

Each and Every Need

A review of the quality of care provided to patients aged 0-25 years old with chronic neurodisability, using the cerebral palsies as examples of chronic neurodisabling conditions



NCEPOD

Improving the quality of healthcare



Swansea University
Prifysgol Abertawe

Each and Every Need

A review of the quality of care provided to patients aged 0-25 years old with chronic neurodisability, using the cerebral palsies as examples of chronic neurodisabling conditions

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Many more children and young people with chronic neurodisability now survive into adult life due to improvements in neonatal and general paediatric care. Importantly, some of these survivors will have additional long-term problems with day-to-day activities including mobility, hearing, vision and communication which need to be considered.

This report follows a trail of child health reviews which began in 2006/7 with the publication of 'Why Children Die' by the Confidential Enquiry into Maternal and Child Health (CEMACH).¹ This was followed by more recent reviews from the Royal College of Paediatrics and Child Health (RCPCH) highlighting deficiencies in care particularly in relation to children and young people with chronic illness.²

Proactive, multidisciplinary care which is underpinned by excellent communication with the patient at the centre, leads to better outcomes when compared to passive monitoring of the natural history of the disabling health condition. Recent NICE guidance has emphasised the need for improvements in care that can and should be made for patients with a cerebral palsy up to the age of 25 years.³

All children and young people with a neurodisability should have the right to receive the same high quality healthcare as anyone else. This should include close attention to detail to ensure their wider needs are appropriately understood and described at every opportunity, including health conditions, family reported issues, technology dependencies and need (or not) for care 24/7. When needs are adequately recognised they are more likely to be dealt with effectively

as part of the overarching care plan. To achieve this goal, exceptional communication between service providers is required using robust networks to ensure that each and every need is met.

More than 40 years ago the Court report⁴ recommended that each 'district' had a multidisciplinary disability team. Formal training and specialisation in neurodisability care for paediatricians followed and has been available in the UK since 2005. However, these changes and recommendations have been only partially adopted in adult health care. Although transition between child and adult healthcare was identified in 2014 by the Children and Young People's Health Outcomes forum⁵ as requiring particular attention, it is woefully lacking in many areas.

Handing on the baton of the leadership of multidisciplinary team care is essential at all transitions, including to adult services. At present there are often no natural successors to lead the team and orchestrate the care in adult practice other than the patient's general practitioner who may or may not have been involved in decision making at an earlier date. The re-organisation of primary care services into larger networks offers an opportunity to bridge the gap in neurodisability services for young people with a neurodisabling condition.

This will depend on clinical champions in general practice being appointed and included in the planning and implementation of transition. Environmental issues are a major challenge for many patients, their families and services. Whilst it is rarely possible to 'fix' the disabling health condition, it should surely always be possible to

1 Pearson, G A (Ed) *Why Children Die: A Pilot Study 2006; England (South, West, North East and West Midlands), Wales and Northern Ireland*. London: CEMACH. 2008

2 Royal College of Paediatrics and Child Health *CHR-UK Programme of Work at the MRC Centre of Epidemiology for Child Health, University College London Institute of Child Health*. September 2013. *Overview of Child Deaths in the four UK countries*.

3 National Institute for Health and Care Excellence (NICE) *Clinical guidelines [NG62]: Cerebral palsy in under 25s: assessment and management*. Published January 2017

4 *Fit for the Future" – a report of the committee on child health services, The Court report 1976*

5 *CYPHOF Report on Long term conditions, Disability and Palliative care subgroup 2014* https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216856/CYP-Long-Term-Conditions.pdf (FREFS).

FOREWORD

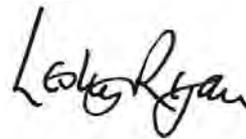
ensure the environment is appropriate, including adequate physical access to clinic services, and equipment to accommodate a range of different needs.

The issue of inadequate transition is not confined to neurodisability. NCEPOD is also leading on a parallel report on young people's mental health which also focuses on transition. Indeed, NICE have published guidance on the importance of it, yet this still appears to be a major failing in how healthcare services are being provided.

Identifying complex conditions and building a picture of individual needs will promote better care and enhance the value of robust datasets, mapping the utilisation of health services with greater clarity. In 2015 the routine Children and Young People's Health Services dataset in England was mandated for central flow to NHS digital for all providers of publicly funded community services. This evolved in 2017 to the all-age Community Services Dataset. This report has demonstrated the potential value of routine national data recording by clinicians at the point of care in all settings and across the UK. This will allow the scrutiny of variations in aspects of healthcare so that they can be addressed for a patient group. Using SNOMED CT as the consistent coding system across all nations will mean that like can be compared with like. Governance arrangements to allow interrogation of these data across the UK must be harmonised to make data analyses as easy as possible, since accessing the data for this part of the study was cumbersome. With the implementation of the new General Data Protection Regulations there is a risk that this will only become worse, and the benefits of using

large datasets to improve care will become outweighed by the bureaucracy of the application process.

As with all NCEPOD reports I must acknowledge the enormous effort that has gone into this study. The teams at Cardiff and Swansea Universities who were committed to gathering and analysing the available national datasets, comprising hundreds of thousands of datapoints. The multidisciplinary study advisory group who helped to design the study and the case reviewers who generously gave up their time. To each clinician who took pains to complete the lengthy questionnaires. The NCEPOD Local Reporters who identified the cases for us, copied the notes and understood the need for making sure they were as complete as they could be. Further thanks are due to our NCEPOD Ambassadors who championed the topic locally, the authors for writing such a detailed report, the researchers for their analysis and guidance on interpreting the data. The whole of the NCEPOD team for running the study to schedule and to our panel of lay representatives for their invaluable insight and non-clinical interpretation of the findings. Finally I thank my fellow Trustees and our clinical co-ordinator's for all their support.



Professor Lesley Regan
NCEPOD Chair

Introduction

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In 2013 the Royal College of Paediatrics and Child Health published their 'Overview of Child Deaths in the Four UK Countries' report.¹ This highlighted a number of key issues, one of which was that two thirds of children who died had a chronic condition, most frequently neurological, reflecting the shift in survival combined with more effective prevention of perinatal deaths. The report was the first of the next generation of child health reviews, based on earlier work by the Centre for Maternal and Child Enquiries (CMACE) formerly the Confidential Enquiry into Maternal and Child Health (CEMACH).

The report presented here is a natural follow-on to the four nation death review, by looking in detail at chronic neurodisability to identify areas of care that could be improved for all patients up to the age of 25 years. A parallel study which is published at the same time by NCEPOD fulfils an additional need identified within the

2013 RCPCH report to examine the care of young people and young adults receiving mental health care in the UK.

What is disability?

The definition of disability from the World Health Organisation brings together the 'medical model' of disability, which considers health conditions, body structure and function, with the 'social model' of disability, which considers factors in the environment that can be disabling, such as physical factors and peoples' attitudes (Figure 1). Disability is thus something that can affect anyone at any time and can vary over time.

There are numerous causes of chronic neurodisability in children and young people, in some cases the cause or precise diagnosis remains ill defined.

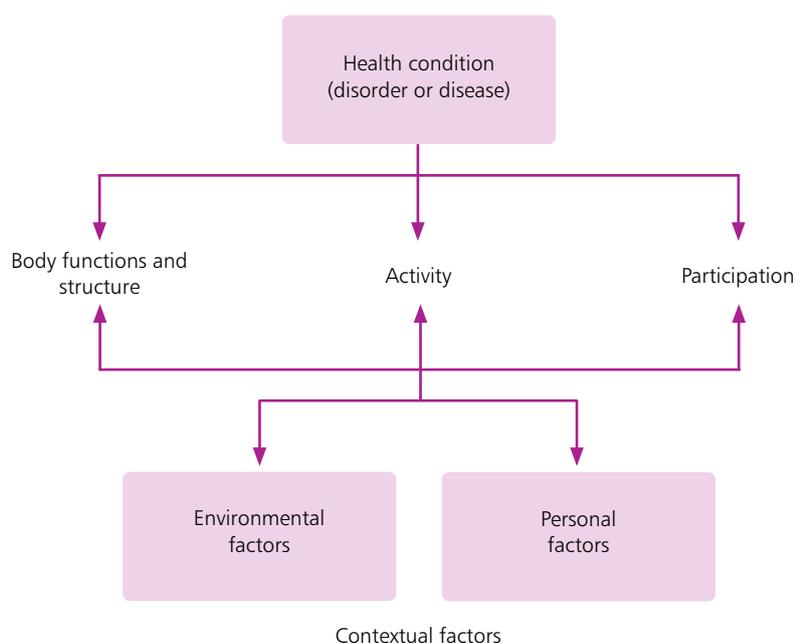


Figure 1 WHO model of disability

Why the cerebral palsies?

'Cerebral palsy' is an umbrella term for a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy and by secondary musculoskeletal problems.

Together the cerebral palsies are the most common cause of physical disability in early childhood, affecting around three per 1000 live births. The majority of children with a cerebral palsy will be diagnosed within the first two years of life. In those with milder symptoms diagnosis may not be possible until four-five years of age and sometimes occurs even later. Infants with severe brain damage, for example associated with prematurity or perinatal complications, may be diagnosed soon after birth.²

Cerebral palsies are a common cause of chronic neurodisability in children and young people and were chosen for this project as exemplar disabling conditions. The cerebral palsies encompass a broad spectrum of severity and can be associated with a wide range of other impairments, including any combination of the following: epilepsies, special communication needs, learning disabilities, hearing impairment, vision impairment, chronic pain, behavioural, emotional and mood issues, autism spectrum conditions, eating, drinking and swallowing issues, drooling, constipation, continence issues, disordered sleep, and skeletal deformities.^{2,3,4}

Additional comorbidities lead in many to an increased incidence of urgent and planned medical and surgical interventions, as well as in some dependency on technologies such as artificial feeding and assisted ventilation. Children and young people with a cerebral palsy are also vulnerable to all of the medical and surgical conditions that can affect anyone else, but these conditions can be more difficult to diagnose and manage in the presence of a cerebral palsy. Those who are least mobile and

most dependent on others for all of their care may develop neurological, respiratory, digestive, musculoskeletal and nutritional complications that require hospitalisation.

Healthcare for children and young people with cerebral palsies is therefore delivered in a range of settings, including emergency departments, acute inpatient wards, critical care units, outpatient clinics, community-based clinics and home visits by many different healthcare providers, including allied health professionals, doctors, surgeons, general practitioners, nurses and healthcare assistants. Studying healthcare in this group reflects this complexity, necessitating multiple organisational and clinical questionnaires to capture the range of settings and professional viewpoints across the age spectrum.

It is well documented across the developed world that service provision for those with cerebral palsies becomes fragmented after adolescence and that service users and their carers can feel 'lost in transition'.^{5,6,7,8} Transition from paediatric to adult services is a complex process, and ideally throughout the transition process healthcare should be delivered in a coordinated and uninterrupted manner. Challenges to successful transition include limited access to adult services, differences between paediatric and adult healthcare systems, inadequate preparation, and changing family roles.⁸ Suboptimal transition to adult services has been linked to a decrease in the utilisation of services by adolescents and deterioration in overall health.⁹

The study presented here has used multiple data sources to collate an overall picture of the services available and the care provided to children and young people with a cerebral palsy. The analysis of routine national datasets has used their potential to provide population based quantitative summary information about NHS utilisation for children and young people with the cerebral palsies in comparison with children and young people without cerebral palsies, showing trends by age, social economic status, inter-country comparisons and comorbidities over time. Analysis of data from clinical questionnaires, case review and organisational data have provided a detailed picture of current practice across healthcare services.

Recommendations

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The overarching aim of this report is to improve the care provided to children and young people aged 0-25 years with a chronic neurodisability. The cerebral palsies have been used in the study as examples of neurodisabling conditions.

The recommendations with a shaded background relate only to patients with a cerebral palsy.

The term 'clinician' has been used to encompass all healthcare professionals, although individual specialties have been listed where appropriate.

The text in italics after each recommendation is a suggestion as to who should be aware of / lead on the recommendation, but this will vary locally so please include all groups who need to be involved.

The **PRINCIPAL RECOMMENDATIONS** have been ranked by all involved as those recommendations of primary importance.

Improving clinical coding and quality of routine data

1 PRINCIPAL RECOMMENDATION

Clinical coding of neurodisabling conditions in all healthcare records and routinely collected datasets must be accurate and consistent if data are to be meaningful, comparable and useful to inform health outcome reviews and patient care.

- a) Cerebral palsy and other chronic neurodisabling conditions should be added to the standard list that *"must always be coded for any admitted patient care episode (including day case patients) when documented in the patient's medical record for the current hospital provider spell, regardless of specialty."*^[i]
- b) Standardised healthcare data should be captured by clinicians each time a patient is seen, in ALL settings (to include community based organisations)

- c) Data collection about patients with neurodisabling conditions must include measures of clinical severity and functional abilities to enable detailed analysis
- d) Clinical coding systems should be harmonised across routinely collected datasets in England, Wales, Scotland and Northern Ireland to enable data analysis throughout the UK
- e) Patient records and routine data collections across different healthcare providers (community care, primary care, secondary care and mental health) should be linked to provide the greatest potential for quantifying healthcare utilisation and patient outcomes on a population basis. *(Responsibility for action rests with Clinicians to capture data about needs at the point of care; Chief Executives to provide easy to use electronic data capture interfaces for clinicians to achieve this; Commissioners to ensure the above are in place and the Governments or those with responsibility in England, Scotland, Northern Ireland, Wales, Guernsey, Jersey and the Isle of Man to ensure that the system specifications for electronic records are adequate for the task in all settings where clinical activity occurs.)*

As hospitals move to electronic patient records, this should facilitate better data linkage between healthcare providers. Work is underway to include SNOMED CT (Systematized Nomenclature of Medicine - Clinical Terms - a standardised vocabulary of clinical terminology) into the routine coding system for UK NHS data. SNOMED CT already captures the 'Surveillance of Cerebral Palsy in Europe' preferred diagnostic terms (including measures of disease and functional severity). These are incorporated into the Community Services Data Set in England and the Community Health Activity Data in Scotland, and NHS providers are mandated to report these diagnostic data at each non-inpatient healthcare contact. However, introduction of SNOMED CT is

RECOMMENDATIONS

taking a phased approach, neither SNOMED CT nor the Community Services Data Set/ Community Health Activity Data is used across the UK.

- 2 Access to existing routinely collected national datasets needs to be improved. The governance and application process to the four nations should be harmonised to promote data linkage and encourage the use of population datasets more effectively and efficiently. *(NHS Digital, NHS England, NHS Scotland, NHS Wales, Northern Ireland Statistics and Research Agency, Guernsey, Jersey and the Isle of Man)*

Recommendations 1 and 2 should therefore be considered as hospital systems are planned to ensure a seamless transition from one coding system to another.

- i. National Clinical Coding Standards ICD-10 5th Edition

Clinical care - diagnosis and management

3 PRINCIPAL RECOMMENDATION

Patients suspected of having a neurodisabling condition should have an expert assessment by clinicians who have the competences to consider the range of possible diagnoses. For those patients with a cerebral palsy, the clinician must be able to recognise and describe the tone variation and distribution pattern of motor impairment, as informed by 'NICE Guideline 62' **[ii]** and the 'Reference and Training Manual of the Surveillance of Cerebral Palsy in Europe' **[iii]**. *(Clinicians, Medical Directors, Commissioners, Regulators, Royal Colleges and Specialty Associations)*

- 4 Patients with a cerebral palsy should have the pattern of their motor impairment (e.g. unilateral/bilateral) and tone variation (spasticity, dyskinesia, dystonia, ataxia or choreoathetosis) assessed and recorded in the clinical notes by the clinician undertaking the assessment. *(Clinicians, Regulators)*
- 5 Patients with a cerebral palsy should have their level of motor functioning described and documented in every clinical communication, using the Gross Motor Function Classification System. *(Clinicians, Regulators)*

- 6 Clinicians offering assessments to consider neurodisabling conditions as possible diagnoses should have timely access to magnetic resonance neuroimaging (MRI), including facilities for sedation and/or general anaesthesia if required. These may be within a network of care. MRI should not be provided without appropriate neuroradiological expertise to inform the imaging protocols used and to accurately interpret the images obtained. *(Clinicians, Medical Directors, Commissioners, Regulators)*

7 PRINCIPAL RECOMMENDATION

Patients with a neurodisabling condition should have access to an appropriate multidisciplinary team to proactively monitor their health status when their needs are complex and/or when there is a change in their functional status, physical condition or environmental situation. For those patients with a cerebral palsy, this access should reflect 'NICE Guideline 62' **[ii]**. *(Medical Directors, Clinical Directors, Clinicians, Commissioners, Regulators)*

- 8 Patients with neurodisabling conditions should have their weight and nutritional status considered at every healthcare encounter and assessed and recorded based on clinical need. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*
- 9 As for all patients, those with a neurodisabling condition who also have a learning disability should have this clearly documented in their clinical records by all healthcare providers (e.g. in primary and/or specialist healthcare). *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Regulators)*
- 10 Oral health and dental care for patients with a neurodisabling condition must be considered as a matter of routine by their lead clinician. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*

11 PRINCIPAL RECOMMENDATION

All patients with complex needs and, where appropriate, their parent carers or legal guardians, should be offered the opportunity to develop a patient-held Emergency Health Care Plan/Emergency Care Summary to facilitate communication in the event of a healthcare emergency.

[iv] This should include as a minimum:

- a) information about the patient's health conditions and treatment;
- b) who to contact in a range of scenarios and what to do;
- c) a statement about what has been discussed and agreed about levels of intervention including palliative care planning; and
- d) the existence of any advance directives (for those over 18 years), lasting power of attorney or any other measure.

The existence of this Emergency Health Care Plan/ Emergency Care Summary must be recorded in all communication and case notes and this should be subjected to local audit. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, General Practitioners, Commissioners, Regulators)*

- 12 Patients with a neurodisabling condition should have an assessment completed by their lead clinician to determine their risk of respiratory compromise. This should be reviewed as appropriate for the complexity of the patient's needs. Those patients at significant risk of respiratory compromise should be assessed by clinicians with expertise in respiratory medicine, in order to discuss with the patient and their family the range of interventions most likely to lead to the best outcome. 'What to do' and 'who to contact' in the event of respiratory symptoms should be documented in the patient-held Emergency Health Care Plan. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*
- 13 As for all patients, those with a neurodisabling condition admitted to an acute general hospital as an emergency should have timely assessment and senior review within 14 hours of admission by a specialist relevant to the emergency as recommended by the Royal College of Paediatrics and Child Health in 'Facing the Future' **[v]** and the Royal College of Physicians of London in the 'Acute Care Toolkit 4' **[vi]** *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*

- 14 Patients should undergo timely review prior to major surgery and/or if they have complex co-morbidity by key team members to ensure optimal preparation and planning. This must include senior members of the surgical, anaesthetic and medical teams. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*
- 15 Pain scoring tools should be understood and used in the peri-operative/peri-procedure period for patients with a neurodisabling condition. Healthcare staff should be trained in their use. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians)*
 - ii.** *NICE Guideline 62 - Cerebral palsy in under 25s: assessment and management*
 - iii.** *Reference and Training Manual of the Surveillance of Cerebral Palsy in Europe*
 - iv.** *Emergency Health Care Plan – Council for Disabled Children and Emergency Care Summary - Scotland*
 - v.** *Facing the Future and Emergency Care Summary - Scotland – Royal College of Paediatrics and Child Health*
 - vi.** *Acute Care Toolkit 4 – Royal College of Physicians*

Clinical care - clinical leads and care plans

- 16 Patients with a neurodisabling condition who need ongoing medical and therapeutic input should always have a named lead clinician to co-ordinate care across healthcare services and all age groups. Any change in lead clinician should include planning and a thorough handover. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, General Practitioners, Commissioners, Regulators)*
- 17 Patients with a neurodisabling condition should be on an appropriate care pathway. For those with a cerebral palsy this should include arrangements for surveillance of hips, spine and growth until skeletal maturity and in the longer term, nutritional surveillance and the identification and management of pain. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*

18 PRINCIPAL RECOMMENDATION

Patients with a neurodisabling condition should have a clear care plan that describes and addresses all of their needs. For those with a cerebral palsy this should specifically include pain, growth, nutritional status, safety of eating and drinking and other medical conditions such as seizures or mental health or behavioural issues. This care plan should be reviewed and updated when in hospital and on discharge to the community. Where the patient has complex needs this should be readily accessible to patients, their parent carers and clinicians e.g. as part of a patient-held patient passport. **[vii]** (*Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators*)

- 19 All medically frail patients with a neurodisabling condition, and where appropriate, their parent carers or legal guardians, must be offered the opportunity to discuss with their lead clinician, their care wishes in the event of serious illness or sudden collapse. This should be recorded in their patient-held Emergency Health Care Plan. This may include discussing Do Not Attempt Cardio Pulmonary Resuscitation decisions and palliative care plans, which should be validated at each point of care according to the existing legal requirements and professional guidance. This is particularly important to have in place at handover during transition to adult services. (*Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, General Practitioners, Commissioners, Regulators*)

vii. *Example of a patient-held passport*

Transition and age appropriate care

- 20 To facilitate transition to adult services there must be a clear, documented plan developed between the young person with complex needs and their multidisciplinary team. NCEPOD supports 'NICE Guideline 43' **[viii]** that transition planning should have begun by the age of 14. (*Clinicians, General Practitioners, Commissioners, Regulators*)

- 21 Healthcare organisations must better consider the needs of young people in the organisation, planning and delivery of healthcare. Age appropriate care must include dedicated physical space as *well* as agreed policies and procedures to be used in all clinical areas to facilitate patient privacy, dignity and inclusion. (*Medical Directors, Clinicians, Commissioners, Regulators*)

22 PRINCIPAL RECOMMENDATION

The transition plan between children's to adults' services should be co-ordinated by the lead clinicians and integrated within other multiagency plans e.g. health education, social care planning and mental healthcare services. The patient's team in primary care must be part of the planning process (*Clinicians, General Practitioners, Commissioners, Regulators*)

- 23 Care pathways for adolescent patients should promote dignity and independence when a hospital stay is needed and include ready access to single room accommodation, space for special equipment and the facility for parent carers to stay on-site when required **[ix]** and as recommended by the Royal College of Physicians of London in the 'Acute Care Toolkit 13'. **[x]** (*Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators*)
- 24 General Practitioner Networks, Federations, Clusters, Health Boards and Partnerships, should consider developing Clinical Champions for neurodisabled patients to lead and help 'bridge the gap' between specialist neurodisability teams and primary/community care. Leads could be engaged in care from the early teens and function as an essential link with the wider paediatric multidisciplinary teams. (*General Practitioners, Royal College of General Practitioners, Commissioners, Regulators*)
- viii.** NICE Guideline 43 - *Transition from children's to adults' services for young people using health or social care services*
- ix.** 'You're Welcome' Standards
- x.** Royal College of Physicians of London in the 'Acute Care Toolkit 13'.

RECOMMENDATIONS

Clinical care – communication

- 25 As for all patients, those with neurodisabling conditions should have their preferred method of communication clearly documented in their clinical records (electronic and/or paper) across all healthcare providers (e.g. in primary and/or specialist healthcare). *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, General Practitioners, Commissioners, Regulators)*
- 26 Each consultation with patients with a neurodisabling condition should be used as an opportunity to enquire whether they and their family have the information and support they need. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Regulators)*
- 27 All healthcare professionals who might work with patients with a neurodisabling condition should be able to make a range of reasonable adjustments to accommodate them, such as providing support for a range of communication, learning and physical access needs. 'Disability Matters' is a key resource that should be embedded in the training of all healthcare professionals. **[xi]** *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*
- 28 Patients with a neurodisabling condition, and where appropriate, their parent carers or legal guardians should have access to information and training in optimum self-management, problem-solving and how to get the right help and support as required in line with 'NICE Guideline 62'. **[ii]** *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*
- 29 Clinicians should be aware of, and comply with, the ethical and legal requirements for consent to surgery as defined by the General Medical Council and requirements for mental capacity assessments which will vary depending on UK country in which they live. These requirements must be communicated clearly to patients and parent carers and documented in the case notes. *(Clinicians, Commissioners, Regulators)*
- 30 Patients with a neurodisabling condition should be involved in all communications and decision-making about their care and management where possible, and where appropriate, with adjustments in place to support their involvement, including specialist speech and language therapists as required. Parent carers or legal guardians must also be included in these conversations as appropriate. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators, Patients)*
- 31 After a period of inpatient care patients with a neurodisabling condition should have their ongoing function and daily needs assessed and documented. Any significant change which would necessitate a planned alteration to day-to-day care must be clearly communicated in discharge plans. The discharge plan should be sent to the patient and their parent carers and their multidisciplinary team including their GP. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*
- ii.** NICE Guideline 62 - Cerebral palsy in under 25s: assessment and management
- xi.** Disability Matters
- 32 Clinicians should be trained to be able to communicate effectively with patients with a range of communication needs. They must be able to make a structured assessment of overall needs alongside management of the presenting condition. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, General Practitioners, Commissioners, NHS Scotland, Regulators)*

Organisation of care

- 33 All providers of healthcare for patients with a cerebral palsy or other chronic neurodisability should have clear care pathways described for patients, parent carers and referrers which are easily available e.g. on the hospital website with named contact details. **[xii]** *(Medical Directors, Directors of Nursing, Clinical Directors, General Practitioners, Commissioners, NHS Scotland, Regulators)*

RECOMMENDATIONS

34 To accommodate patients with neurodisabling conditions all healthcare facilities should:

- a) Be fully accessible;
- b) Have appropriate high quality equipment available including hoists, weighing scales, height measuring facilities, places to allow changing and wheelchairs to support participation in everyday activities and proactive independence. These should be easily available and maintained regularly. *(Medical Directors, Directors of Nursing, Clinical Directors, Commissioners, NHS Scotland, Regulators)*

35 Hospitals should review their day-case facilities and policies to ensure they are inclusive for neurodisabled patients with complex needs. *(Medical Directors, Directors of Nursing, Clinical Directors, Commissioners, NHS Scotland, Regulators)*

xii. *British Academy of Childhood Disability – Quality Principles for Paediatric Disability Services*

Whilst each recommendation should be read to determine if it is relevant to you or your organisation, the table below summarises a quick glance view of which ones should be looked at depending which ‘audience’ you are. A gap analysis tool, by audience is available on the report study page at www.ncepod.org.uk

Audience	Recommendation number(s)
Chief Executives	1
Clinical Directors	7,8,9,10,11,1,13,14,15,16,17,18,19,23,25,26,27,28,30,31,32,33,34,35
Clinicians	1,3,4,5,6,7,8,9,10,11,12,13,14,15,16,17,18,19,20,21,22,23,25,26,27,28,29,30,31,32
Commissioners	1,3,6,7,8,10,11,12,13,14,16,17,18,19,20,21,22,23,24,25,27,28,29,30,31,32,33,34,35
Directors of Nursing	8,9,10,11,12,13,14,15,16,17,18,19,23,25,26,27,28,30,31,32,33,34,35
General Practitioners	11,16,19,20,22,24,25,32,33
Guernsey	1,2
Isle of Man	1,2
Jersey	1,2
Medical Directors	3,6,7,8,9,10,11,12,13,14,15,16,17,18,19,21,23,25,26,27,28,30,31,32,33,34,35
NHS Digital	2
NHS England	1,2
NHS Scotland	32,33,34,35
NHS Wales	1,2
Northern Ireland	1,2
Patients	30
Regulators	3,4,5,6,7,8,9,10,11,12,13,14,16,17,18,19,20,21,22,23,24,25,26,27,28,29,30,31,32,33,34,35
Royal College of General Practitioners	1,2
General Practitioners	24
Royal Colleges	3
Specialty Associations	3

Summary

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The overarching aim of this study was to review the quality of care provided to patients with a cerebral palsy, as examples of a neurodisability condition. The interfaces between different care providers was assessed as well as transition from child to adult services. Children and young people with a cerebral palsy have many complex needs and whilst areas of good practice were seen, much room for improvement was identified.

At the very point of diagnosis, the term recorded in medical records to describe the cerebral palsy was often incorrect and frequently did not include specific information about the type of cerebral palsy or tone variation. From routinely collected population datasets, it was clear that although the cerebral palsies are chronic conditions, they are not coded at every contact point with NHS services. **5**

As part of the clinical assessment to determine the cause of the cerebral palsy, the study highlighted variation in access to Magnetic Resonance Imaging, including facilities for sedation and/or general anaesthetic. There was also variation in access to neuroradiological expertise to interpret the images obtained. Important clues to other diagnoses, including developmental brain anomalies and neurometabolic conditions, will be missed if neuroimaging is not undertaken. Accurate diagnosis informs accurate management. **5**

Despite being an internationally recognised system for describing gross motor function that informs clinical management, the Gross Motor Function Classification System (GMFCS) level of fewer than one in three children, young people and young adults with cerebral palsies was documented in their case notes. **8**

Good communication underpins all clinical practice and is encouraged by the General Medical Council and professional bodies, but there was lack of sufficient efforts seen to have been made to communicate directly with this group of patients in a third of the sample. There was

room for improvement in the documentation of inclusion of these patients in discussions and decision-making in four out of ten cases reviewed. There was poor communication in relation to needs, support, emergency health care planning and consent for procedures. **6**

Multidisciplinary team working is key for this group of complex patients, yet this was viewed as inadequate in 137/285 (48.1%) inpatients from the cases reviewed. Discharge summaries about episodes of inpatient care were not copied to lead clinicians for cerebral palsy care in almost half of cases and were only copied to the community physiotherapist in 30% for day case patients and 38% for admitted patients. If the wider team do not know what is happening for the patient, there can be no proactive, joined-up care. Good multidisciplinary team working depends on quality team leadership; however, our study evidenced considerable variation in clarity about who was leading multidisciplinary teams, this being especially the case for young adults with cerebral palsies. **7**

Routine national data showed that children and young people with cerebral palsies had similar trends of 'consultation' with primary care across the age groups to those without the conditions. However, those with cerebral palsies had a higher rate of consultation and number of consultations per year compared to other children and young people in all age categories. It is important for GPs to be aware of the potential multifaceted needs of this patient group, how to manage what they can in primary care and how to access clearly published care pathways when more specialist opinions or care are needed. The data suggested that children and young people with cerebral palsies attended primary and secondary healthcare settings significantly more frequently than those without cerebral palsy. Whilst the rate of outpatient attendances increased over time outpatient attendances decreased significantly with age whilst primary care attendance increased markedly between 15-25 years of age. **7** **12**

SUMMARY AND OVERALL QUALITY OF CARE

Peer reviewed data showed that a quarter of patients with a cerebral palsy, whose admission was unplanned, were seriously ill. Not all were seen in a timely fashion by senior clinicians, and recording of this event was poor. When appropriate, few patients had emergency healthcare planning in place.

Evidence from the case note reviews confirmed that clinical care was in need of improvement, including the recognition and management of aspects such as pain, learning disability, emotional and mental health and support needs. Weighing and measuring patients accurately to ensure adequate nutrition and accurate calculations for medication doses and fluids were inconsistent. Many patients in this study had unsafe swallows that were infrequently assessed. Hip and spine surveillance was variable, with hip status frequently not documented. 

Documentation was found to be wanting in this study: the wider health needs of one in ten children, young people and young adults with cerebral palsies were inadequately described in their case notes, including their preferred communication method and level of learning ability. Documentation about adjustments required to meet needs was missing in the case notes of half of the study sample. Often it was reported that basic equipment needed to meet simple needs were absent, such as hoists, wheelchairs, weighing scales and changing places. These issues were reported by the parent carers as well as clinicians in the hospitals who responded.  

Documentation of consent to procedures was found to be inadequate or inappropriate in a substantial number of cases reviewed where the patient was admitted for a procedure or surgery under general anaesthesia.

This study highlights considerable uncertainty about how and when transition to adult care occurred. NICE published guidance in 2016,¹⁰ the same year that NHS Scotland set generic “gold standards” for leadership and planning of transition in healthcare.¹¹ However, translation into practice does depend on there being equivalent services for young adults “on the other side of the divide”, to those available in paediatric services. Since this is hardly ever the case for patients with cerebral palsies or other neurodisabling conditions, the gap that opens up poses enormous challenges for patients and their families as well as health and social care providers, with a large burden of complex healthcare falling on to GPs. Peer review and the routine data highlighted that transition can take longer for children and young people with cerebral palsies than for those without. Also, the interface with different specialties involved throughout the transition period varied with the proportion of outpatient appointments for specialties managing mental health and learning disabilities increasing significantly between 10 and 25 years of age, but hospital admissions for the same specialties decreased with age.

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