



Research Article

An Assessment of the Allied Health Professional Support Available for Children With Cerebral Palsy Across The United Kingdom: A Cross-Sectional Survey

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Abstract

Aim: To establish any variability in access to physiotherapy and allied healthcare services for children living with Cerebral Palsy (CP) across the United Kingdom (UK).

Method: A cross-sectional survey was developed by clinicians and distributed to members of the Association of Paediatric Chartered Physiotherapists. Participants all worked within the UK, with children living with neurodisability. The survey included 19 questions. Descriptive statistics were used for analysis of the closed questions, and thematic analysis for open questions.

Results: Two hundred and nine physiotherapists, from throughout the UK, completed the survey. Results demonstrate variability in service provision including appointment frequency (one to 52 per year), wheelchair service waiting times (<1 to >12 months), and varied continuity of services during school holidays. Seven percent of respondents reported that their patients did not have access to tertiary neurodisability services. All regions reported that COVID-19 had a negative impact, which for many, remained unrectified.

Interpretation: There is significant heterogeneity in service provision for children living with CP across the UK. Whilst high quality research is required to ascertain the effect of these services on patient outcomes, there is a need to develop a uniform standard of care, and to reduce the degree to which a postcode lottery determines healthcare provision.

Keywords: Allied health; Cerebral palsy; Inequality; Physiotherapy, Service provision; Survey

Background

Cerebral palsy (CP) is the most common motor disorder of childhood, with a UK prevalence of approximately two per 1000 live births.(1) The Gross Motor Function Classification System (GMFCS) is a validated system that categories children living with CP into groups one to five based on their functional abilities.

(2) The National Institute for Health and Care Excellence (NICE) recommend a multi-disciplinary approach to the care of children living with CP.(1,3) This involves a team which can accommodate for the child's individual needs; including paediatricians, surgeons, nurses, physiotherapists, occupational therapists, dietitians, psychologists, and speech and language therapists.(3) Furthermore, children should have access to specialist local or regional services such as paediatric neurodisability services [3].

Physiotherapists constitute an integral part of these patients' Multi-Disciplinary Team (MDT), and are often the professionals who have the initial and most frequent contact with the patient. (4) Physiotherapists aim to improve muscle strength and endurance, optimise function, and provide post-operative input where appropriate. (5,6) A systematic review and meta-analysis published in 2022 found that strength training in children and adolescents living with spastic CP had benefits for gross motor function, muscle strength, gait speed, balance, and maximum work resistance. (7) However, the benefits of strength training have short-lasting effects, and as such, the study found it was essential for the participants to have regular strength training sessions to maintain the positive effects over time. (7) Other studies have corroborated that strength training has a positive impact on function in these individuals, with some suggesting that it also improves symptoms such as fatigue and pain (8,9)

Despite this, there are no existing UK guidelines outlining the recommended frequency or intensity of physiotherapy provision for these patients. (1,3) Without clear guidelines, it is plausible that service provision may differ based on geographical location, a so-called 'postcode lottery.' A previous study has demonstrated marked variation in physiotherapy provision for children living with CP in Northern Ireland, but no previous study has considered this across the UK. (10) Establishing a consensus of treatment, independent of geographical region, remains a key priority within many UK healthcare organisations. (11) In 2020, The Royal College of Paediatrics and Child Health named health inequality as a priority. (12) In October 2022, the Arthritis and Musculoskeletal Alliance outlined the scale of musculoskeletal health inequalities across the UK, and called on professionals to take action to reduce this. (13) The Cerebral Palsy Integrated Pathway (CPIP) is a recent example of the benefits of equity of access and uniformity across geographical regions, with regard to outcomes for children living with CP. (14) CPIP was initially implemented in Sweden in 1994, and offered regular physical and radiological examination of children living with CP. Studies have shown that this regular surveillance has led to a significantly lower incidence of hip dislocation, due to earlier surgical intervention. (14) CPIP has since been implemented in countries including Norway, Denmark, Iceland, Scotland and now England.

The rationale for this study was based on the lack of national guidelines for the provision of physiotherapy for paediatric patients living with CP in the UK. It was hypothesised that this may result in significant geographical variation of available services. Furthermore, it is known that health inequality remains a significant problem within the UK. (11–13) At a time where the recent pandemic, increased waiting times and the cost-of-living crisis are further contributing towards health inequity, it is imperative to establish uniform care across regions. Although an area with a paucity of research, there is evidence which

supports regular physiotherapy for children living with CP. (7–9) Inspiration has been drawn from initiatives such as CPIP, which have demonstrated the benefits of equity of access, and uniformity of care across regions. Further examples of initiatives which have endeavored to tackle inequality in care include the paediatric orthopaedic Getting It Right First Time (GIRFT) initiative, as well as the British Society for Children's Orthopaedic Surgery (BSCOS) who have released consensus statements for treating conditions as DDH, bone and joint infections and clubfoot. (15–17)

The primary aim of this study was to identify any variability in the provision of physiotherapy and related services for children living with CP across the UK. The secondary aim was to determine how service provision had been affected by the COVID-19 pandemic, and whether it had returned to pre-pandemic standards.

Methods

Study design

A descriptive observational study was performed using a cross-sectional survey distributed to members of the Association of Paediatric Chartered Physiotherapists (APCP).

Survey Instrument

An online survey was written by five clinicians involved in the treatment of children living with CP: three paediatric orthopaedic consultants, one paediatric neurodisability consultant and one foundation doctor. The survey was piloted on chartered paediatric physiotherapists working in a Central London University Teaching hospital, to assess its acceptability and feasibility. The survey comprised of 19 questions and took approximately six minutes to complete. It asked respondents to report the UK region and clinical context in which they worked. It then asked respondents about service provision for children living with CP in the area in which they worked, e.g., frequency and length of physiotherapy appointments, waiting times for allied services and access to specific networks and resources. Questions regarding frequency of physiotherapy appointments were subdivided by GMFCS level. (The full survey can be found in Appendix one). The invitation to participate was distributed to members via an official email from the APCP coordinator. This email contained a link to the questionnaire which was delivered via the online survey software and questionnaire tool, Survey Monkey (Momentive.) The questionnaire did not collect any identifying information about the children, and as such, ethical approval was not deemed necessary. This study was prospectively registered with the hospital Clinical Audit department (registration number: AUDI002246.)

Study Population

The survey was distributed to members of the APCP. Inclusion criteria for participating physiotherapists were (1) currently working as a physiotherapist in the UK, and (2) currently

working with children with neurodisability. The survey was distributed to all APCP members (n = 2201), from 1st June to 30th August 2022. Participants could only answer the survey once. The survey remained open for twelve weeks. Three reminder emails were sent during this time.

Data Analysis

Descriptive statistics were used for analysis of the closed questions that formed most of the survey. Data was presented as numbers, with the corresponding percentage; N (%). Percentages were recorded to the first decimal place. Grounded theory was used to analyse qualitative data obtained from the open questions. (18) Responses were initially coded and refined into themes. The responses were analysed anonymously.

Results

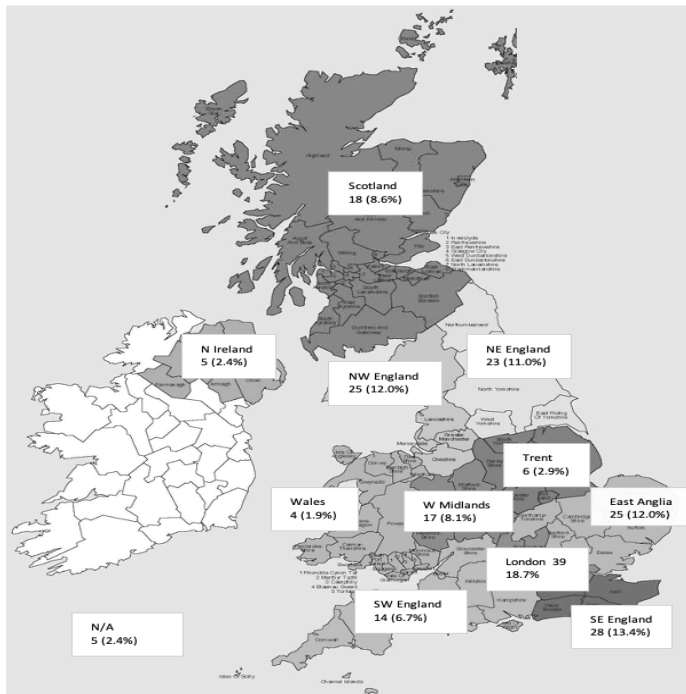
Two hundred and nine physiotherapists responded to the survey. The broad UK regions represented by this survey are presented in Figure 1. Within each broad region, there was representation from an extensive array of both NHS trusts and community providers. Table 1 demonstrates the different clinical environments in which respondents work. Most respondents work within the community (83.2%), or within schools (53.4%). 12.5% of respondents work in alternative settings including the private sector, charitable sector, hospices, and nurseries.

Workplace settings	N = 208
Primary care – Community centre	173 (83.2%)
Primary care – School	111 (53.4%)
Secondary care – District General Hospital	37 (17.8%)
Secondary care- Tertiary centre	25 (12.0%)
Other	26 (12.5%)

Table 1: Setting of physiotherapy provision.

Frequency and length of physiotherapy appointments

A higher GMFCS level equated with increased frequency of physiotherapy appointments throughout the regions. (Figure 2) There was wide variation in the frequency of physiotherapy appointments offered at every GMFCS level; from weekly sessions, to every seven to eleven months. There was also variation in the length of the appointments. Most respondents (75.5%) reported appointment length to be between 31-60 minutes. However, 3% reported 15-30 minutes, and 19.8% reported more than 60 minutes. No respondents reported less than fifteen minutes. Most respondents (66.7%) reported that children received physiotherapy at school; whilst others responded that physiotherapy was received at home (58.3%), at the hospital/community centre (48.2%) and at a combination of the above (51.8%.) Other locations cited included Child Development Centres, nurseries, and leisure centres. The majority (92.0%) of respondents confirmed that children who received physiotherapy at school continued to receive it during the holidays. However, 56.4% reported that the frequency of the appointments was reduced compared to term time. Of those who reported reduced frequency physiotherapy, many reported that they saw children only once over school holidays.



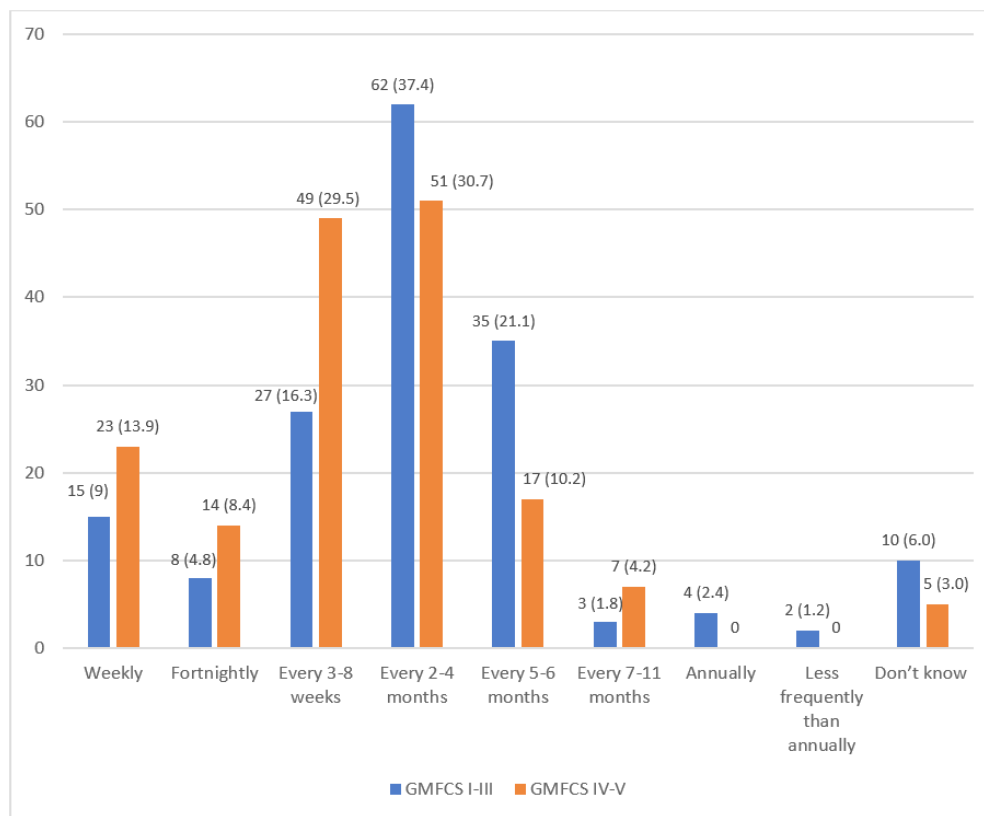


Figure 2: Frequency of physiotherapy appointment according to GMFCS level.

Waiting times for allied services

There was a wide variation reported in waiting times for children to obtain new wheelchairs. Most respondents (28.8%) reported an average of eight weeks to four months for children on their caseload to obtain an appointment. Twenty-eight reported more than six months wait, and forty-six didn't know what the waiting time was (Figure 3). Those who specified other (19 respondents) commented that this depended on various factors including the wheelchair provision service, whether it is provided through the NHS or privately, the child and their needs, and availability at the time. Ninety-five respondents (59.0%) reported that hydrotherapy was offered to children on their caseload, whereas 63 respondents (39.1%) reported that it was not.

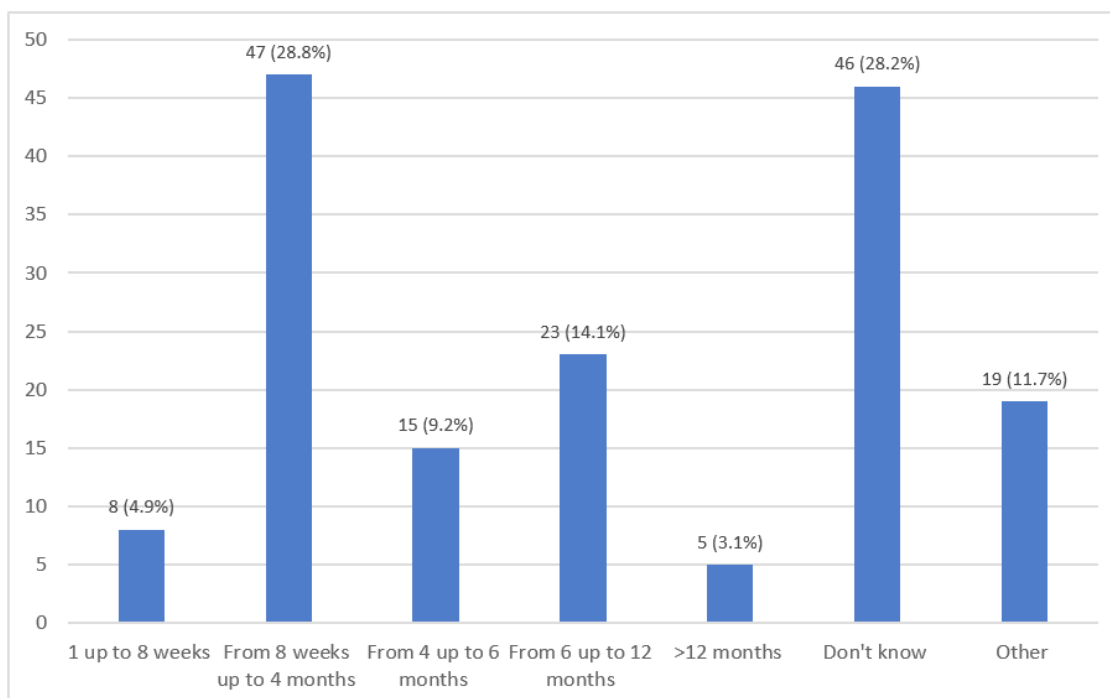


Figure 3: Reported waiting times for wheelchair service.

There was marked variability in the average waiting time for children to have an orthotist appointment, with one respondent reporting waiting for one week, and others reporting waiting over one year. The majority (58.6%) reported waiting up to eight weeks.

Access to networks and resources

Forty-one respondents (25%) were unsure whether children had access to networks with regional neurodisability centres, and twelve respondents (7%) reported that they did not have access. One hundred and sixty respondents (97.6%) reported that children on their caseload had specific and appropriate interventions offered, including botulinum toxin A/B, intrathecal baclofen and selective dorsal rhizotomy. One respondent reported that children on their caseload were not offered these interventions, and three (1.8%) were not sure. One hundred and forty-three respondents (87.2%) reported that children on their caseload had access to a specialist orthopaedic care, whereas 15 respondents (9.2%) reported they did not (Table 2).

	Referral network with regional neurodisability centre	Specific and appropriate interventions offered *	Access to specialist orthopaedic care
Yes	111 (67.8%)	160 (97.6%)	143 (87.2%)
No	12 (7.3%)	1 (0.6%)	15 (9.2%)
Don't know	41 (25.0%)	3 (1.8%)	9 (5.5%)

Table 2: Reported access to networks, interventions, and resources.

One hundred and twenty-one respondents (74.7%) felt there was not adequate staffing in their region to provide children with appropriate physiotherapy, whilst only 28 respondents (17.3%) felt it was sufficient.

The vast majority (97.5%) of respondents reported that the service provision in the region was affected by the pandemic, with 41.1% reporting that their service provision had not returned to pre-pandemic standard. Respondents were asked to elaborate on service provision during the pandemic and re-establishment post-pandemic, and these themes can be found in Tables 3 and 4. Beyond variation seen by geographical locations, many commented on disparities e.g., that private physiotherapy units were quicker to reinstate their service compared with NHS services due to many paediatric physiotherapists being redeployed to adult COVID-19 wards. Furthermore, many

commented upon an increase in referrals to private physiotherapy post-pandemic due to long waiting lists and a backlog within the NHS, as well as services such as hydrotherapy not re-opening.

‘Was service provision for children in your region affected by the pandemic?’
Increasingly virtual
Reduced capacity and staff shortages
Prioritisation based on needs / risk
Variable – private vs NHS, hospital vs community, mainstream vs special educational needs (SEN) schools
School closures
Increased waiting times
Increase in Did Not Attend (DNA)

Table 3: Themes identified in response to open-ended question regarding influence of pandemic.

‘If service provision was affected, is it now back to pre-pandemic standard?’
Increased parental involvement and less reliance on service
Increased waiting lists and backlogs
Staff shortages
Variable – DGH’s vs tertiary centres, private vs NHS
Deterioration in function and increased complexity
Increasing use of virtual appointments

Table 4: Themes identified in response to open-ended question regarding ongoing consequences of pandemic.

Discussion

This cross-sectional survey offers information on the availability of physiotherapy and associated services for children living with CP across the UK. The key findings demonstrate marked variability in; frequency and length of appointments, service provision during school holidays, waiting times for allied services, and access to networks and resources. The reported disparities in service provision were not only geographical; but between NHS vs private sector, mainstream school vs special educational needs (SEN) school, district general hospitals (DGH) vs tertiary centres. This is consistent with previous studies which have suggested that the school in which children attend, (mainstream vs SEN) contributes significantly to the amount and consistency of physiotherapy received. (10) Parkes et al. found that children in SEN schools received treatment more frequently and were more likely to have home visits than children in mainstream schools, however, as more children in mainstream schools received

treatment in outpatient centres, this tended to be less disrupted during school holidays. (10) The fact that schools constitute one of the main settings for physiotherapy was confirmed by this survey. As previously suggested, this may lead to inconsistency in provision of physiotherapy during school holidays, with some children not receiving any at all. Despite no evidence that appropriate seating influences outcomes for children living with CP, the authors argue it is clearly unacceptable for children who are awaiting a wheelchair to wait over six months. Further work could consider what, if any, substitutes families use during this waiting period, and the impact that this has on the children.

There was consensus in this survey that service provision was adversely affected by the COVID-19 pandemic and is yet to return to pre-pandemic standards. It may be beneficial to develop and implement Standardised Operating Procedures to ensure that services would not experience such a severe disruption if similar circumstances were to recur. It is evident that the service has not returned to pre-pandemic standards, which can be seen across the NHS [16]. There was the suggestion that, in the wake of the pandemic, more families were utilising physiotherapy in the private sector. It has previously been found that some families have relied on the private sector to provide what they feel is adequate care; a study performed in Ireland in 2004 found that 16% of families surveyed supplemented their child’s physiotherapy with a private practitioner. (10) This seems to be particularly prevalent during school holidays, where many children experience a hiatus in NHS physiotherapy provision. (10) Respondents in this survey suggested that private physiotherapy was less disrupted, and quicker to resume during the pandemic compared with NHS physiotherapy, where many professionals were redeployed to adult wards. However, private physiotherapy is not a viable option for all families, and creates further systemic inequality in the treatment of children living with CP.

This survey included participants from all over the UK providing strong evidence of disparity of service provision for cerebral palsy in the UK. However, this survey has limitations. The questions were subdivided by GMFCS status (1-3 vs 4-5), with the rationale of dividing ambulatory and non-ambulatory children. This subdivision has limitations as it is acknowledged that within GMFCS 1-3 the need for physiotherapy depends on numerous other factors such as age, spasticity level, co-morbidities, and previous interventions. Acknowledging the inevitable variation in individual needs of each child, categorisation based on mobility level was deemed appropriate to reflect the average service delivery, with the caveat that specific children would fall outside this categorisation. Furthermore, the survey asked about frequency and length of appointments with physiotherapists but didn’t consider implementation of programmes which may be provided by physiotherapists and facilitated and delivered by other professionals within schools or by parents. The areas within the

UK that were associated with poor resources and services were not specified. This survey had promised to be anonymous with the aim of identifying variability and not highlighting a specific region as an outlier. The survey clearly stated that identifiable data would not be used in the dissemination of the results, and this has been honoured. It was also not possible to calculate the exact percentage of APCP members who answered the survey as not all physiotherapists are APCP members and many members either don't work with children with neurodisability or are not currently based in the UK and therefore the denominator for calculating participation is not available. It was felt that the participation numbers and geographic distribution was significant and offered a good representation.

There have been recent efforts within paediatric orthopaedics to establish consensus in treatment and levels of service through the British Society for Children's Orthopaedic Surgery (BSCOS) consensus statements and CPIPS (14,19). The next step would be to aspire to achieve the same in allied health service provision. This survey demonstrates that, despite NICE's recommendation, there are still children in the UK that don't have access to tertiary neurodisability services. [3]

This survey has highlighted inequality in service provision for children living with CP across the UK. Whilst high quality research is required to evaluate and ascertain the effect of the adjunct service provision on patient outcomes, there is a need to develop a uniform service across the UK, and to reduce the degree to which a postcode lottery determines access to care for these children.

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Appendix 1

Questionnaire

1. In which Association of Paediatric Chartered Physiotherapists (APCP) region do you work?

- East Anglia
- London
- North East England
- North West England
- Northern Ireland
- Scotland
- South East England
- South West England
- Trent
- Wales
- West Midlands

2. Please specify the precise trust/community centre you are associated with (This information is pivotal as we believe there is a large variability within the regions)

3. Are you involved in the management of children with neurodisability?

- Yes
- No

4. In which of the following setting's do you work? (Tick as many as applicable)

- Community
- Secondary care – District General Hospital
- Secondary care- Tertiary centre
- School
- Other (Please specify)

5. On average, how often are walking children, (GMFCS I-III or equivalent) on your case load, offered a physiotherapy appointment?

- Weekly
- Fortnightly
- Every 3-8 weeks
- Every 2-4 months

- Every 5-6 months
- Every 7-11 months
- Annually
- Less frequently than annually
- Don't know

6. On average, how often are non-walking children (GMFCS IV-V or equivalent) on your case load, offered a physiotherapy appointment?

- Weekly
- Fortnightly
- Every 2-8 weeks
- Every 2-4 months
- Every 4-6 months
- Every 6-12 months
- Annually
- Less frequently than annually
- Don't know

7. On average, how much time. Is spent during physiotherapy appointments with these children on your case load?

- Less than 15 minutes
- 15-30 minutes
- 31-60 minutes
- > 60 minutes
- Don't know

8. Where do these children receive physiotherapy?

- At school
- At home
- At the hospital/ community centre
- Combined
- Other (Please specify)

9. For children who receive their physiotherapy at school, do they receive physiotherapy during school holidays? And if so, how frequently?

- No
- Yes. Same frequency
- Yes. Reduced frequency – Please specify

10. What is the average waiting time for children on your caseload to obtain a new wheelchair?

- 1 up to 8 weeks
- From 8 weeks up to 4 months
- From 4 up to 6 months
- From 6 up to 12 months
- > 12 months
- Don't know
- Other (please specify)

11. Is hydrotherapy offered to children with neurodisability on your caseload?

- Yes
- No
- Don't know

12. From referral, what is the average waiting time for children with neurodisability on your caseload to have an initial orthotist appointment?

- <1 week
- From 1 week up to 8 weeks
- From 2 up to 4 months
- From 4 up to 6 months
- From 6 up to 12 months
- > 12 months
- Don't know

13. Do these children have access to and referral networks with regional neurodisability centres?

- Yes
- No
- Don't know

14. Are specific interventions offered (e.g., botulinum toxin A/B, intrathecal baclofen, selective dorsal rhizotomy) to these patients where appropriate?

- Yes
- No
- Don't know

15. Do these children have access to a specialist orthopaedic centre?

- Yes
- No
- Don't know

16. I feel there is adequate staffing to provide children living with neurodisability in my region with adequate physiotherapy.

- Strongly disagree
- Disagree
- Unsure
- Agree
- Strongly agree

17. Was service provision for children in your region affected by the pandemic?

- No
- Yes (please comment)

18. If service provision was affected, is it now back to the pre-pandemic standard?

- Not applicable
- Yes
- No (please provide additional information)

19. Would you like to share any additional comments regarding service provision for children living with neurodisability?

20. Contact details. In submitting these details, you consent to the data being held as an electronic record for the purpose of this study and contacting you at a later date.