

Therapy and equipment needs of people with cerebral palsy and like disabilities in Australia

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Australian Government

**Australian Institute of
Health and Welfare**

Outline

- Estimate population of people with CP and like disabilities from national disability survey
 - Compare population group to people who use specialist CP services
 - Identify need, met need and unmet need
 - Describe barriers to meeting needs
 - Estimate the cost of unmet therapy and equipment need
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Project objectives

- Review literature about definitions, costs and benefits of therapy
 - Identify and quantify met and unmet need for therapy and equipment
 - Examine the effects of therapy and equipment on individual functioning and participation—do they make a difference?
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Main information sources

- 2003 ABS Survey of Disability, Ageing and Carers
 - Commonwealth-State/Territory Disability Agreement National Minimum Data Set
 - CP Australia agency records
 - Archetypal cases
 - Focus groups
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Estimates of cerebral palsy and like disabilities in Australia

- 33,800 in total (2003)
 - 31,800 lived in households
 - Of these, 26,500 needed help with basic daily activities
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Identifying CP-like disabilities from population data

- Who may need therapy and equipment?
 - Physical impairment → activity limitations
 - Impairments in multiple life domains
 - Barriers to participation in social and community life and employment
 - Focus on early onset
 - ▶ **acquired brain injury disability group**
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Baseline estimate of CP-like disabilities

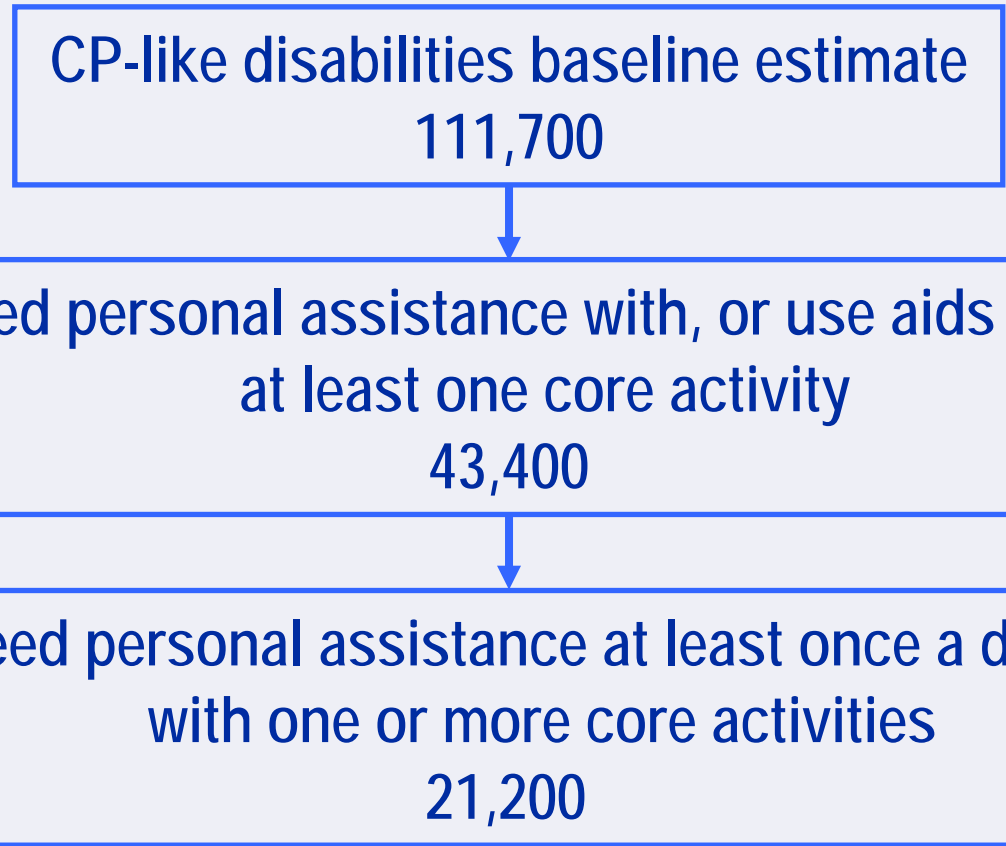
All people with ABI-related long-term conditions, with a disability
438,300

Aged under 45
171,400

Main condition occurred before age 30
138,200

With physical/diverse or hearing or speech disabilities
111,700

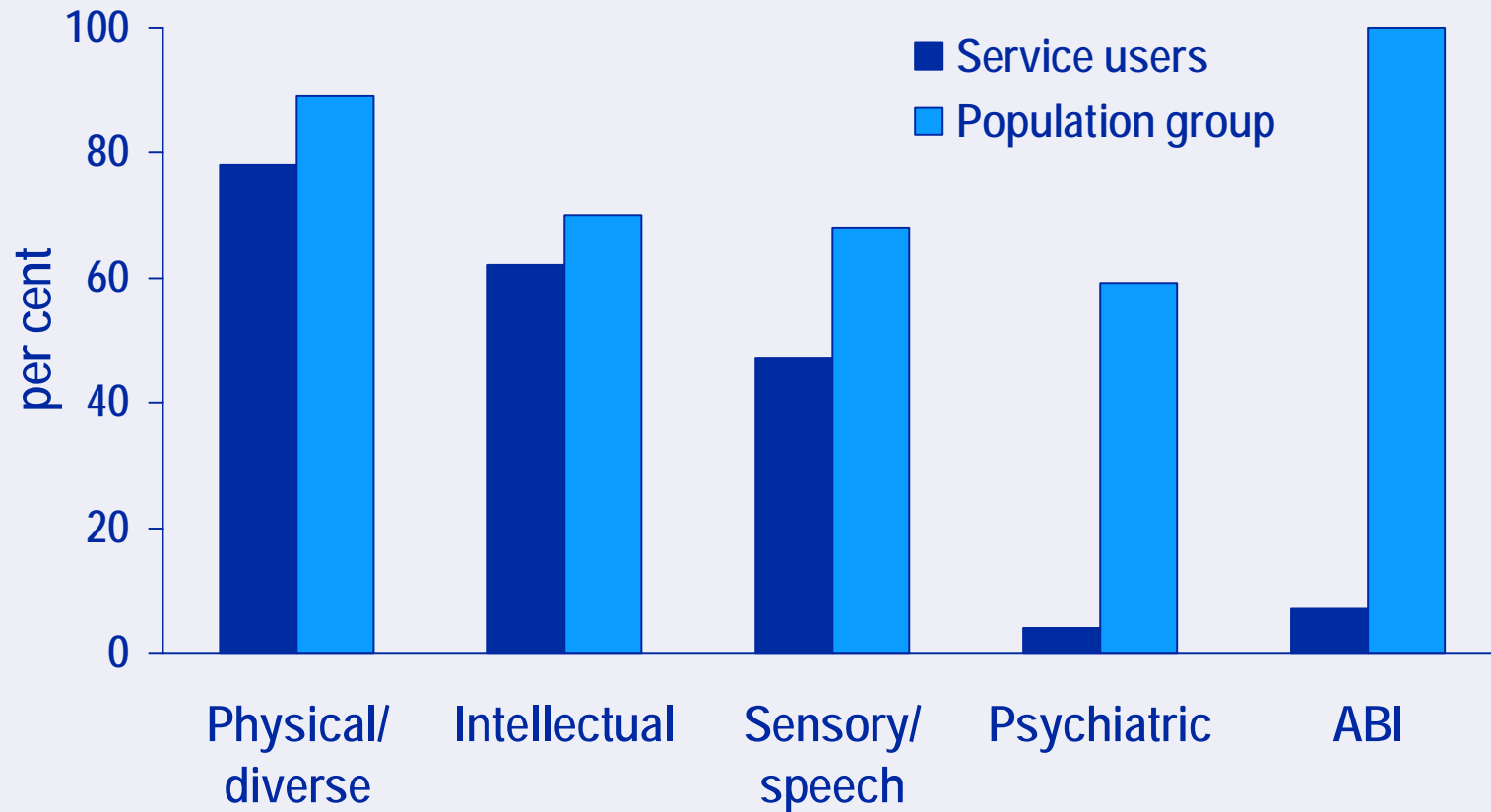
Candidates for therapy and equipment



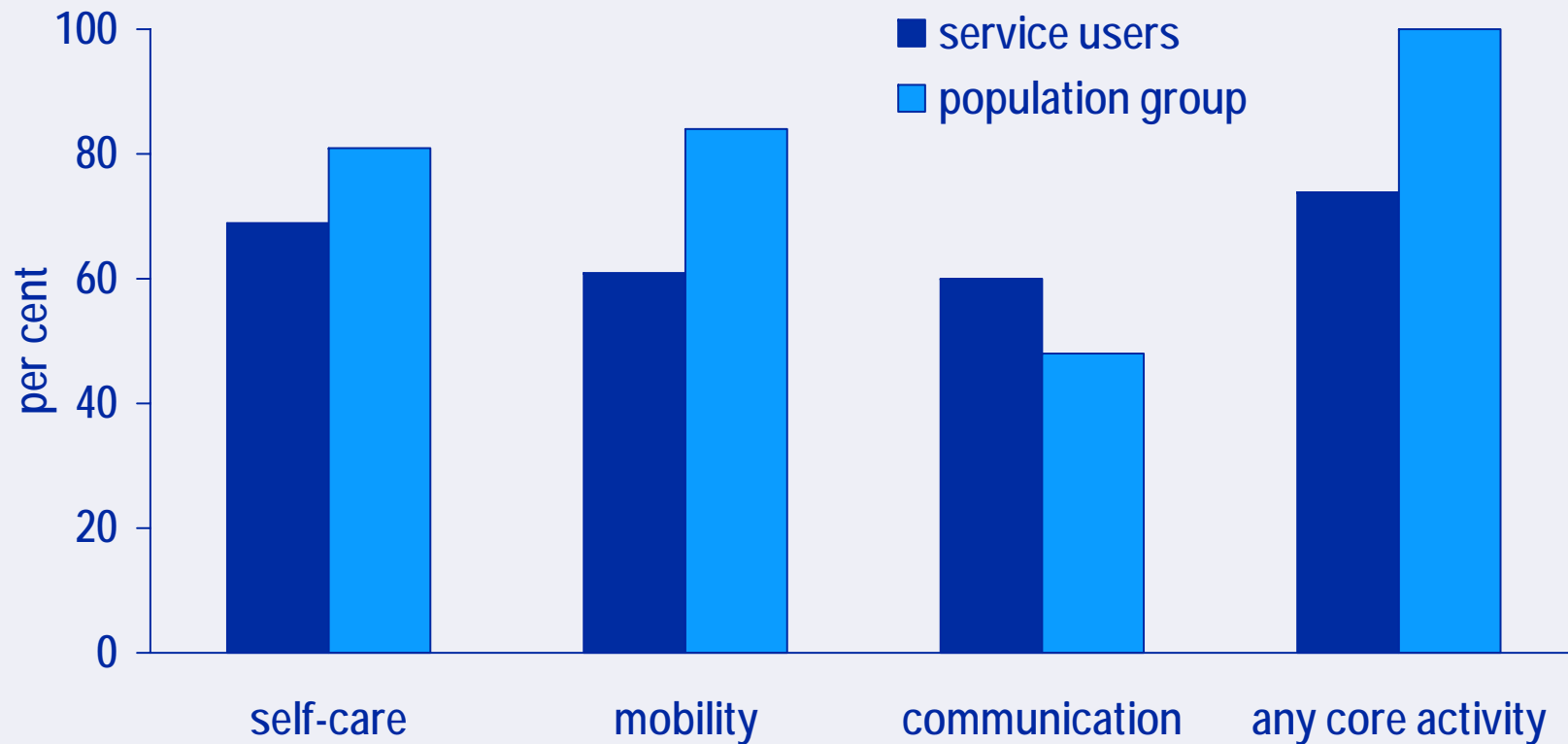
Users of CSTDA-funded services provided by CP agencies

- 7 CP agencies nationally
 - 411 service outlets
 - 9,398 service users in 2003-04
 - 58% of service users aged less than 20 years old
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Service users and CP-like population group – disability groups



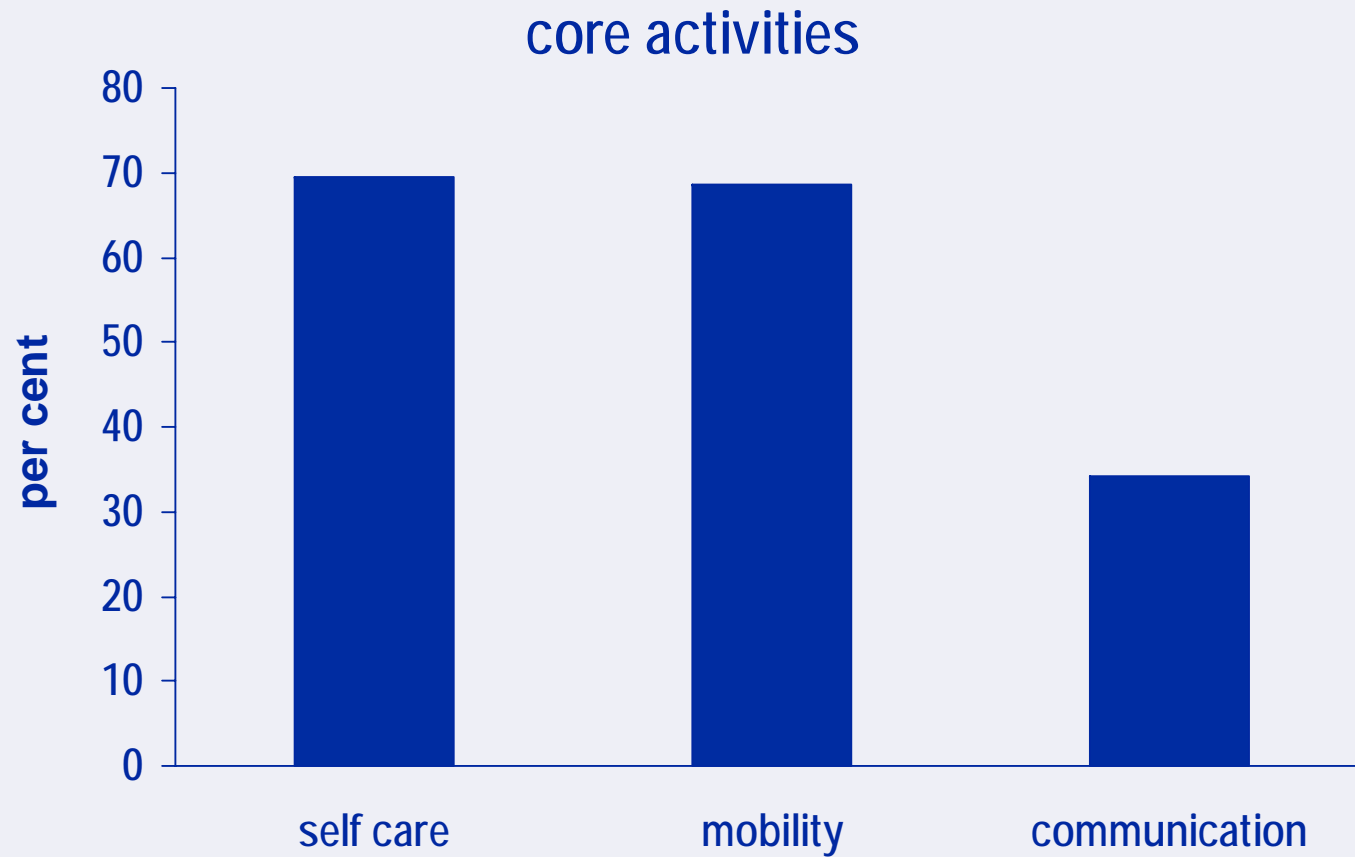
Service users and CP-like population group – support needs



Therapy and equipment needs

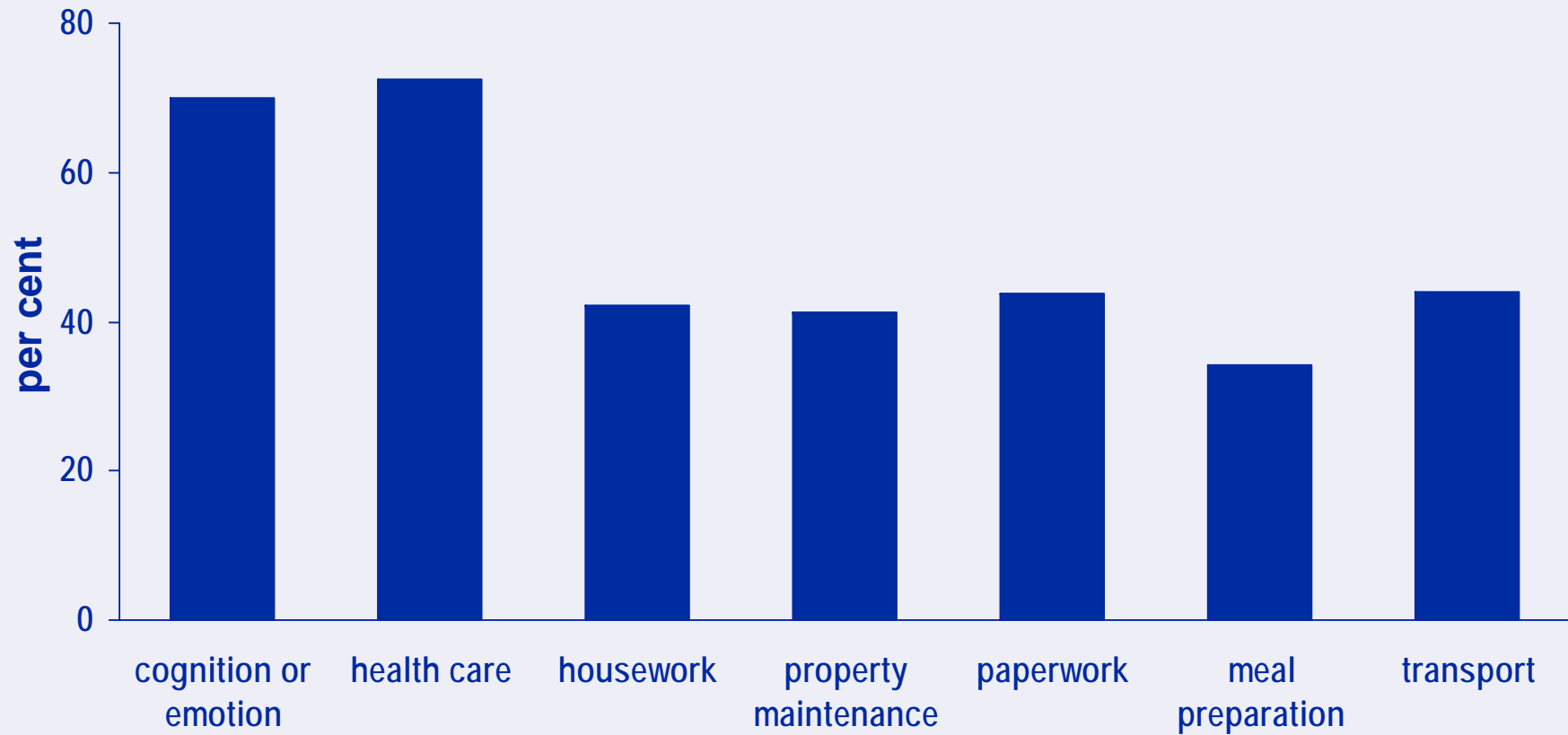
- What are the needs of people with CP and like disabilities?
 - What services are people receiving?
 - Does therapy make a difference?
 - What needs remain unmet?
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Need for assistance

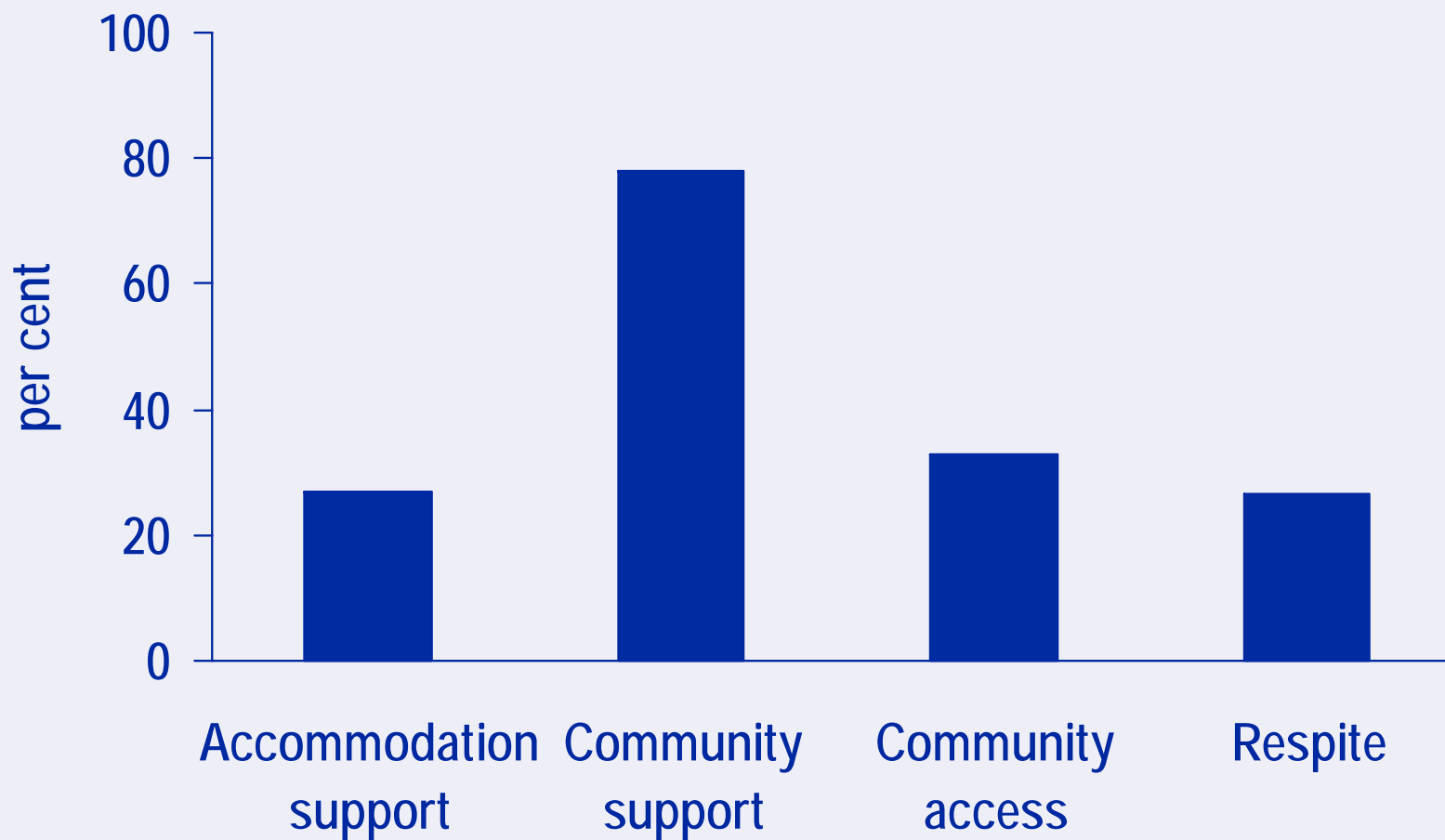


Need for assistance

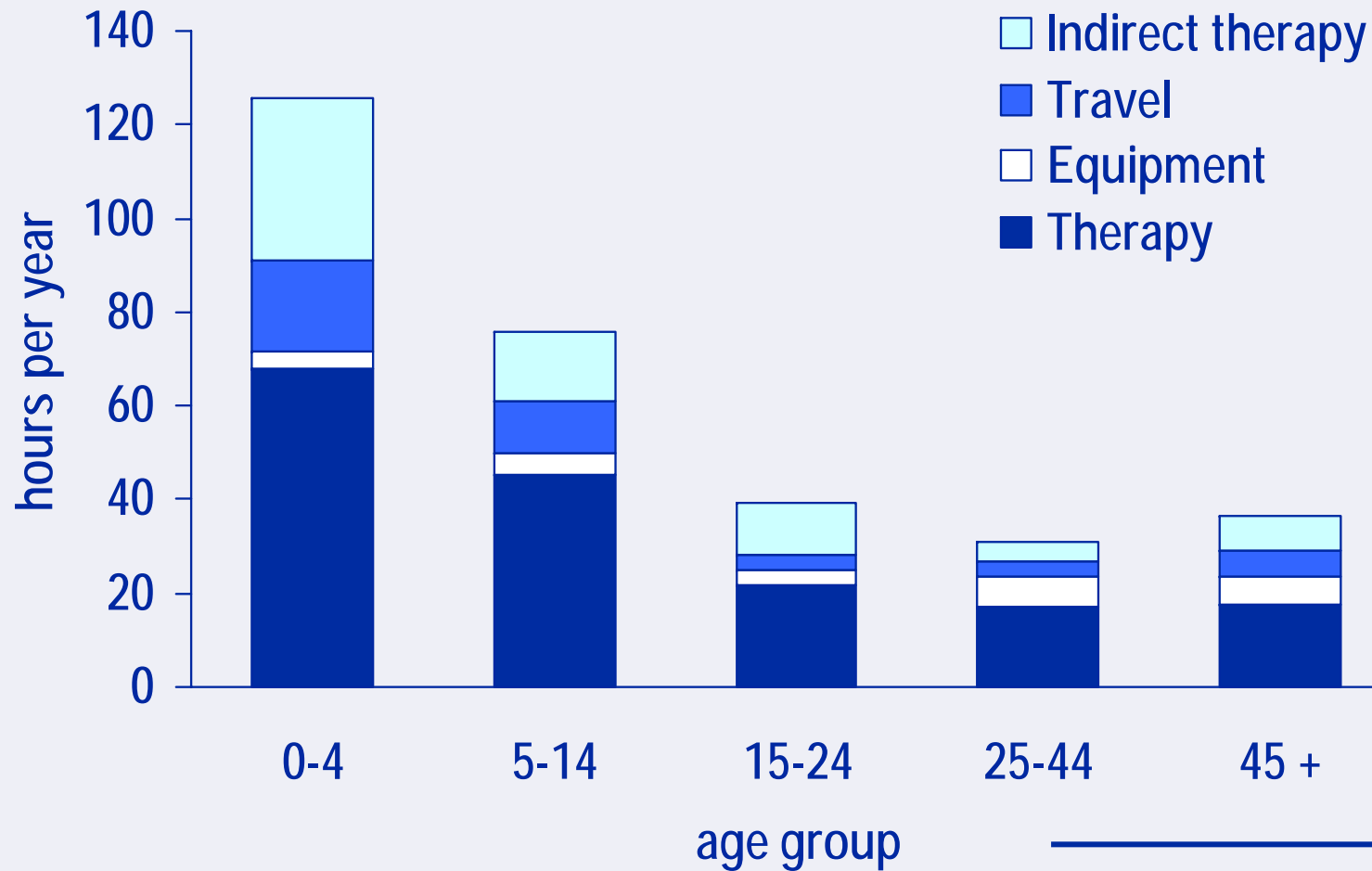
non-core activities



Services received



Services received



Benefits of therapy

“Without it, I’d be lying in bed unable to move.”

“Therapy is helping her become better integrated in society.”

“Having somebody else helping and taking the pressure off us...has untold benefits.”

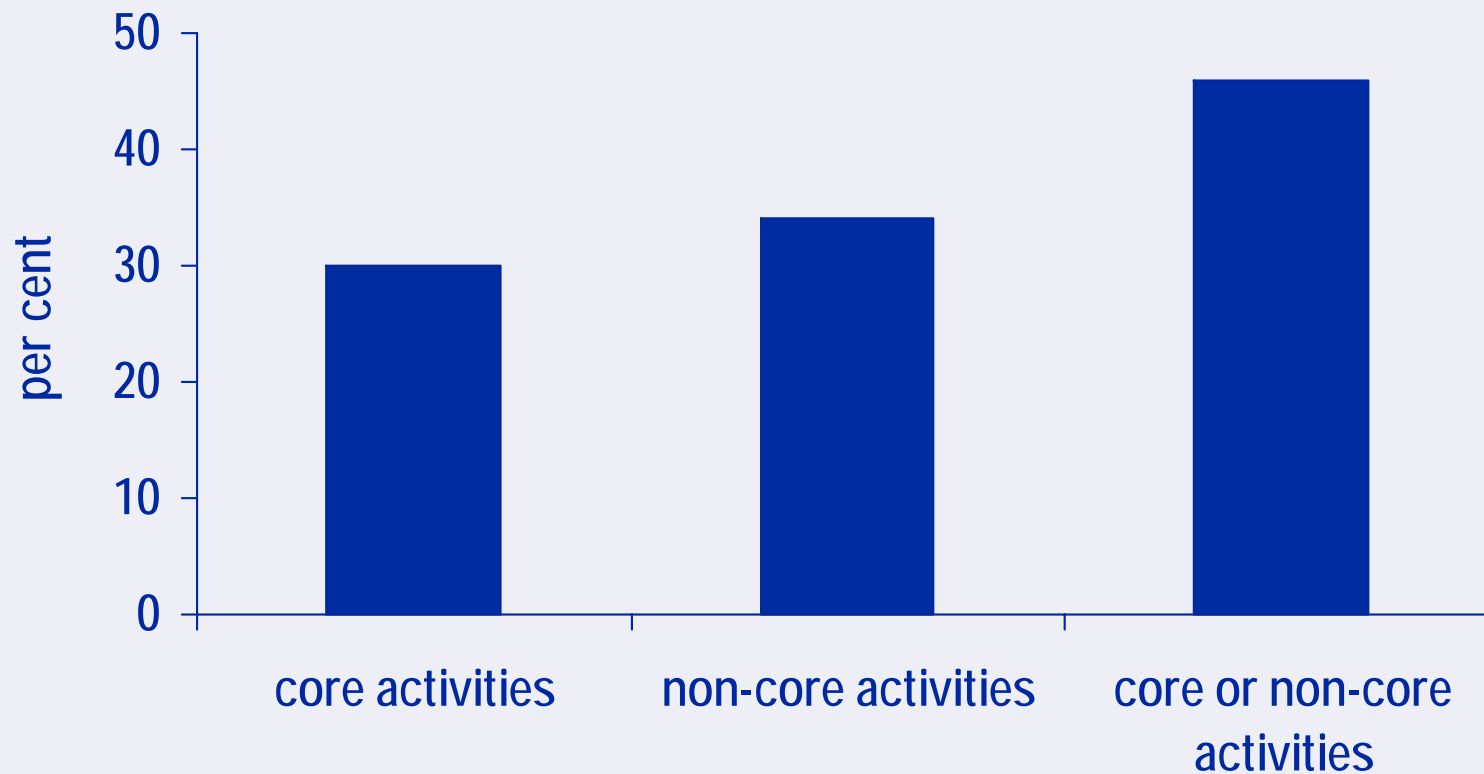
Benefits of equipment

“Equipment allows me to do the things I want to do.”

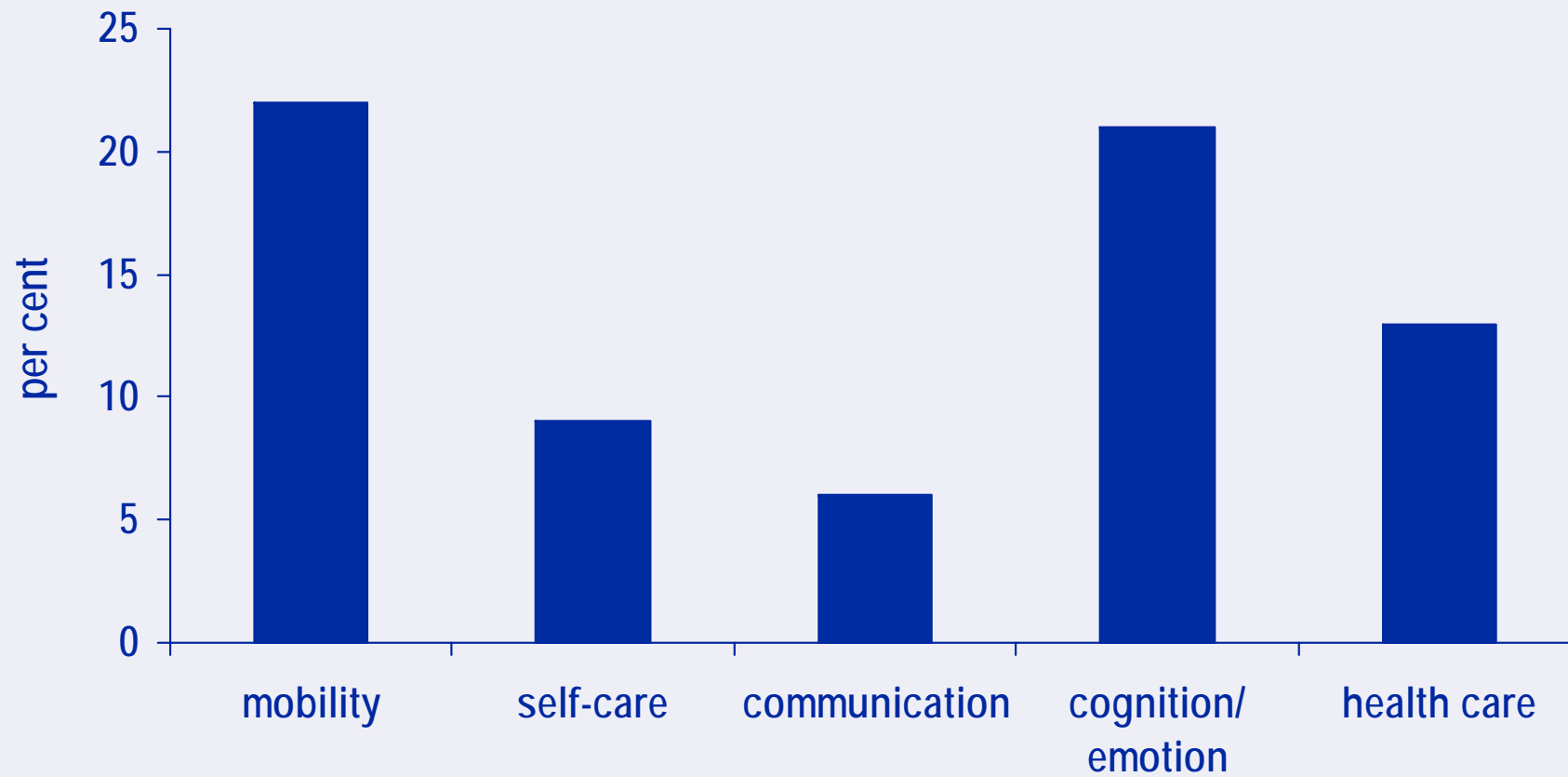
“Equipment makes it possible for people to express who they are and allows them to make lifestyle decisions.”



Partly met and unmet need



Partly met and unmet need



Barriers to receiving therapy and equipment

■ Financial considerations

“We’re all driven by the crisis situation [due to lack of funding].”

“We’d like to provide therapy rather than chase up money.”

“It’s hard to stay positive...you feel as if you are begging for everything.”

Barriers to receiving therapy and equipment

■ Lack of information and coordination

“You have to be extremely proactive. So much work is involved.”

“When you’re given all this information it’s hard for you to integrate it.”

“The system is very fragmented.”

Barriers to receiving therapy and equipment

■ Administration and regulations

“The service system doesn’t look at the person as a whole person.”

“We are bogged down in bureaucracy. We work through constraints.”

“Often the family have been through so many changes in the system that they don’t bother to ask any more.”

Waiting lists

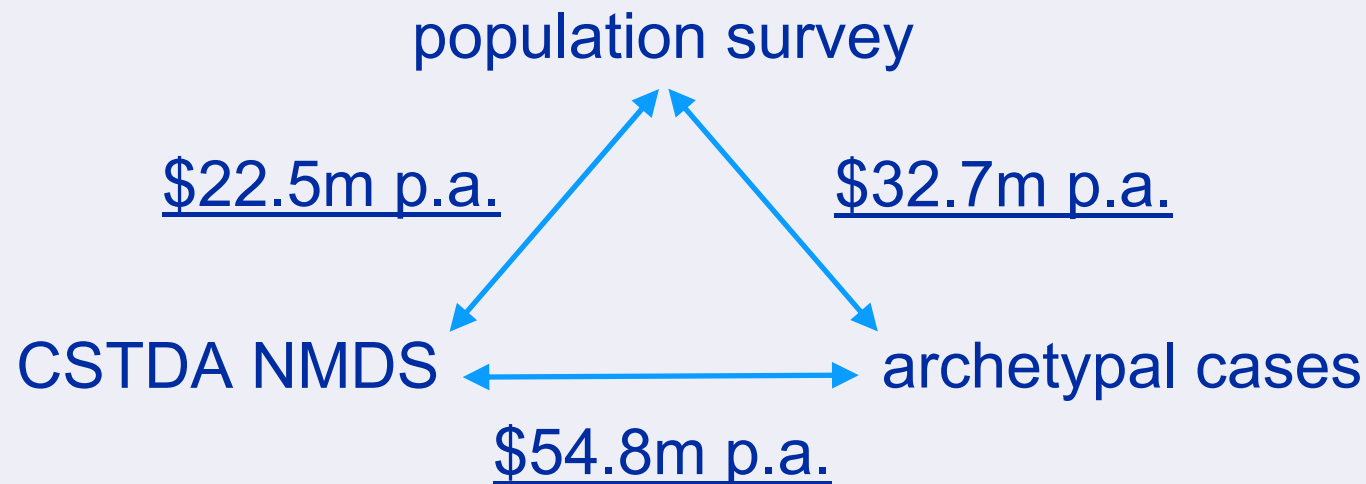
- Waiting for therapy
 - regional variation
 - prioritisation
 - particularly affects adults
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Waiting lists

- Waiting for equipment
 - eligibility rules
 - availability
 - impact of waiting for equipment
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Quantifying unmet need

- Combining data sources to estimate unmet need for therapy:



Quantifying unmet need

- Estimated cost of meeting unmet need for equipment nationally:
 - \$3.5 million to \$4.4 million p.a.
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For a copy of the full report

www.aihw.gov.au/publications
