



CHRONIC NEURODISABILITY STUDY

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

ORGANISATIONAL QUESTIONNAIRE

10. ALLIED HEALTH PROFESSIONALS - ADULT INPATIENT 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 with the best overall knowledge of physiotherapy, occupational therapy, speech and language therapy, dietetics, clinical psychology etc. delivered to disabled young adults in adult inpatient settings within this organisation. 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 which services are available for young adults with cerebral palsies who may need them whilst inpatients within this organisation. (Please tick all that apply)

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Orthotist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dietician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist nurse for disabled adults	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Learning disability nurse specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist dental services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Epilepsy nurse specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Continence specialist practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinical psychology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

B. WHEELCHAIR SERVICES

- 2a. Is there access to appropriate wheelchair provision for all young adults people who need them in your organisation WHILST INPATIENTS? Yes No

- 2b. If YES to either of the above, what is the average waiting time?

- 2c. Is there access to appropriate wheelchair provision for all young adults who need them in your organisation ON DISCHARGE? Yes No

- 2d. If yes to either of the above, what is the average waiting time?



2e. Please give any additional comments:

C. OTHER EQUIPMENT

3a. For young adults who are inpatients, please indicate which of the following equipment is available and, where available, its location for use? (Please tick all that apply)

	New provision possible within this organisation		If available, location and support for use		
	Yes	No	Whilst an inpatient	On discharge home	NA
Standing frames	<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"/>
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"/>
Orthoses	<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"/>
Low-tech communication aids	<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"/>
Specialist seating	<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"/>

Please give any comment:

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

Standing frames

Weeks Unknown

Walking frames/devices

Weeks Unknown



3b. Continued.

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

High-tech communication aids

Weeks Unknown

Specialist seating

Weeks Unknown

Equipment for self-care including bathing, dressing, mealtimes

Weeks Unknown

3c. 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 INPATIENT YOUNG ADULTS WITH CEREBRAL PALSIES INCLUDING WHEELCHAIR USERS WHO ARE TOTALLY DEPENDENT ON OTHERS FOR ALL CARE (def)

4a. In general, across this inpatient 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"/>



4a. Continued.

	Yes	No
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"/>

4b. If yes to any of the above, please give details:

E. SUPPORT SERVICES

- 5a. For inpatients, are specialist occupational therapy services to assess the need for housing adaptations in place for disabled young adults? Yes No
- 5b. If YES, what is the average waiting time for assessment? Weeks Unknown
- 5c. What is the average waiting time for adaptations to be carried out? Months Unknown

F. COMMUNICATION ISSUES

6. Whilst an inpatient, are young adults given the opportunity to speak to health professionals without a parent present if they prefer to? Yes No
7. How does communication take place between allied health professionals providing inpatient care for disabled young adults and the allied health professionals who provide usual outpatient/community care?
- Routinely by telephone or email Written report on discharge
- On an ad hoc basis No specific communication



8. Is there access to a key worker/lead professional for families when disabled young adults require inpatient care?
- Routinely available for all disabled children/young people and families
 - Only available for those with the most complex disabilities
 - Not available

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 adults 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 adults 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 adults 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 adults with cerebral palsies in adult services? (Tick all that apply)
- For those with a learning disability
 - For those without a learning disability
 - Unknown
14. Are there SOCIAL CARE services for young adults with cerebral palsies? (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.

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