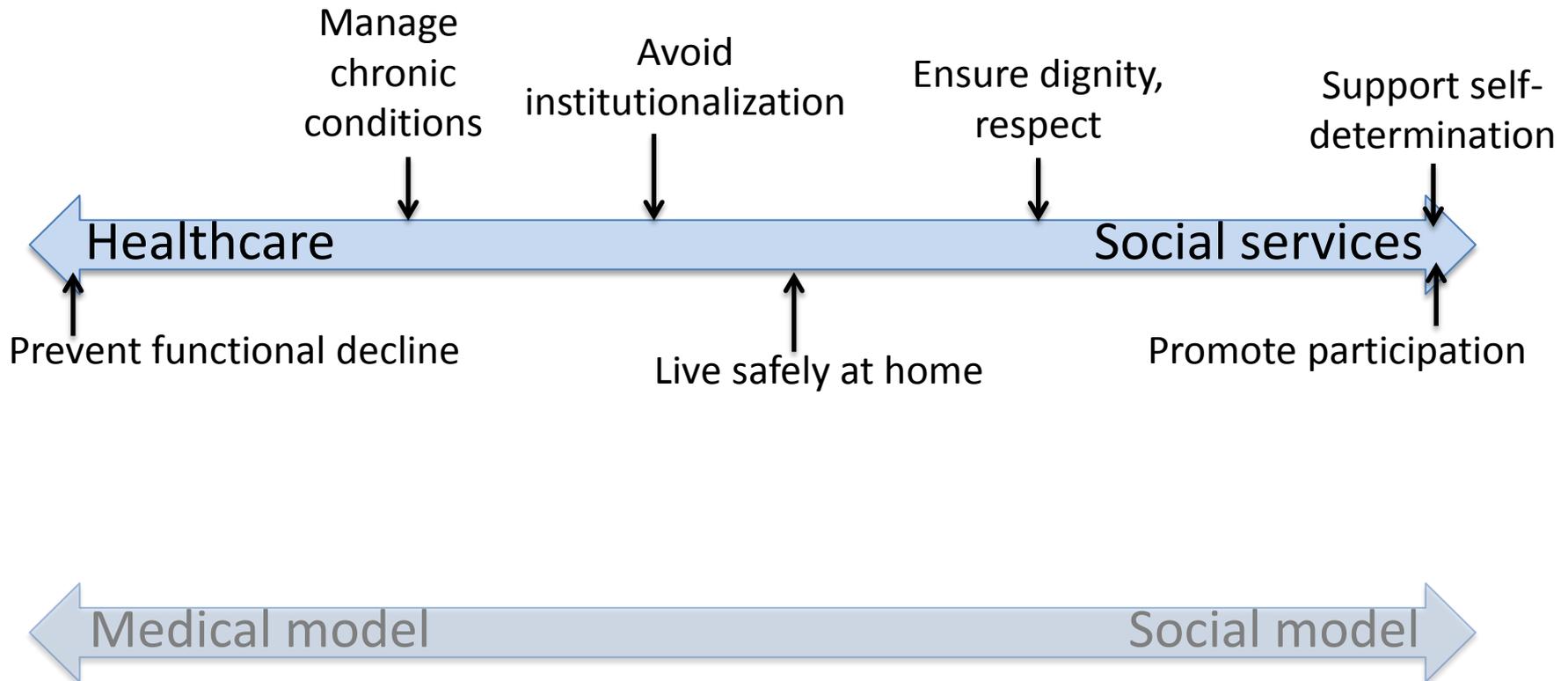
How do we conceptualize disability?



LTSS paradigms

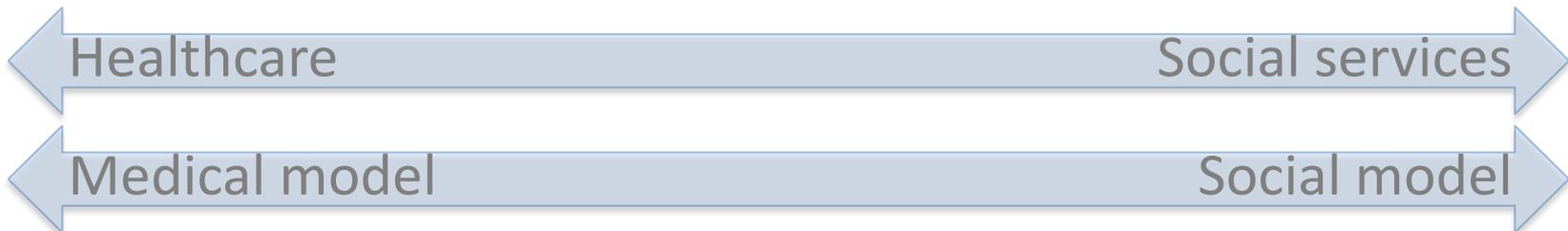
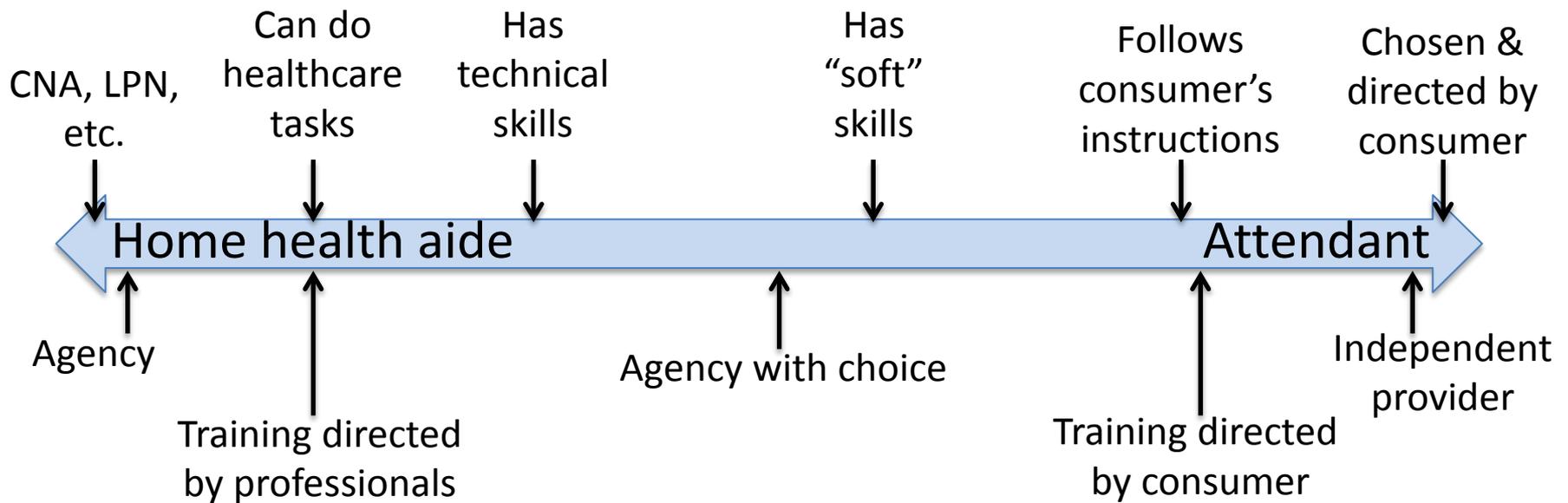


What is the primary goal of LTSS?



LTSS workforce paradigms

What characterizes workers providing LTSS?



Worker training & certification can be controversial

- Many disability advocates and consumers oppose **required** training/certification
 - Medicalization/professionalization
 - Loss of control
 - Who's the boss?
 - What happens when 'proper' method conflict with preferred method?
- Some consumers don't want workers trained
- Barriers to entry
 - Inability of family, chosen workers to continue working or enter workforce
 - Requirements might worsen scarcity of workers

Worker training/certification issues

- Washington State experience
 - 2007: 58% of consumers had difficulty finding new provider
 - 2012: Training requirements doubled
 - 2013: 42% of workers failed certification & 24% passed late
 - Consumers report service disruptions, worker scarcity
- Is training model different for agency v. indep. provider?
 - Are paid family and/or other IPs exempt?
- Mandatory versus voluntary training
 - Can consumer decide?
- What's in the curriculum?
 - Who controls it?
 - Does it emphasize technical skills or consumer direction?

Conclusions

- People with LTSS needs
 - Typically reside in community, often have modest needs
 - ½ of those are non-elderly
 - Many have multiple types of disability
 - Many are poor or near-poor
- Unmet need is highly prevalent, even in HCBS programs
 - People need more help & transportation
 - Major cause of low community participation, isolation
- The LTSS workforce
 - Consumers report problems with retention and choice & control
 - Required worker training is controversial because seen as return to medical model
 - Consider tradeoffs between required training/certification and
 - Barriers to workforce entry
 - Consumers' desire for choice & control, independent providers including family