Characteristics and Needs of Long-Term Services & Supports Users

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The need for LTSS

Population needing LTSS, by age, and setting

- **Children**: 0.3 million
- **Working ages**: 4.8 million
- **Elderly**: 6.8 million

Source: Author’s analysis of data from the 2012 National Health Interview Survey & 2010 Census
Top-ranked primary causes of disability among LTSS population

<table>
<thead>
<tr>
<th></th>
<th>Children</th>
<th>Working ages</th>
<th>Elderly</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Developmental disability</td>
<td>Back/spine problem</td>
<td>Arthritis</td>
</tr>
<tr>
<td>2</td>
<td>Intellectual disability</td>
<td>Intellectual disability</td>
<td>Back/spine problem</td>
</tr>
<tr>
<td>3</td>
<td>ADD/Learning disability</td>
<td>Arthritis</td>
<td>Heart condition</td>
</tr>
<tr>
<td>4</td>
<td>Mental health</td>
<td>Mental health</td>
<td>Dementia</td>
</tr>
<tr>
<td>5</td>
<td>Visual impairment</td>
<td>Heart condition</td>
<td>Diabetes</td>
</tr>
</tbody>
</table>

Source: Author’s analysis of 2010 data from the Survey of Income and Program Participation
Functional limitations among LTSS users

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
- Childhood onset: 24%
- Birth/infancy onset: 76%

Working ages
- Adult onset: 68%
- Birth/infancy onset: 22%
- Childhood onset: 10%

Elderly
- Elderly onset: 51%
- Adult onset: 41%
- Birth/infancy onset: 4%
- Childhood onset: 4%

Source: Author’s analysis of data from the 2012 National Health Interview Survey
Poverty & near-poverty

Source: Author’s analysis of data from the 2013 National Health Interview Survey
<table>
<thead>
<tr>
<th>Level (# of activities)</th>
<th>Typically need help with:</th>
<th>Pop. (millions)</th>
<th>Gets unpaid help</th>
<th>Gets paid help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low (1–2)</td>
<td>Getting out (+ housework)</td>
<td>6.6</td>
<td>93%</td>
<td>8%</td>
</tr>
<tr>
<td>Medium (3–5)</td>
<td>+ preparing meals (+ managing meds + managing money)</td>
<td>3.0</td>
<td>92%</td>
<td>14%</td>
</tr>
<tr>
<td>High (6–8)</td>
<td>+ bathing + dressing (+ transferring)</td>
<td>1.4</td>
<td>91%</td>
<td>20%</td>
</tr>
<tr>
<td>Very high (9–10)</td>
<td>+ eating + toileting</td>
<td>1.1</td>
<td>89%</td>
<td>22%</td>
</tr>
</tbody>
</table>

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

Sources: Cash & Counseling 3-state eval., 1999-2003; NCI-AD 6-state 2015-16 mid-year results; Cal MediConnect eval 2016. Mitra et al., Unmet need for HCBS..., Disab & Health Jnl 2011
What do they need?

- Homemaker/chore services: 35%
- Transportation: 32%
- Personal care services: 30%
- Companion services: 16%
- Vehicle/home modifications: 15%
- Home health services: 15%
- Technology/equipment: 13%
- Home-delivered meals: 13%
- Housing assistance: 13%

Source: NCI-AD 6-state 2015-16 mid-year results
Community participation

**Participation among adults needing LTSS**

- **Works outside the home (ages 18–64)**
  - Needs LTSS: 12%
  - Doesn't need LTSS: 74%

- **Leisure/social activities**
  - Needs LTSS: 46%
  - Doesn't need LTSS: 86%

- **Gets out with friends/family**
  - Needs LTSS: 62%
  - Doesn't need LTSS: 93%

- **Community activities**
  - Needs LTSS: 29%
  - Doesn't need LTSS: 58%

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:

- Health limitations: 66%
- Transportation: 44%
- Cost: 22%
- Accessibility/equipment: 18%
- Not enough help: 13%

Sources: NCI-AD 6-state 2015-16 mid-year results; HCBS Experience of Care Svy 10-state results 2105
Consumer-reported difficulties with help received

- Workers change too often: 32%
- Can't choose/change workers: 30%
- Don't do things preferred way: 20%
- Don't arrive/leave on schedule: 14%
- Workers took money: 10%
- Not competent & well-trained: 8%
- Don't treat with respect: 7%
- Don't know what help needed: 5%
- Feels unsafe around workers: 4%

Sources: NCI-AD 6-state 2015-16 mid-year results; HCBS Experience of Care Svy 10-state results 2105
Disability paradigms

How do we conceptualize disability?

Medical model:
- Fix, cure, treat

Social model:
- Home & community living
- Rights, advocacy, legislation
- Control, choice, freedom

Institutions
LTSS paradigms

What is the primary goal of LTSS?

- Ensure dignity, respect
- Prevent functional decline
- Manage chronic conditions
- Avoid institutionalization

Healthcare

Medicare model

Social services

Social model

Support self-determination

Promote participation

Live safely at home
LTSS workforce paradigms

What characterizes workers providing LTSS?

- **Home health aide**
  - Can do healthcare tasks
  - Has technical skills
  - Agency
  - Training directed by professionals

- **Attendant**
  - Has “soft” skills
  - Follows consumer’s instructions
  - Chosen & directed by consumer
  - Independent provider

- **Agency**
- **Agency with choice**

- **CNA, LPN, etc.**

- **Social model**
- **Medical model**

- **Healthcare**
- **Social services**
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?

Sources: PHI, Washington Case Study of Personal Care Aide Training Requirements, 2016
Conclusions

• People with LTSS needs
  – Typically reside in community, often have modest needs
    • \( \frac{1}{2} \) 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