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## ORIGINAL ARTICLE

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

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## Abstract

**Aim:** To describe use of health services, unmet needs relating to health services, and identify factors associated with service use among adults with cerebral palsy (CP) in Ireland.

**Method:** Data relating to demographics, secondary diagnoses, current use of health services and assistive devices, and unmet needs for both were obtained on adults with CP from the National Physical and Sensory Disability Database. Logistic regression was used to identify factors associated with service use.

**Results:** A total of 1268 adults with CP were included in this study. Over half were male (56%) and 78% lived with parents, siblings, or other family relatives. Physiotherapy, occupational therapy, and orthotics/prosthetic services were the most commonly used services, used by 57%, 48%, and 35% of the sample respectively. Unmet needs were highest for physiotherapy (23%) and occupational therapy services (13%). Age, sex, living arrangements, and wheelchair use were frequently associated with current service use.

**Interpretation:** Adults with CP used a wide range of health services and unmet needs were reported for all services. The findings highlight a need for planning and development of services to meet their needs, regardless of their age, mobility level, or living arrangements.

Cerebral palsy (CP) is a common childhood neurodevelopmental condition. Although motor impairments are a key feature,<sup>1</sup> individuals with CP also experience associated impairments such as epilepsy, cognitive, visual, hearing, or speech impairments.<sup>1,2</sup> Most children with CP survive well into adulthood.<sup>3</sup> As adults, those with CP may experience several comorbidities including pain and decline in their mobility.<sup>4,5</sup> However, it has been reported that health service use by individuals with CP decreases following transition from child to adulthood, possibly because of lack of available health service.<sup>6,7</sup>

A mixed-methods systematic review found that adults with CP visit a range of health professionals such as general practitioners, dentists, physiotherapists, occupational therapists, rehabilitation specialists, speech and language therapists, and psychologists.<sup>8</sup> However, most studies described health service use in relatively small samples (< 300 adults), which may result in imprecise estimates of the proportion using each service.<sup>8</sup> Studies that included larger samples were limited to young adults<sup>9–11</sup> or focused on specialist medical services, emergency department visits, general practitioners, and inpatient and outpatient services.<sup>12,13</sup> There is still a lack of evidence about

**Abbreviations:** CHO, community health care organization; NIDD, National Intellectual Disability Database;; NPSDD, National Physical and Sensory Disability Database;; SLT, speech and language therapy..

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the use of therapy, respite, personal assistance, and support services in a large sample of adults with CP across all ages. Further, few studies examined the association between health service use and characteristics of adults with CP,<sup>8</sup> which may improve our understanding of the barriers and facilitators to service use. Characteristics examined were limited to sex, functional mobility, poverty status, pain, fatigue, use of mobility device, anatomical distribution of CP, presence of other health conditions, and impairments such as speech and cognitive impairment among adults with CP.<sup>8,14,15</sup>

The systematic review also highlighted that adults experienced context-specific challenges in accessing needed services.<sup>8</sup> These challenges may result in unmet health needs. A health need occurs when a person requires a health service to minimize the impact of their condition or manage their functional disability.<sup>16</sup> This becomes an unmet health need if the individual reports the service is not provided or is inadequate.<sup>16</sup> Although unmet needs are widely used as an indicator of service delivery and resource allocation,<sup>16,17</sup> there is a lack of studies describing unmet needs for a range of health services among adults with CP. A study of adults with CP from the USA found that only half of those who needed physical rehabilitation received it.<sup>18</sup> Young adults from the Netherlands reported unmet needs relating to information (79%), mobility (66%), and health care (66%), which included a need for more physiotherapy services.<sup>19</sup>

Although an understanding of health service use, characteristics associated with service use, and unmet needs among adults with CP may support service development and delivery, there are gaps in the current evidence base. Therefore, this study aimed to describe current health service use and related unmet needs among adults with CP in Ireland. A secondary aim was to identify characteristics associated with health service use. Specifically, we examined associations between health service use and age, sex, living arrangements, epilepsy, speech and language disorders, intellectual disability, hearing or visual impairments, and wheelchair use. We hypothesized that adults with CP have high unmet need because of ageing and lack of access to services. We also hypothesized that age is negatively associated with health service use and that wheelchair users and people with secondary impairment are more likely to use health services.

## METHOD

### Study design

This study was a secondary analysis of cross-sectional data from the Irish National Physical and Sensory Disability Database (NPSDD) collected in 2017.

### Data source

The NPSDD is a voluntary database of people with physical and sensory disabilities, which includes data on current

### What this paper adds

- Adults with cerebral palsy (CP) in Ireland used a wide range of therapeutic, respite, personal assistance, and support services.
- Unmet needs were highest for physiotherapy and occupational therapy services.
- Adults aged 25 years and above were less likely to use therapy services compared with younger adults.
- Adults living with parents, siblings, or family relatives were less likely to use personal assistance and physiotherapy services.

use and requirement for specialized health and personal social services.<sup>20</sup> It has been managed by the Health Research Board for disability service planning in Ireland since 2002.<sup>20</sup> The total number of people with physical and sensory disabilities aged 18 to 65 years, registered on the NPSDD in 2017 was 20 676.<sup>20</sup> It includes data on the range of health and personal social services, additional to generic services, which may be required by people with physical or sensory disabilities for the purpose of achieving health and social gain and maximum quality of life.<sup>20</sup> These services may be provided by, on behalf of, or in partnerships with the Health Service Executive, which is the publicly funded health care system in Ireland.<sup>21</sup>

The NPSDD includes anonymized data on people who are using services at the time of data collection or would require services in the following 5 years.<sup>20</sup> Regional disability database teams are responsible for collating data from providers of services to people with physical and sensory disabilities that are funded by the Health Service Executive.<sup>20,22</sup> The current administrative regional structures are aligned geographically into nine community health care organizations (CHOs).<sup>23</sup> A key worker or a named person from the service provider who knows their service user well interviews the service user and inputs data into the web-based system.<sup>22</sup> The people responsible for inputting data received training on data collection procedures. The data collected from the service providers are submitted to the Health Research Board annually.<sup>20</sup> Data include information on primary and secondary diagnosis (categorized according to the International Classification of Diseases, 10th Revision), demographics, and use of and requirements for therapeutic intervention and rehabilitation services, personal assistance and support services, respite and residential services, and assistive devices.<sup>20,24</sup>

Those whose data are included on the NPSDD provided consent for the data to be used for service planning and research.<sup>22</sup> Data are anonymized before being accessed at a national level. For this study, raw data were only accessible to the Health Research Board research team. Ethical approval for this analysis was obtained from the Royal College

of Surgeons in Ireland Research Ethics Committee (REC 201911010).

## Participants

Data on all adults aged 18 to 65 years with a primary or secondary diagnosis of CP were extracted from the NPSDD. Data on the following participant characteristics were extracted: age (categorized as 18–24y; 25–34y; 35–44y; 45–54y; and 55–65y), sex, area of residence categorized according to CHO, living arrangements (categorized as living alone; living with spouse or partner and/or children; living with parents, siblings, or other family relatives; living full-time in a residential service; living with non-relatives [e.g. friends and neighbours, foster family, and other]); and presence of epilepsy, speech and language disability, intellectual disability, hearing impairment, or visual impairment. The Health Research Board also manages an additional database for disability planning in relation to people with intellectual disabilities: the National Intellectual Disability Database (NIDD). Those with CP and intellectual disability are likely to be included in the NIDD rather than the NPSDD and are therefore not included in this analysis. As diagnosis is not recorded in the NIDD, we were unable to identify adults with CP and intellectual disability in the NIDD to include in this study. The latest data collected from the NPSDD were in 2017, after which the NPSDD was merged with the NIDD into the National Ability Support System database in 2019.<sup>25</sup> Owing to the challenges with data collection and COVID-19, coverage of people with CP in the National Ability Support System database was considerably less than coverage of people with CP in NPSDD.

## Outcomes

Data were obtained on the number of people (1) using assistive devices and (2) requiring assistive devices (i.e. those who required an assessment for the assistive product or had an assessment but had not received the assistive product). Data were also obtained on the number of people currently using the following services: physiotherapy; occupational therapy; speech and language therapy (SLT); psychology or counselling; chiropody; clinical nutrition; orthotics or prosthetics; public health nursing or continence advisory; social work; complementary therapy; personal assistance; home help; home care assistance; respite services; and assistive technology or client technology services. Respite services included planned residential respite with high/low support, planned home-based respite, or holiday respite.

For each service, people also reported if (1) the service was not required; (2) an assessment was required; (3) the service was required: they were assessed and on a waiting list; (4) the service was required: they were assessed but unable to benefit from services; (5) they were assessed as requiring an enhancement to their current services; (6) they

**TABLE 1** Participant characteristics (*n*=1268)

Characteristic		<i>n</i>	%
Age, years	18–24	416	32.8
	25–34	348	27.4
	35–44	204	16.0
	45–54	175	13.8
	55–65	125	9.9
Sex	Male	709	55.9
	Female	559	44.1
Area of residence	CHO Area 1 (Donegal, Sligo/Leitrim, West Cavan, Cavan/Monaghan)	93	7.3
	CHO Area 2 (Galway, Roscommon, Mayo)	99	7.8
	CHO Area 3 (Clare, Limerick, North Tipperary/East Limerick)	78	6.2
	CHO Area 4 (Kerry, North Cork, North Lee, South Lee, West Cork)	293	23.1
	CHO Area 5 (South Tipperary, Carlow/Kilkenny, Waterford, Wexford)	99	7.8
	CHO Area 6 (Wicklow, Dun Laoghaire, Dublin South East)	101	8.0
	CHO Area 7 (Kildare/West Wicklow, Dublin West, Dublin South City, Dublin South West)	202	15.9
	CHO Area 8 (Laois/Offaly, Longford/Westmeath, Louth, Meath)	150	11.8
	CHO Area 9 (Dublin North, Dublin North Central, Dublin North West)	153	12.1
Living arrangements	Parents, siblings, or other family relatives	981	77.3
	Alone	110	8.7
	Full-time residential service	90	7.0
	Spouse, partner, and/or children	61	4.8
	Non-relative (friends, neighbours, foster family, and other)	26	2.0
Secondary diagnosis	Epilepsy	105	8.3
	Visual impairment	58	4.6
	Speech impairment	47	3.7
	Hearing impairment	42	3.3
	Intellectual disability	20	1.6

CHO, community health care organization.

required assessment for enhanced services; (7) they were assessed as requiring enhanced service but unable to benefit from services. An enhanced service is when an individual is

**TABLE 2** Use and unmet needs relating to assistive devices ( $n=1268$ )

Assistive devices category	Type of equipment/device	Current use, $n$ (%)	Required assistive devices, $n$ (%)
Mobility (wheelchair/dexterity)	Powered wheelchair	291 (22.9)	39 (3.1)
	Manual regular wheelchair	279 (22.0)	12 (0.9)
	Manual specialized wheelchair	239 (18.8)	19 (1.5)
	Grab rails and bars	144 (11.3)	13 (1)
	Adapted vehicles	106 (8.4)	11 (0.9)
Orthotics and prosthetics	Lower limb orthosis	264 (20.8)	23 (1.8)
	Orthopaedic footwear	223 (17.6)	26 (2.0)
	Upper limb orthosis	87 (6.9)	8 (0.6)
	Upper or lower limb prosthesis	2 (0.2)	–
Vision	Special computer equipment	22 (1.7)	6 (0.5)
	Print display magnification	7 (0.6)	–
	Magnifier	5 (0.4)	–
	Audible/tactile devices	4 (0.3)	–
Hearing	Hearing aids	42 (3.3)	6 (0.5)
	Alerting devices	10 (0.8)	–
	Personal listening devices	4 (0.3)	–
	Fax or telephone	3 (0.2)	–
Communication	High-tech communication device	42 (3.3)	7 (0.6)
	Low-tech communication device	20 (1.6)	–
	Assistive products for training in alternative and augmentative communication	2 (0.2)	–
Home/activities of daily living	Powered beds	170 (13.4)	7 (0.6)
	Powered hoist	126 (9.9)	9 (0.7)
	Specialized chairs	81 (6.4)	11 (0.9)
	Adapted toilet seats	51 (4)	–
	Pressure relieving mattress	50 (3.9)	–
	Manual bath aids	37 (2.9)	–
	Aids for grasping, holding, and reaching	15 (1.2)	7 (0.6)
	Kitchen aids	14 (1.1)	5 (0.4)
	Stair lifts	9 (0.7)	5 (0.4)

Cells with fewer than five counts are not reported.

currently using the service but requires further assessment and/or intervention. We identified the number of people requiring a service by combining those who reported options 2 to 4. We calculated the number of people requiring enhanced services by combining those who reported options 5 to 7. Further information on this is available in Appendix S1. According to our definition of unmet needs ('when a person requires a health service to minimize the impact of their condition or manage their functional disability but the individual reports the service is not provided or is inadequate'),<sup>16</sup> people who reported options 2 to 7 had an unmet need.

## Data analysis

A data analysis plan was prepared by researchers at the Royal College of Surgeons in Ireland. Analysis was conducted by a

researcher at the Health Research Board using SPSS version 26 (IBM Corp. 2019, Armonk, NY, USA). Data were summarized using frequencies and percentages. Logistic regression was used to examine characteristics associated with use of physiotherapy, occupational therapy, SLT, psychology or counselling, public health nursing or continence advisory services, personal assistance, and assistive technology or client technical services. Characteristics examined were age, sex, living arrangements, ambulatory status, and presence of epilepsy, intellectual disability, speech and language disability, hearing impairment, or visual impairment. For each service, separate logistic regression models were fitted with service use as the dependent variable and all characteristics entered as independent variables. Similarly, logistic regression was used to examine characteristics associated with unmet needs relating to physiotherapy, occupational therapy, SLT, psychology or counselling, public health nursing

or continence advisory services, personal assistance, and assistive technology or client technical services. The outcome was presence of an unmet need relating to the service. We assessed the logistic regression model fit using a Hosmer–Lemeshow test, where  $p$ -values greater than 5% indicated no evidence of poor fit.

## RESULTS

This study included 1268 adults with CP (Table 1). One-third of the sample was aged 18 to 24 years and 56% were male. Participants were from all geographical areas in Ireland. The distribution of participants across CHOs was similar to the distribution of the general population across CHOs, except CHO 4 (Table S1). Most participants lived with parents, siblings, or other family relatives (77%). Seventy per cent ( $n=892$ ) reported living with a primary carer. Of these, 90% reported the primary carer was a parent. Fifty-eight per cent of primary carers were aged 19 to 49 years, 26% were aged 50 to 59 years, 11% were 60 to 69 years, and 5% were 70 years or over. Approximately 8% of adults had a secondary diagnosis of epilepsy, 5% had visual impairment, 4% had speech and language disability, 3% had hearing impairment, and 2% had an intellectual disability.

### Assistive devices

Use of and need for assistive devices are described in Table 2. Almost half of participants (46%) used at least one type of wheelchair. Almost one-quarter (23%) of participants used a powered wheelchair, 22% used a manual regular wheelchair,

and 19% used a manual specialized wheelchair. Twenty-one per cent used lower limb orthoses and 18% used orthopaedic footwear. The most commonly used aids for hearing, communication, and vision were hearing aids (3%), high-tech communication devices (3%), and special computer equipment (2%) respectively. Use of powered beds (13%) and powered hoists (10%) were the most commonly used aids relating to home adaptations or activities of daily living. A powered wheelchair was the most commonly required aid (3%), followed by orthopaedic footwear (2%) and lower limb orthosis (2%).

### Health services

Current use of each service, need for a service, and need for an enhanced service are presented in Table 3. Physiotherapy was most commonly used (57%), followed by occupational therapy (48%), orthotics or prosthetics services (35%), and public health nursing or continence advisory (24%). Home care assistance, complementary therapy services, clinical nutrition, and home help were the least commonly used services.

The most commonly required services were physiotherapy (16%), occupational therapy (10%), personal assistance (7%), and chiropody (7%) (Table 3). The enhanced services were required most commonly for physiotherapy (7%) and occupational therapy (4%). The unmet needs were most commonly reported for physiotherapy (23%), occupational therapy (13%), and chiropody (8%) services. The proportion of enhanced services among those using services are described in Table S2.

Characteristics associated with health service use are presented in Table 4. When we fitted logistic regression

**TABLE 3** Health service use and unmet need ( $n=1268$ )

Service	Current use, $n$ (%)	Required service, $n$ (%)	Required enhanced service, $n$ (%)	Unmet need, $n$ (%)
Physiotherapy	724 (57.1)	206 (16.2)	87 (6.9)	293 (23.1)
Occupational therapy	608 (47.9)	121 (9.5)	45 (3.5)	166 (13.1)
Orthotics and prosthetics	438 (34.5)	43 (3.4)	14 (1.1)	57 (4.5)
Public health nursing or continence advisory	301 (23.7)	43 (3.4)	12 (0.9)	55 (4.3)
Social work	293 (23.1)	27 (2.1)	8 (0.6)	35 (2.7)
Psychology or counselling	284 (22.4)	57 (4.5)	18 (1.4)	75 (5.9)
Respite services <sup>a</sup>	264 (20.8)	59 (4.7)	40 (3.2)	99 (7.9)
Personal assistance	229 (18.1)	84 (6.6)	19 (1.5)	103 (8.1)
Assistive technology/client technology	206 (16.2)	38 (3.0)	12 (0.9)	50 (3.9)
Speech and language therapy	189 (14.9)	46 (3.6)	22 (1.7)	68 (5.3)
Chiropody	152 (12.0)	82 (6.5)	21 (1.7)	103 (8.2)
Home help	123 (9.7)	50 (3.9)	8 (0.6)	58 (4.5)
Clinical nutrition	121 (9.5)	38 (3.0)	3 (0.2)	41 (3.2)
Complementary therapy	114 (9.0)	63 (5.0)	11 (0.9)	74 (5.9)
Home care assistance	91 (7.2)	30 (2.4)	7 (0.6)	37 (3.0)

<sup>a</sup>Includes planned residential respite with high/low support serviced, use of planned home-based respite, and holiday respite services.

**TABLE 4** Characteristics associated with current use of health services ( $n=1268$ )

Factor	Physiotherapy OR (95% CI); $p$	Occupational therapy OR (95% CI); $p$	Speech and language therapy OR (95% CI); $p$
Age, years			
18–24	(Reference)	(Reference)	(Reference)
25–34	<b>0.30 (0.21–0.42); &lt;0.001</b>	<b>0.27 (0.20–0.38); &lt;0.001</b>	<b>0.27 (0.18–0.41); &lt;0.001</b>
35–44	<b>0.13 (0.09–0.19); &lt;0.001</b>	<b>0.21 (0.14–0.32); &lt;0.001</b>	<b>0.11 (0.06–0.22); &lt;0.001</b>
45–54	<b>0.13 (0.08–0.20); &lt;0.001</b>	<b>0.18 (0.11–0.28); &lt;0.001</b>	<b>0.10 (0.05–0.23); &lt;0.001</b>
55–65	<b>0.15 (0.09–0.24); &lt;0.001</b>	<b>0.33 (0.20–0.54); &lt;0.001</b>	<b>0.09 (0.03–0.23); &lt;0.001</b>
Sex			
Male	(Reference)	(Reference)	<b>1.58 (1.11–2.27); 0.012</b>
Female	1.23 (0.96–1.57); 0.103	1.07 (0.84–1.37); 0.579	(Reference)
Living arrangements			
Alone	(Reference)	(Reference)	(Reference)
Spouse or partner and/or children	<b>0.40 (0.20–0.79); 0.008</b>	0.63 (0.31–1.30); 0.211	3.95 (0.61–25.37); 0.148
Parents, siblings, or other family relatives	<b>0.57 (0.36–0.89); 0.014</b>	0.86 (0.53–1.39); 0.530	3.13 (0.72–13.68); 0.130
Non-relative (friends, neighbours, foster family, and other)	0.67 (0.27–1.72); 0.408	2.05 (0.78–5.39); 0.147	<b>8.04 (1.36–47.47); 0.021</b>
Full-time residential service	0.73 (0.41–1.31); 0.292	1.06 (0.58–1.96); 0.844	<b>7.24 (1.54–34.11); 0.012</b>
Epilepsy			
Absence	(Reference)	(Reference)	(Reference)
Presence	0.77 (0.49–1.19); 0.243	0.95 (0.61–1.49); 0.831	1.42 (0.79–2.56); 0.237
Speech problems and language disorder			
Absence	(Reference)	(Reference)	(Reference)
Presence	1.38 (0.68–2.78); 0.372	<b>2.16 (1.05–4.43); 0.036</b>	<b>6.59 (3.38–12.83); &lt;0.001</b>
Intellectual disability			
Absence	(Reference)	(Reference)	(Reference)
Presence	2.14 (0.73–6.31); 0.167	1.01 (0.39–2.66); 0.979	<b>2.92 (1.01–8.47); 0.048</b>
Hearing impairment			
Absence	(Reference)	(Reference)	(Reference)
Presence	0.73 (0.37–1.43); 0.357	0.72 (0.36–1.46); 0.365	0.79 (0.23–2.73); 0.704
Visual impairment			
Absence	(Reference)	(Reference)	(Reference)
Presence	1.16 (0.64–2.10); 0.620	1.00 (0.56–1.79); 0.997	0.72 (0.31–1.69); 0.448
Wheelchair use			
Absence	(Reference)	(Reference)	(Reference)
Presence	<b>2.01 (1.55–2.61); &lt;0.001</b>	<b>4.48 (3.43–5.85); &lt;0.001</b>	<b>2.60 (1.81–3.74); &lt;0.001</b>

Bold type indicates  $p < 0.05$ . OR, odds ratio; CI, confidence interval.

models with each service as the dependent variable, we found the following results. We checked the model fit using the Hosmer–Lemeshow test and there was no evidence of poor model fit. Odds ratios for each characteristic were adjusted for all other characteristics in the model. Adults who used a wheelchair were more likely to use all services examined, compared with adults who did not use a wheelchair. Adults aged 25 to 34 years, 35 to 44 years, 45 to 54 years, and 55 to 65 years were less likely to use physiotherapy, occupational therapy, SLT, psychology or counselling, and

assistive technology or client technology services than 18- to 24-year-olds. Conversely, adults aged 55 years and over were 2.16 times (95% confidence interval [CI] 1.27–3.66) more likely to use the public health nursing or continence advisory than adults aged 18 to 24 years. Males were 1.58 times (95% CI 1.11–2.27) more likely to use SLT than females, and females were 1.40 times (95% CI 1.06–1.86) more likely to use public health nursing or continence advisory than males. Participants living with ‘parents, siblings, or family relatives’ were less likely to use physiotherapy, public

Psychology or counselling OR (95% CI); <i>p</i>	Public health nursing or continence advisory OR (95% CI); <i>p</i>	Personal assistance OR (95% CI); <i>p</i>	Assistive technology/client technology OR (95% CI); <i>p</i>
(Reference)	(Reference)	(Reference)	(Reference)
<b>0.33 (0.23–0.46); &lt;0.001</b>	0.80 (0.54–1.18); 0.258	1.38 (0.88–2.15); 0.156	<b>0.59 (0.39–0.89); 0.012</b>
<b>0.21 (0.13–0.35); &lt;0.001</b>	1.51 (0.98–2.32); 0.059	<b>1.73 (1.06–2.83); 0.029</b>	<b>0.47 (0.28–0.78); 0.003</b>
<b>0.15 (0.08–0.26); &lt;0.001</b>	1.36 (0.85–2.18); 0.201	1.34 (0.78–2.30); 0.297	<b>0.37 (0.21–0.66); 0.001</b>
<b>0.13 (0.06–0.26); &lt;0.001</b>	<b>2.16 (1.27–3.66); 0.005</b>	1.24 (0.67–2.32); 0.496	<b>0.33 (0.17–0.65); 0.001</b>
(Reference)	(Reference)	(Reference)	(Reference)
0.99 (0.75–1.32); 0.953	<b>1.40 (1.06–1.86); 0.017</b>	1.26 (0.92–1.73); 0.146	1.14 (0.83–1.58); 0.414
(Reference)	(Reference)	(Reference)	(Reference)
0.42 (0.13–1.33); 0.139	<b>0.35 (0.16–0.75); 0.007</b>	0.66 (0.28–1.54); 0.333	0.71 (0.25–2.02); 0.518
0.65 (0.35–1.20); 0.166	<b>0.50 (0.31–0.80); 0.004</b>	<b>0.56 (0.32–0.97); 0.039</b>	0.79 (0.41–1.53); 0.485
1.35 (0.47–3.82); 0.578	1.88 (0.74–4.79); 0.185	1.33 (0.45–3.88); 0.604	0.59 (0.15–2.35); 0.451
1.62 (0.78–3.37); 0.197	<b>0.25 (0.13–0.48); &lt;0.001</b>	0.63 (0.32–1.24); 0.183	1.08 (0.50–2.31); 0.854
(Reference)	(Reference)	(Reference)	(Reference)
1.12 (0.69–1.82); 0.654	1.31 (0.81–2.12); 0.272	1.05 (0.60–1.86); 0.855	1.00 (0.55–1.78); 0.987
<b>2.70 (1.16–6.25); 0.021</b>	(Reference)	(Reference)	(Reference)
(Reference)	1.42 (0.72–2.81); 0.307	0.87 (0.39–1.92); 0.720	1.40 (0.69–2.85); 0.352
(Reference)	(Reference)	(Reference)	(Reference)
1.24 (0.45–3.42); 0.681	1.67 (0.63–4.46); 0.307	0.57 (0.15–2.09); 0.392	0.43 (0.09–1.94); 0.271
(Reference)	(Reference)	(Reference)	(Reference)
0.35 (0.10–1.17); 0.088	0.48 (0.19–1.21); 0.117	0.30 (0.09–1.03); 0.056	1.57 (0.67–3.69); 0.299
(Reference)	(Reference)	(Reference)	(Reference)
0.87 (0.45–1.69); 0.678	0.89 (0.45–1.78); 0.738	0.76 (0.34–1.72); 0.513	1.27 (0.62–2.64); 0.516
(Reference)	(Reference)	(Reference)	(Reference)
<b>1.43 (1.06–1.91); 0.018</b>	<b>3.70 (2.75–4.97); &lt;0.001</b>	<b>8.32 (5.66–12.24); &lt;0.001</b>	<b>6.54 (4.51–9.51); &lt;0.001</b>

health nursing or continence advisory, and personal assistance services than people living alone. Adults with speech and language disability were 2.16 times more likely (95% CI 1.05–4.43) to use occupational therapy and 6.59 times (95% CI 3.38–12.83) more likely to use SLT than those without speech and language disability. Adults without speech and language disability were 2.70 times (95% CI 1.16–6.25) more likely to use psychology or counselling services than those with speech and language disability. Adults with a cooccurring intellectual disability were 2.92 times (95% CI

1.01–8.47) more likely to use SLT than adults without an intellectual disability.

The association between characteristics and unmet needs is reported in Table S3. Age was associated with unmet needs relating to physiotherapy, occupational therapy, psychology or counselling, public health nurse or continence advisory, and assistive technology or client technology services. Living arrangements were associated with unmet needs relating to physiotherapy services. Epilepsy was associated with unmet needs for SLT services. Wheelchair use was associated with

psychology or counselling, personal assistance, and assistive technology or client technology services.

## DISCUSSION

This study aimed to describe health service use, characteristics associated with service use, and unmet needs among adults with CP. Physiotherapy was the most commonly used service, used by 57% of adults, and the most commonly required service, with a further 16% requiring physiotherapy but not receiving it. In adjusted analysis age, sex, living arrangements, wheelchair use, intellectual disability, and speech and language disability were associated with use of several services.

There were similarities and differences between our findings and previous studies. The percentages using SLT and clinical nutrition were identical to those reported in a systematic review.<sup>8</sup> Use of physiotherapy, occupational therapy, and psychology or counselling was higher in this study compared with previous review findings.<sup>8</sup> Differences may be due to differences in health systems and service delivery models between countries. When compared with a sample of adults with CP from the UK, which has a similar but not identical health care system to Ireland, use of physiotherapy was higher in Ireland and use of respite and social work was lower.<sup>26</sup> However, people in the UK sample were younger and had more severe functional mobility impairments than in our sample, which probably explains some differences in service use.

Those requiring a service or requiring enhancement of an existing service were regarded as having unmet needs.<sup>16</sup> In this study, unmet needs for therapeutic services was relatively high, with 23% and 13% of adults having unmet needs for physiotherapy and occupational therapy respectively. These findings are in line with previous studies that highlighted a need for more physiotherapy<sup>19,27</sup> or physical rehabilitation<sup>18</sup> among adults with CP. A study from the USA showed only 51.4% of adults with CP who needed physical rehabilitation, which included physical therapy, occupational therapy, and SLT, received it.<sup>18</sup> High unmet needs for therapy may relate to an awareness of the benefits of such services and recognition of a need for these services with age.<sup>28</sup> Unlike other services, therapeutic services are typically provided throughout childhood,<sup>29</sup> and thus lack of therapeutic services in adulthood may be more obvious to adults with CP who have accessed these services since diagnosis.<sup>30,31</sup>

Adults with CP also had high unmet needs for personal assistance and chiropody. Although only 18% and 12% of the sample used personal assistance and chiropody, a further 7% required the services. The high unmet needs for services may suggest demand exceeds supply, or possibly adults not seeking services because of previous experience of accessing services. Studies have previously identified a need for personal assistance among adults with CP, including support with medical care, personal care, preparing

meals, household chores, and managing finances.<sup>27,32</sup> The relatively high unmet needs for personal assistance suggests that adults with CP are not being adequately supported to live independently. This is in conflict with the right to live independently and inclusion in the community as outlined in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities.<sup>33</sup>

Although only 21% of the sample used respite services, a further 5% required respite services, but were not receiving it. Parents of young people with CP in the USA reported challenges in finding reliable respite services, which had an impact on spouse time spent together.<sup>34</sup> In our sample, 70% lived with a primary carer, who was most commonly a parent, indicating that inadequate provision of respite is likely to increase the burden on ageing parents.

The current study found that the older adults (>25y) were less likely to use therapeutic services compared with younger adults (<25y). Although studies have examined the association between age and service use in children with CP<sup>35</sup> or compared service use between children and adults with CP,<sup>7</sup> no study has examined the association between age and therapy use in adults with CP. However, our findings support those from qualitative studies that highlighted reduced access to therapy as people with CP age.<sup>8</sup> Previous studies reported lack of access to therapy<sup>36</sup> services such as physiotherapy,<sup>30,31</sup> and occupational therapy<sup>31</sup> services after transitioning from paediatric services,<sup>30,31,36</sup> or from lack of insurance coverage for physical or occupational therapy in adults.<sup>37</sup> Other possible explanations for reduced therapy service use among older adults might be adults' acceptance of their condition and/or ageing, or lack of awareness of the potential benefits of therapy services. Adults with neurodevelopmental impairments such as CP present with accelerated ageing;<sup>38</sup> therefore there is a need for services with specific expertise.<sup>39</sup>

Adults with CP who use a wheelchair were more likely to use all the services examined, even after controlling for comorbidities such as epilepsy and speech and language disabilities. This finding is consistent with other studies.<sup>14,40,41</sup> Another study found that ambulatory adults were more likely to use physiotherapy, occupational therapy, and SLT compared with non-ambulatory adults.<sup>19</sup> Although wheelchair users may have additional needs that require access to some services, ambulatory adults may experience challenges accessing services because their disability is not as visible.

Interestingly, adults living with parents/family members/relatives were less likely to use personal assistance than adults living alone. This may be because, in the context of limited resources, funding for personal assistance is more likely to be allocated to people living alone. It may be assumed that family members will provide the support that is not provided by a personal assistant. However, adults with CP may want to live independently with the support of a personal assistant, while still living with family; these are not always mutually exclusive choices. Alternatively,

some families may be reluctant to have personal assistants in their home and prefer to provide support rather than seek external support. We also found those living with family were less likely to use physiotherapy, suggesting that families might support the completion of physiotherapy or exercise programmes in place of regular access to physiotherapy. These combined findings further suggest that families are providing support in the absence of appropriate services. The confidence interval around some factors was very wide, which indicates that the results should be interpreted with caution.

This study was limited as the database used is voluntary and limited to disabled people who are currently using services or will need services in the next 5 years. Similar to the national survey conducted in France,<sup>42</sup> this NPSDD data collection was not designed to study a representative sample, but rather include those willing to register for disability service planning in Ireland. Also, the data obtained on variables were measured from a questionnaire which may be subject to bias. Data on Gross Motor Function Classification System (GMFCS) levels were not collected as part of the NPSDD. However, 46% of the people used at least one type of wheelchair, which indicates that 46% were in GMFCS levels III, IV, or V. Data describing adults aged 19 to 39 years in the Northern Ireland CP Register indicated 32% were in GMFCS levels III, IV, and V.<sup>3</sup> However, in the Register the GMFCS level was measured at 5 years of age. It is likely that mobility declined among some adults with CP<sup>43</sup> between the age of 5 years and 19 years, and therefore the proportion of adults with CP aged 19 to 39 years in Northern Ireland using a wheelchair is likely to be greater than 32%. In previous studies with relatively large samples of adults with CP, the percentage of wheelchair users or percentage of people in GMFCS levels III to V ranged from 52% to 64%.<sup>9,41</sup> People with intellectual disability are underrepresented in this study as they were probably included in the NIDD rather than the NPSDD. Studies reported that intellectual disability is strongly associated with increasing GMFCS level and secondary conditions such as epilepsy.<sup>44</sup> Although, nearly half of our participants were wheelchair users, people in GMFCS level V are probably underrepresented as most people classified in that level have intellectual disability and are probably on the NIDD. Similarly, people with secondary impairments are also probably underrepresented in our sample because secondary impairments and intellectual disability are strongly associated and people with intellectual disability were on the NIDD.<sup>3</sup> In summary, our sample does not represent the whole population of adults with CP. It does, however, provide a summary of services used and unmet needs for an important subset of adults with CP in Ireland, specifically those with physical impairment without intellectual disability. This subset anecdotally has particular difficulties accessing services because their lack of intellectual disability often results in them being ineligible to access adult disability services.

In conclusion, adults with CP used a wide range of health services, and had unmet needs for several services. Unmet

needs were particularly high for therapeutic services, respite, chiropody, and personal assistance. The findings highlight the need for a lifespan perspective for planning and developing equitable services to meet the needs of adults with CP, regardless of their age, mobility level, or living arrangements.

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## DATA AVAILABILITY STATEMENT

The data are not publicly available due to privacy or ethical restrictions.

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## SUPPORTING INFORMATION

The following additional material may be found online.

**Appendix S1:** Data response on required services.

**Table S1:** Community health care organization (CHO) proportion compared to the general population.

**Table S2:** Percentage of people currently using services who require an enhanced service.

**Table S3:** Characteristics associated with unmet need for health services.

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