CHRONIC NEURODISABILITY STUDY
National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

ORGANISATIONAL QUESTIONNAIRE
4. COMMUNITY PAEDIATRICS

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 palsy.

To examine the interface between different care settings

To examine the transition of care

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 make 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 0 5 3
### DEFINITIONS

<table>
<thead>
<tr>
<th>Reasonable adjustments</th>
<th>“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. <a href="http://www.cqc.org.uk/content/glossary-terms-used-guidance-providers-and-managers#">http://www.cqc.org.uk/content/glossary-terms-used-guidance-providers-and-managers#</a>)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interagency strategic partnership arrangements</td>
<td>A formal mechanism for considering the strategic needs of the local population of disabled children and young people</td>
</tr>
<tr>
<td>Out of hours</td>
<td>18:00 – 07:59 Monday to Friday and all day Saturday and Sunday</td>
</tr>
<tr>
<td>Accessibility of services</td>
<td>To be fully accessible, a service must have:  - Accessible parking for the disabled  - Ramp access  - Doors wide enough for wheelchair access  - Accessible toilets  - Changing place for children and young people of all ages with cerebral palsy who are incontinent and need to be changed  - Hoists  - Accessible, height adjustable beds and examination couches  - Appropriate scales e.g. wheelchair scales, hoist scales  - Reasonable adjustments made to accommodate the specific needs of the disabled person</td>
</tr>
<tr>
<td>Individualised Emergency Health Care/Personal Resuscitation plan</td>
<td>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.</td>
</tr>
<tr>
<td>Capacity</td>
<td>As defined in the Mental Capacity Act 2005 (applies in E&amp;W) and equivalent legislation in Scotland and NI  See <a href="https://www.disabilitymatters.org.uk/course/view.php?id=62">https://www.disabilitymatters.org.uk/course/view.php?id=62</a></td>
</tr>
<tr>
<td>Best-interests decision-making</td>
<td>See <a href="https://www.disabilitymatters.org.uk/course/view.php?id=63">https://www.disabilitymatters.org.uk/course/view.php?id=63</a></td>
</tr>
</tbody>
</table>
A. THE TRUST/ORGANISATION/PROVIDER/HEALTH BOARD

1a. Up to what age does this organisation provide paediatric community/specialist disability care? (What does this organisation define as a child?) □ Years

1b. What does this organisation define as an adolescent? (age range in years)

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

B. POPULATION OVERVIEW, DATA AND STRATEGIC ISSUES

2. Is there a lead clinician or team for the care of disabled children and young people within this service? □ Yes □ No

C. ACCESS TO SERVICES FOR CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSIES

3a. Is there an agreed, written care pathway for assessment, diagnosis and management of children and young people with cerebral palsies who are seen in this service? □ Yes □ No

3b. Does this include:

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hip surveillance</td>
<td></td>
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<tr>
<td>Magnetic Resonance Imaging of head and/or spine</td>
<td></td>
<td></td>
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<tr>
<td>Pain identification and management</td>
<td></td>
<td></td>
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<tr>
<td>Anthropometric measurement and monitoring of growth and nutrition</td>
<td></td>
<td></td>
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<tr>
<td>Spine monitoring and when to refer to spinal orthopaedic surgeon</td>
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<td></td>
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</tbody>
</table>

3c. If yes to 3a, where is this pathway published so that referrers and parents know how to access the service? (Answers may be multiple)

□ Local Offer (England) □ Organisation website □ Not published

□ Written referral guidance for GPs, health visitors etc.

□ Other (Please specify)
D. OPERATIONAL SERVICE DELIVERY MODEL FOR CLINICAL SERVICES

4. Does this community/specialist disability care service provide clinics for children and young people with cerebral palsy that are: (please tick all that apply)

- [ ] Non-specialist - seen as part of general community clinical caseload
- [ ] Specialist uni-disciplinary, i.e. each specialist sees the child or young people separately
- [ ] Multi-disciplinary for postural management (please specify which professionals are involved in the MDT clinics in the space below)
- [ ] Multi-disciplinary for feeding management (please specify which professionals are involved in the MDT clinics in the space below)
- [ ] Outreach clinics in special schools
- [ ] Other (Please specify)

5. How do the various health professionals within this service work together in delivering healthcare for children and young people with cerebral palsy? (please tick all that apply)

- [ ] Regular meetings
- [ ] Multidisciplinary clinics
- [ ] Co-location of professionals
- [ ] Other (Please specify)
- [ ] Ad hoc meetings focused on specific individuals
- [ ] No meetings but communicate regularly by letter or email
- [ ] No regular arrangements for joint working

6. Please indicate how the following services are accessed for children and young people who are patients in the community? (Please tick all that apply)

<table>
<thead>
<tr>
<th>Service Description</th>
<th>On-site</th>
<th>Off-site through a formal network</th>
<th>Off-site through an informal network</th>
<th>No access</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paediatrician with specialist expertise in neurodisability/cerebral palsy</td>
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<tr>
<td>Paediatric neurologist</td>
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<tr>
<td>Paediatric gastroenterologist</td>
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<tr>
<td>Paediatric surgeon/general surgeon with an interest in children</td>
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<tr>
<td>Paediatrician with specific interest in epilepsy</td>
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<tr>
<td>Orthopaedic surgeon with expertise in children and young people’s cerebral palsy</td>
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<tr>
<td>Paediatric pain specialist</td>
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<tr>
<td>Professional Specialisation</td>
<td>On-site</td>
<td>Off-site through a formal network</td>
<td>Off-site through an informal network</td>
<td>No access</td>
</tr>
<tr>
<td>----------------------------</td>
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</tr>
<tr>
<td>Orthopaedic surgeon with expertise in children and young people's cerebral palsy</td>
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<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>Spinal orthopaedic surgeon with paediatric expertise</td>
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<tr>
<td>ENT surgeons with paediatric expertise</td>
<td>☐</td>
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<td>☐</td>
<td>☐</td>
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<tr>
<td>Audiology with paediatric expertise</td>
<td>☐</td>
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<tr>
<td>Ophthalmology with paediatric expertise</td>
<td>☐</td>
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<tr>
<td>Paediatric respiratory physician</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>Paediatric physiotherapist</td>
<td>☐</td>
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<td>☐</td>
<td>☐</td>
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<tr>
<td>Paediatric dietician</td>
<td>☐</td>
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<tr>
<td>Paediatric occupational therapist</td>
<td>☐</td>
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<tr>
<td>Paediatric clinical psychology</td>
<td>☐</td>
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<tr>
<td>Paediatric speech and language therapist - communication</td>
<td>☐</td>
<td>☐</td>
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<td>☐</td>
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<tr>
<td>Paediatric speech and language therapist - dysphagia, feeding and swallowing</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>Children's specialist community nurse</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Children and young people's learning disability nurse specialist</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>Children's epilepsy nurse specialist</td>
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<tr>
<td>Paediatric continence specialist practitioner</td>
<td>☐</td>
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<tr>
<td>Child and adolescent mental health service</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Child and adolescent mental health service specifically for children and young people with learning disability</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Specialist children and young people's dental services</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Psychological support for parents/family members</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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</tr>
</tbody>
</table>
### E. SERVICES AND PROCEDURES

**7a.** Which of the following procedures/interventions can be accessed for children and young people with cerebral palsy seen in the community?

<table>
<thead>
<tr>
<th>Procedure</th>
<th>On-site</th>
<th>Off-site through a formal network</th>
<th>Off-site through an informal network</th>
<th>No access</th>
</tr>
</thead>
<tbody>
<tr>
<td>Magnetic resonance imaging without sedation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Magnetic resonance imaging with sedation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Magnetic resonance imaging under general anaesthetic</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standardised pelvic x-ray for hip surveillance</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>pH studies</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Botulinum toxin injections under sedation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gait analysis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**7b.** If MRI is undertaken, is this arranged for children and young people with suspected cerebral palsy:
- [ ] Routinely
- [ ] Selectively depending on clinical assessment

*(If MRI is selectively undertaken, please specify criteria)*

**7c.** Is there specialist paediatric neuroradiological expertise available to interpret MRI findings (not necessarily onsite)?
- [ ] Yes
- [ ] No

**7d.** If yes, is this available:
- [ ] Routinely
- [ ] On an ad hoc basis

**7e.** What is the waiting list time for "routine" MRI from the paediatric outpatient department for disabled children and young people? (in weeks)

- No sedation: [ ] Weeks
- Under sedation: [ ] Weeks
- Under general anaesthetic: [ ] Weeks
### F. ACCESSIBILITY

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

8a. In general, across this outpatient service are there any problems with access to:

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

8b. If yes to any of the above, please give details:

### G. SYMPTOM MANAGEMENT

9a. For children and young people with cerebral palsy at GMFCS levels I and II (independently mobile without the need for devices) healthcare is most likely to be led by:

- [ ] GP
- [ ] Community paediatrician
- [ ] General paediatrician
- [ ] Disability paediatrician
- [ ] Orthopaedic surgeon only
- [ ] Orthopaedic surgeon and paediatrician
- [ ] Other (Please specify)
9b. For children and young people with cerebral palsy at GMFCS levels III and IV (dependent on devices or wheelchairs for mobility, but not completely dependent on other people, able to self-propel manually or in power chair) healthcare is most likely to be led by:

- [ ] GP
- [ ] Community paediatrician
- [ ] General paediatrician
- [ ] Disability paediatrician
- [ ] Orthopaedic surgeon only
- [ ] Orthopaedic surgeon and paediatrician
- [ ] Other (Please specify) [ ]

9c. For children and young people with cerebral palsy at GMFCS level V (completely dependent on other people to propel wheelchairs for mobility) healthcare is most likely to be led by:

- [ ] GP
- [ ] Community paediatrician
- [ ] General paediatrician
- [ ] Disability paediatrician
- [ ] Orthopaedic surgeon and paediatrician
- [ ] Other (Please specify) [ ]

10. Is there a policy of ALWAYS enquiring about the presence (or not) of pain at each consultation?  [ ] Yes  [ ] No

11a. In general, who is responsible for hip surveillance? (Tick all that apply)

- [ ] Physiotherapist
- [ ] GP
- [ ] Community paediatrician
- [ ] General paediatrician
- [ ] Disability paediatrician
- [ ] Orthopaedic surgeon
- [ ] Ad hoc hip surveillance
- [ ] No standardised hip surveillance in place

11b. In general, who is responsible for spine surveillance for those at GMFCS III-V? (Tick all that apply)

- [ ] Physiotherapist
- [ ] GP
- [ ] Community paediatrician
- [ ] General paediatrician
- [ ] Disability paediatrician
- [ ] Orthopaedic surgeon
- [ ] Ad hoc hip surveillance
- [ ] No standardised hip surveillance in place

12a. If a scoliosis or other spinal curvature is identified, is a referral made to the spinal orthopaedic surgeon?  [ ] Yes  [ ] No

12b. If YES, is this:

- [ ] Immediately on identification of the curvature
- [ ] When the clinician thinks the curvature may need surgical intervention
- [ ] Not referred to spinal orthopaedic surgeon, managed conservatively

13. Are evidence-based guidelines (e.g. NICE CG137/SIGN 143) followed for the assessment and management of patients with epilepsy?  [ ] Yes  [ ] No
### G. SUPPORT SERVICES

14a. What FAMILY SUPPORT systems are available for children and young people with cerebral palsies who attend paediatric clinics? (Please tick all that apply)

<table>
<thead>
<tr>
<th>Service</th>
<th>On-site</th>
<th>Off-site through a formal network</th>
<th>Off-site through an informal network</th>
<th>No access</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children's social work team</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Parents information officer</td>
<td></td>
<td></td>
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<tr>
<td>Carer support groups</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical psychology</td>
<td></td>
<td></td>
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<tr>
<td>Parent carer forum/council</td>
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<tr>
<td>Young people's forum</td>
<td></td>
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<td></td>
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<tr>
<td>Young carer support</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Short breaks</td>
<td></td>
<td></td>
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<tr>
<td>Advice on benefits and financial support</td>
<td></td>
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<tr>
<td>Sibling support including psychology</td>
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</tr>
</tbody>
</table>

Other (Please specify)

**Children's social work team**

14b. If a CHILDREN’S SOCIAL WORK TEAM is available, does this team support:

- [ ] All families with disabled children and young people routinely
- [ ] Only involved if there are safeguarding issues

14c. What are the thresholds for the involvement of the team? (Please specify)

**Short breaks**

15. Are short breaks available for all disabled children, young people and their families who need them?

- [ ] Yes  
- [ ] No
16. Other than a social worker, is there a family liaison officer/support worker/carer’s centre team for children and young people who are seen by this service? □ Yes □ No

School support
17. What SCHOOL SUPPORT systems are in place for children and young people with cerebral palsy seen by this service? (Please tick all that apply)
   □ Specialist teachers for children and young people with physical and medical needs
   □ Specialist teachers for children and young people with vision impairments
   □ Specialist teachers for children and young people with hearing impairments
   □ Specialist teachers/team for children and young people with autism spectrum disorders
   □ Educational psychology
   □ Other (Please specify)

18. Are you able to recommend accessible leisure opportunities that are available locally? □ Yes □ No

H. COMMUNICATION ISSUES
19. Whilst under this service, are children and young people given the opportunity to speak to health professionals without a parent present if they prefer to? □ Yes □ No
20a. Are “Right from the Start” (or equivalent) guidelines embedded in this community/disability service to inform communication about diagnosis? □ Yes □ No
20b. Has there been specific training in ‘Right from the Start’ (or equivalent) in this service? □ Yes □ No
21. Are parents given written information at the time of diagnosis? □ Yes □ No
22. Are parents provided with sources of information and support? (Please tick all that apply)
   □ Locally
   □ Nationally
   Please specify

I. COMMUNICATION IN AN EMERGENCY
23a. Is there an agreed system in place for preparing written emergency health care plans (which may include personal resuscitation plans) for those with the most complex medical/surgical needs? □ Yes □ No
23b. How well is this system implemented in the regular care of severely disabled children and young people?
   □ Completely (all patients with complex needs have such a plan in place)
   □ Partially
   □ Not implemented
24. Are written communications, including Emergency Health Care Plans and 24 hour postural management plans, available in other languages or formats if required?  
   Yes  No

25. For children and young people seen in this service, is there access to a key worker/lead professional for families?
   - Routinely available for disabled children/young people and families
   - Only available for those with the most complex disabilities
   - Only available for pre-school children

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**J. TRAINING**

26. Is any training provided (either for specific procedures or broad areas of management) for children and young people seen by this community/disability service in aspects of self management?  
   Yes  No

27. Is any training provided for parent carers of disabled children and young people seen by this service in aspects of management, including technology dependencies (for example ventilator, gastrostomy tube, VP shunt)?  
   Yes  No

28. Does this service provide training for care workers locally in aspects of management of cerebral palsy?  
   Yes  No

29a. Does this service provide training for other professionals providing services for disabled children, young people and their families (e.g. doctors, therapists, teachers, social workers, health visitors, school staff, leisure providers etc)?  
   Yes  No

29b. If yes, does this training include any of the following?
   - Disability training at induction
   - Disability training embedded in regular training
   - No disability-specific training
   - Other (Please specify)

29c. Are disabled children, young people and/or families involved in delivering any of the above training?  
   Yes  No

29d. If yes to question 29c, please provide details.

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**K. TRANSITION TO ADULT SERVICES**

30a. 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
30b. Does the recognised transition framework or policy specify the following elements? (Please tick all that apply)

- [ ] A designated specific care coordinator at transition?
- [ ] Clear written information including that of a key/lead contact within a particular agency?
- [ ] Clear information about emergency and out of hours access to advice if needed after transition?
- [ ] Regular and consistent age appropriate support at transition?

31. What arrangements are in place for young people under this service to support person-centred transition to adult services? (Please tick all that apply)

- [ ] Specialist transition team/Person-centred planners
- [ ] Specialist learning disability transition nurse/s
- [ ] Specialist disabled children's social work team to support transition
- [ ] No specific transition arrangements
- [ ] Other (Please specify) [ ]

32a. Within this organisation is transition to adult neurodisability services for young people based primarily on age? [ ] Yes [ ] No

32b. If yes, at what age does transition generally occur between paediatric neurodisability services and services for adults? (Please specify)

33. Is there a designated professional that leads on the planning of transition care between neurodisability services for young people and adults? [ ] Yes [ ] No

34. Does this organisation monitor how well the transition policy works? [ ] Yes [ ] No

35. 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

36. To what services do young people with cerebral palsy transfer when leaving paediatric services, when ongoing secondary healthcare is needed? (Answers may be multiple)

- [ ] No services to transfer to
- [ ] Specific transfer arrangements with GP
- [ ] Neuro-rehabilitation specialist
- [ ] Other specialist physician/surgeon (please specify)

37. Are there MENTAL HEALTH services for young people with cerebral palsy in adult services:

- [ ] For those with a learning disability
- [ ] For those without a learning disability
- [ ] Both
- [ ] Unknown

38. Are there SOCIAL CARE services for young people with cerebral palsy in adult services: (Please tick all that apply)

- [ ] For those with a learning disability
- [ ] For those without a learning disability
- [ ] For those who are completely dependent on others for all of their care
- [ ] Unknown
39. Are there services available to support young people with cerebral palsy with access to appropriate:
   - Work experience
   - Employment
   - Training
   □ Yes □ No
   □ Yes □ No
   □ Yes □ No

L. DECISION-MAKING WITH CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSY

40a. Is capacity routinely assessed for young people aged 16 years or over who receive general paediatric outpatient care where there are concerns that the young person may have an impairment of brain or mind?
   □ Yes □ No

40b. Does this always occur?
   □ Yes □ No

41a. Is a best interests decision-making process embedded in your service for young people over 16 years of age who have been assessed as not having capacity to make a specific decision at a specific time and in specific circumstances?
   □ Yes □ No

42. Are there systems in place for the views of children and young people to inform service design and delivery?
   □ Yes □ No

43. Are there systems in place for the views of parent carers to inform service design and delivery?
   □ Yes □ No

M. PALLIATIVE AND END OF LIFE CARE

40. Who provides palliative care for children and young people with cerebral palsy under this service?
   (Please select all that apply)
   □ GP
   □ General paediatrician
   □ Community paediatrician
   □ Paediatrician with specific expertise in disability (disability, community or general with specific expertise) and palliative care
   □ Paediatric palliative care consultant locally
   □ Paediatric palliative care consultant regionally
   □ Adult palliative care consultant
   □ Community children's nurse
   □ Specialist palliative care nurse
   □ Other (Please specify)

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE
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