

# RESEARCH BRIEF

## Use of health services and unmet needs among adults with cerebral palsy in Ireland

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## Executive summary

- In this study we described what health services adults with cerebral palsy (CP) used in Ireland, unmet needs and factors associated with current use of health services.
- Physiotherapy was the most commonly used and required services among adults with CP.
- Although respite was not one of the most commonly used services, 15% of those currently using it reported needing additional respite.
- Older adults were less likely to use therapy services compared to younger adults.
- Adults who use a wheelchair were more likely to use all the health services studied.
- Adults living with parents, siblings or family relatives were less likely to use personal assistance services.
- The findings highlight a need for planning and development of services to meet the needs of adults with CP, regardless of their age, mobility level or living arrangements.

## Why is this issue important?

Cerebral palsy (CP) is the most common childhood disability. However, at least 90% of children with CP survive into adulthood<sup>1</sup>.

The majority of people living with CP are adults, and we estimate that approximately 6,000 to 7,000 adults live with CP in Ireland. Although CP is defined as a non-progressive condition, adults with CP often experience complications as they age, such as functional decline, balance problems, fatigue, pain and falls<sup>2-4</sup>. Adults with CP also experience increased risk of non-communicable diseases<sup>5</sup> and mental health conditions<sup>6</sup>. Although most people living with CP are adults, coordinated health services are typically not available after childhood and adults report challenges in accessing appropriate health services to meet their needs<sup>7</sup>.

## What we did?

We conducted a secondary analysis of cross-sectional data as depicted in the figure below. The outcome 'unmet health need' was defined as services that are not provided or are inadequate<sup>8</sup>. In our analysis this included when a service was required but not currently used, as well as if an enhancement to an existing service was required.

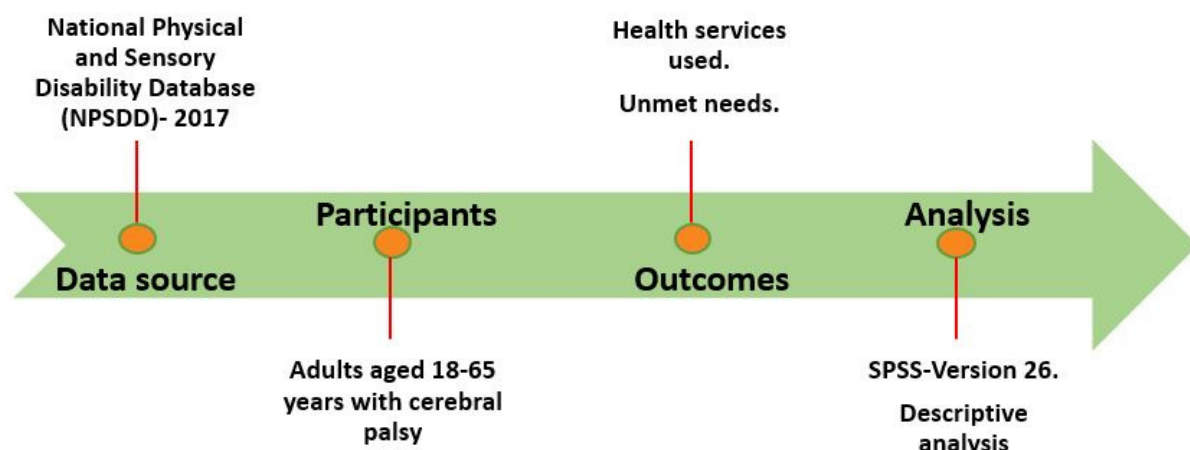


Figure 1. Study Methodology

## What did we find?

- The 1268 adults with CP included in the study used a wide range of health services in Ireland (figure 2). The most commonly used services were physiotherapy (57%) and occupational therapy (48%) services.
- Unmet need was highest for physiotherapy, with 16% requiring physiotherapy services and 7% requiring an enhancement to their current physiotherapy service.
- Among this sample, 15% of adults who used respite reported the current provision was inadequate.

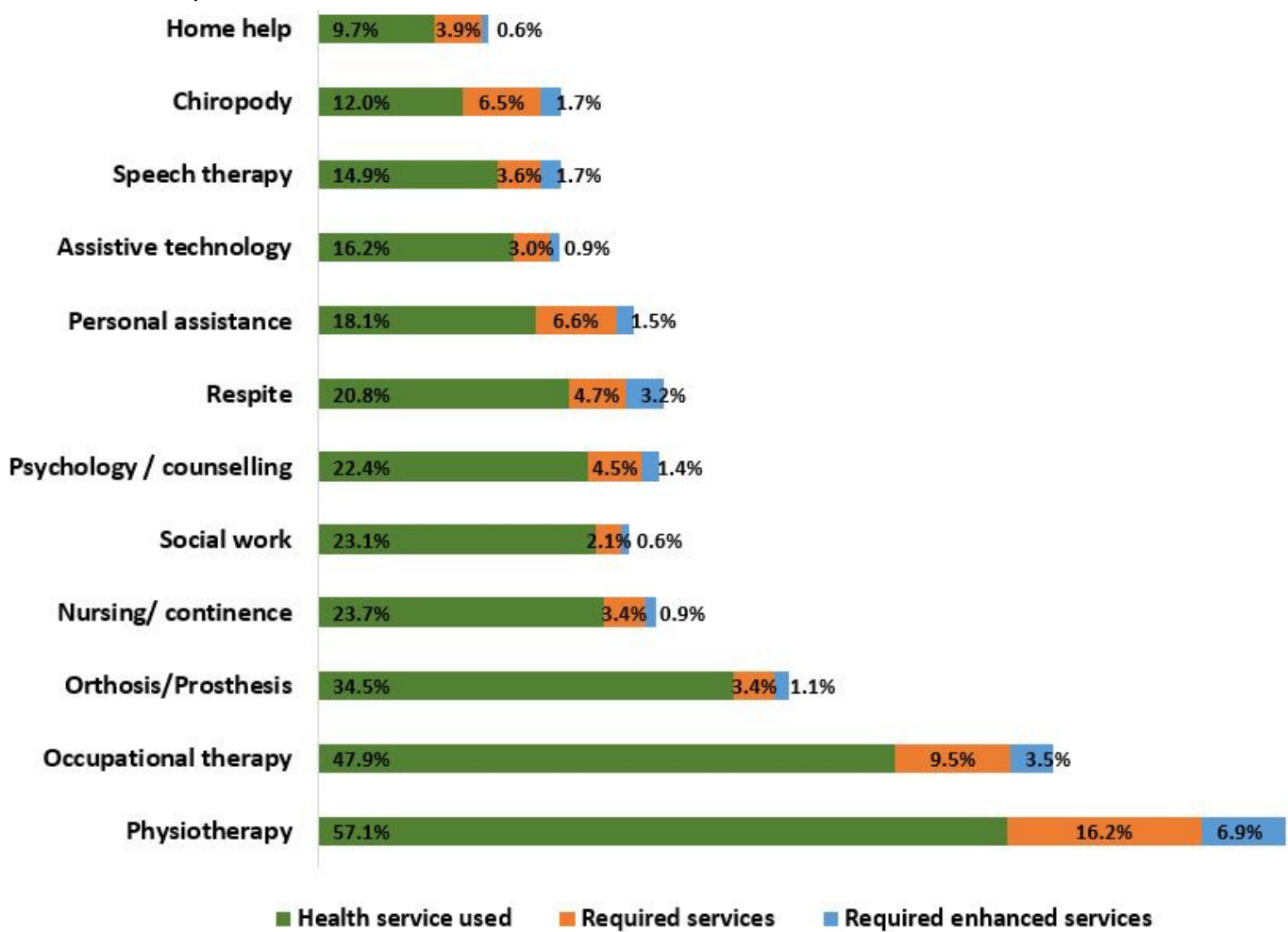


Figure 2. Health service use and Unmet needs

- All older age groups were less likely to use therapy services, compared to adults aged 18-24 years.
- Participants living with parents or siblings or family relatives were less likely to use physiotherapy, public health nursing or continence advisory and personal assistance services than people living alone.
- Adults who used a wheelchair were more likely to use all the services, than adults who did not use a wheelchair.

## Conclusion

- Adults with CP in Ireland used a wide range of health services, but many adults require services that are not currently provided.
- Our findings of a decrease in therapy use with age may indicate a lack of access to services rather than lack of need.
- Relatively high unmet need for respite and personal assistance, and association between living arrangements and current use of personal assistance and physiotherapy, suggests families are providing this support.
- Qualitative research on service use among adults with CP in Ireland is needed to fully understand the context for service use and unmet needs.
- Access to health services is a right under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (Article 25).

## Recommendations

- Many adults with CP require a range of therapeutic, specialist, respite, personal assistance, and support services, which they do not currently access.
- There is a need to develop therapeutic services based on need rather than age of people with CP.
- Adults with CP should have access to personal assistance regardless of their living arrangements.
- More research is required to identify health services currently available to adults with CP, gaps in service provision, and the experiences of using health services among adults with CP in Ireland.

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