



CHRONIC NEURODISABILITY STUDY

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

ORGANISATIONAL QUESTIONNAIRE

9. ALLIED HEALTH PROFESSIONALS - ADULT 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 young adults in clinical and community settings. Please link with colleagues (to include surgeons) as need 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

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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 ADULTS as defined by this organisation. Throughout this questionnaire patients will be referred to as young adults.

1. Please indicate how the following services are accessed for young adults with cerebral palsies who may need them. (Please tick all that apply)

	Via a formal network	Via an informal network	No access
Neuro-rehabilitation consultant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neurology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Orthopaedic surgeon (general)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spinal orthopaedic surgeon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gastroenterologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General surgeon with expertise in disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Orthotist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dietician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist nurse for disabled adults	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Learning disability nurse specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist dental services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Epilepsy nurse specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Continence specialist practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ENT with disability expertise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Audiology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



1. Continued

	Via a formal network	Via an informal network	No access
Ophthalmology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinical psychology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Which of the following procedures/interventions can be requested by an allied health professional for young adults with cerebral palsies seen within the outpatient department? (Please tick all that apply)

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Standardised pelvic xrays for hip surveillance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gait analysis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Botulinum toxin injections under sedation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

B. WHEELCHAIR SERVICES

3a. How are wheelchair services delivered for young adults with cerebral palsies? (Please tick all that apply)

- General wheelchair service Private provision No service (Please go to question 4)

3b. Can the wheelchair service for young adult provide the following? (Please tick all that apply)

- Maintenance/repair Sports wheelchairs
 Bespoke wheelchairs based on individual needs Power wheelchairs
 Emergency out of hours service for maintenance/repair Other specialist wheelchairs

3c. 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

4a. Please indicate which of the following are available, and in which settings, for young adults 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 young adults 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"/>

Please give any comment:

4b. Where equipment is available, what is the waiting time?

Standing frames

Weeks Unknown

Walking frames/devices

Weeks Unknown

Sleep systems for young adults with cerebral palsies at GMFCS III-V (non-walkers) based on individual assessment

Weeks Unknown

Orthoses

Weeks Unknown

Hand splints

Weeks Unknown

Low-tech communication aids

Weeks Unknown



4b. Continued.

- High-tech communication aids Weeks Unknown
- Specialist seating Weeks Unknown
- Equipment for self-care including bathing, dressing, mealtimes Weeks Unknown

4c. Where NOT AVAILABLE within your organisation, how far is the nearest provision?

- Standing frames Miles Unknown
- Walking frames/devices Miles Unknown
- Sleep systems for young adults with cerebral palsies at GMFCS III-V (non-walkers) based on individual assessment Miles Unknown
- Orthoses Miles Unknown
- Hand splints Miles Unknown
- Low-tech communication aids Miles Unknown
- High-tech communication aids Miles Unknown
- Specialist seating Miles Unknown
- Equipment for self-care including bathing, dressing, mealtimes Miles Unknown

D. ACCESSIBILITY

ACCESSIBILITY OF SERVICES FOR ALL YOUNG ADULTS 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"/>



5a. Continued.

	Yes	No
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 young adult	<input type="checkbox"/>	<input type="checkbox"/>

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

E. COMMUNICATION ISSUES

6. Whilst an outpatient, are young adults given the opportunity to speak to health professionals without a parent present if they prefer to? Yes No
7. Does every young adult 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

F. TRANSITION TO ADULT SERVICES

8. 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
9. Is there continuity of PHYSIOTHERAPY for young adults with cerebral palsies? (Tick all that apply)
 For those with a learning disability For those without a learning disability Unknown
10. Is there continuity of OCCUPATIONAL THERAPY for young adults with cerebral palsies? (Tick all that apply)
 For those with a learning disability For those without a learning disability Unknown
11. Is there continuity of SPEECH AND LANGUAGE THERAPY for young adults with cerebral palsies? (Tick all that apply)
 For those with a learning disability For those without a learning disability Unknown



12. Are there MENTAL HEALTH services for young adults with cerebral palsies? (Tick all that apply)

For those with a learning disability For those without a learning disability Unknown

13. Is there continuity of SOCIAL CARE for young adults 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

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