



CHRONIC NEURODISABILITY STUDY

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

ORGANISATIONAL QUESTIONNAIRE

8. ALLIED HEALTH PROFESSIONALS - PAEDIATRIC OUTPATIENT CARE

Name of Trust/Board/Organisation: _____

CONFIDENTIAL

Who completed this questionnaire?

Name: _____

Position: _____

What is this study about?

This study explores the quality of health care for children and young people aged 0-25 with chronic neurodisability across the UK.

Aims:

To identify remediable factors in the quality of care provided children and young people chronic disabling conditions, the cerebral palsies.

To examine the interface between different care settings

To examine the transition of care

Who should complete this form?

The lead allied health professional in this organisation with the best overall knowledge of physiotherapy, occupational therapy, speech and language therapy, dietetics, clinical psychology etc, delivered to disabled children and young people in clinic and community settings. Please link with colleagues as needs be to inform the most accurate possible response.

To ensure confidentiality of the data, completed questionnaire must be returned directly to NCEPOD in the SAE provided.

How to complete the form:

Information will be collected using two methods; box cross and free text, where your opinion will be requested.

This form will be electronically scanned. Please use a black or blue pen. Please complete all questions with either block capitals or a bold cross inside the boxes provided e.g.

Following crisis or emergency referral, are there any standards set for assessment from time of referral?

Yes No

If you make a mistake, please "black-out" the incorrect box and re-enter the correct information, e.g.

Yes No

Unless indicated, please mark only one box per question.

Questions or help?

A list of definitions is provided on pages 2 of the questionnaire.

If you have any queries about this study or this questionnaire, please contact

cp@ncepod.org.uk

Or telephone: 020 7251 9060

Thank you for taking the time to complete this questionnaire. The findings of the study will be published in late 2017.

ORGANISATIONAL ID



7 9 5 7 4 4 6 3 1 0 8 8 6

DEFINITIONS

Reasonable adjustments	“Employers and organisations such as hospitals, care homes and GP surgeries must take steps to remove the barriers people face because of their disabilities” (CQC, 2015. http://www.cqc.org.uk/content/glossary-terms-used-guidance-providers-and-managers#)
Interagency strategic partnership arrangements	A formal mechanism for considering the strategic needs of the local population of disabled children and young people
Out of hours	18:00 – 07:59 Monday to Friday and all day Saturday and Sunday
Accessibility of services	To be fully accessible, a service must have: <ul style="list-style-type: none"> o Accessible parking for the disabled o Ramped access o Doors wide enough for wheelchair access o Accessible toilets o Changing place for children and young people of all ages with cerebral palsies who are incontinent and need to be changed o Hoists o Accessible, height adjustable beds and examination couches o Appropriate scales e.g. wheelchair scales, hoist scales o Reasonable adjustments made to accommodate the specific needs of the disabled person
Individualised Emergency Health Care/Personal Resuscitation plan	Plan agreed with the lead clinician, that documents what has been discussed and agreed and with whom, about appropriate levels of intervention for the child/young person (e.g. any advance statements, advance decisions to refuse treatment, do not attempt cardiopulmonary resuscitation decisions, variations from advanced life support guidelines, treatment or intervention limitations.
Capacity	As defined in the Mental Capacity Act 2005 (applies in E&W) and equivalent legislation in Scotland and NI See https://www.disabilitymatters.org.uk/course/view.php?id=62
Best-interests decision-making	See https://www.disabilitymatters.org.uk/course/view.php?id=63
Gross Motor Function Classification System (GMFCS)	See: https://www.canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r



A. SERVICES AND PROCEDURES

Please complete this questionnaire in relation to the care provided to CHILDREN AND ADOLESCENTS as defined by this organisation. Throughout this questionnaire children and adolescents will be referred to as children and young people.

1. Please indicate which services are available for children and young people with cerebral palsies who may need them. (Please tick all that apply)

	Via a formal network	Via an informal network	No access
Paediatric physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric dietitian	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric clinical psychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric speech and language therapist - communication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric speech and language therapist - dysphagia, feeding and swallowing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children's specialist community nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children and young people's learning disability nurse specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children's epilepsy nurse specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric continence specialist practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist children and young people's dental service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychological support for parents/family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Orthotist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

B. WHEELCHAIR SERVICES

- 2a. How are wheelchair services delivered for children and young people with cerebral palsies? (Please tick all that apply)

- Specialist paediatric service
 Part of adult service
 Private provision
 No service (Please go to question 3)



2b. Can the wheelchair service for children and young people provide the following? (Please tick all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Maintenance/repair | <input type="checkbox"/> Sports wheelchairs |
| <input type="checkbox"/> Bespoke wheelchairs based on individual needs | <input type="checkbox"/> Power wheelchairs |
| <input type="checkbox"/> Emergency out of hours service for maintenance/repair | <input type="checkbox"/> Other specialist wheelchairs |

2c. Are wheelchair services adequate for meeting the needs of the local population? (Where adequate means timely assessment, easy access, high quality assessment and provision, clear pathways for maintenance and repair.) Yes No

C. OTHER EQUIPMENT

3a. Please indicate which of the following are available, and in which settings, for children and young people with cerebral palsies? Where available please indicate whether a new referral is required for each episode of care? (Please tick all that apply)

	New provision possible within this organisation		If available, location and support for use			New referral required		
	Yes	No	Whilst an inpatient	On discharge home	NA	Yes	No	NA
Standing frames	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking frames/devices	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleep systems for children and young people with cerebral palsies at GMFCS III-V (non-walkers) based on individual assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Orthoses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hand splints	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Low-tech communication aids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
High-tech communication aids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist seating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Equipment for self-care including bathing, dressing, mealtimes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



3b. Where equipment is available, what is the waiting time?

Standing frames	<input type="text"/> <input type="text"/>	Weeks	<input type="checkbox"/> Unknown
Walking frames/devices	<input type="text"/> <input type="text"/>	Weeks	<input type="checkbox"/> Unknown
Sleep systems for children and young people with cerebral palsies at GMFCS III-V (non-walkers) based on individual assessment	<input type="text"/> <input type="text"/>	Weeks	<input type="checkbox"/> Unknown
Orthoses	<input type="text"/> <input type="text"/>	Weeks	<input type="checkbox"/> Unknown
Hand splints	<input type="text"/> <input type="text"/>	Weeks	<input type="checkbox"/> Unknown
Low-tech communication aids	<input type="text"/> <input type="text"/>	Weeks	<input type="checkbox"/> Unknown
High-tech communication aids	<input type="text"/> <input type="text"/>	Weeks	<input type="checkbox"/> Unknown
Specialist seating	<input type="text"/> <input type="text"/>	Weeks	<input type="checkbox"/> Unknown
Equipment for self-care including bathing, dressing, mealtimes	<input type="text"/> <input type="text"/>	Weeks	<input type="checkbox"/> Unknown

3c. Where NOT AVAILABLE within your organisation, how far is the nearest provision?

Standing frames	<input type="text"/> <input type="text"/>	Miles	<input type="checkbox"/> Unknown
Walking frames/devices	<input type="text"/> <input type="text"/>	Miles	<input type="checkbox"/> Unknown
Sleep systems for children and young people with cerebral palsies at GMFCS III-V (non-walkers) based on individual assessment	<input type="text"/> <input type="text"/>	Miles	<input type="checkbox"/> Unknown
Orthoses	<input type="text"/> <input type="text"/>	Miles	<input type="checkbox"/> Unknown
Hand splints	<input type="text"/> <input type="text"/>	Miles	<input type="checkbox"/> Unknown
Low-tech communication aids	<input type="text"/> <input type="text"/>	Miles	<input type="checkbox"/> Unknown
High-tech communication aids	<input type="text"/> <input type="text"/>	Miles	<input type="checkbox"/> Unknown
Specialist seating	<input type="text"/> <input type="text"/>	Miles	<input type="checkbox"/> Unknown
Equipment for self-care including bathing, dressing, mealtimes	<input type="text"/> <input type="text"/>	Miles	<input type="checkbox"/> Unknown

4a. Are there any issues with waiting times for any of the above services or equipment? Yes No

4b. If YES, please give details:



D. ACCESSIBILITY

ACCESSIBILITY OF SERVICES FOR ALL CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSIES INCLUDING WHEELCHAIR USERS WHO ARE TOTALLY DEPENDENT ON OTHERS FOR ALL CARE

5a. In general, across this outpatient service are there any problems with access to:

	Yes	No
Accessible parking for the disabled	<input type="checkbox"/>	<input type="checkbox"/>
Ramped access	<input type="checkbox"/>	<input type="checkbox"/>
Doors wide enough for wheelchair access	<input type="checkbox"/>	<input type="checkbox"/>
Accessible toilets	<input type="checkbox"/>	<input type="checkbox"/>
A changing place providing privacy for essential personal care	<input type="checkbox"/>	<input type="checkbox"/>
Accessible height adjustable beds and examination couches	<input type="checkbox"/>	<input type="checkbox"/>
Hoists	<input type="checkbox"/>	<input type="checkbox"/>
Appropriate scales (e.g. wheelchair scales, hoist scales)	<input type="checkbox"/>	<input type="checkbox"/>
Reasonable adjustments made to accommodate the specific needs of the disabled child or young person	<input type="checkbox"/>	<input type="checkbox"/>

5b. If yes to any of the above, please give details:

E. SUPPORT SERVICES

- 6a. Are specialist occupational therapy services to assess the need for housing adaptations in place for children and young people with cerebral palsies? Yes No
- 6b. If YES, what is the average waiting time for assessment? Weeks Unknown
- 6c. What is the average waiting time for adaptations to be carried out? Months Unknown

F. COMMUNICATION ISSUES

7. Whilst an outpatient, are children and young people given the opportunity to speak to health professionals without a parent present if they prefer to? Yes No



8. Does every child and young person with a cerebral palsy at Gross Motor Function Classification System (GMFCS) level III to V (non-walkers) have a written 24-hour postural management plan that has been agreed with the person, their family and multi-disciplinary team? Yes No NA

G. TRANSITION TO ADULT SERVICES

9. Does this organisation have clear policies in place to ensure continuity of patient care, including close handover between professionals, and familiarisation with case histories, at all interfaces and points of transitions of care? Yes No
10. Is there a policy for young people to be offered the opportunity to be seen separately from their parent/carer in this service? Yes No
11. Is there continuity of PHYSIOTHERAPY for young people with cerebral palsies in adult services? (Tick all that apply)
- For those with a learning disability For those without a learning disability Unknown
12. Is there continuity of OCCUPATIONAL THERAPY for young people with cerebral palsies in adult services? (Tick all that apply)
- For those with a learning disability For those without a learning disability Unknown
13. Is there continuity of SPEECH AND LANGUAGE THERAPY for young people with cerebral palsies in adult services? (Tick all that apply)
- For those with a learning disability For those without a learning disability Unknown
14. Is there continuity of MENTAL HEALTH for young people with cerebral palsies in adult services? (Tick all that apply)
- For those with a learning disability For those without a learning disability Unknown
15. Is there continuity of SOCIAL CARE for young people with cerebral palsies in adult services? (Tick all that apply)
- For those with a learning disability For those without a learning disability Unknown
- For those who are completely dependent on others for all of their care

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE



Funding for this study was provided by The Healthcare Quality Improvement Partnership (HQIP) as part of The Clinical Outcome Review Programme into Child Health.

NCEPOD
Ground Floor, Abbey House
74-76 St John Street
London
EC1M 4DZ

