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7 – Multidisciplinary care

Study Advisory Group question: Are robust frameworks of multidisciplinary care always available within the service provision?

Why is this important? Patients with a cerebral palsy have complex needs, requiring input from different specialties at different points in their care. Underpinning this there should be a defined care pathway to ensure that all team members are aware of their needs. This requires good leadership that overlaps with primary care and social care whilst ensuring proper safeguarding.

Leadership of multidisciplinary care

Every multidisciplinary team needs clear leadership to ensure excellent communication and effective co-ordination of care and this will depend on the age and level of disability. A lead clinician for disability care was reported to be in place by 351/403 (87.1%) leads for paediatric inpatient care, but was found to be documented in the case notes in only 240/380 (63.2%) of the cases reviewed for children and young people with cerebral palsies. Leads for care of adults with cerebral palsies reported a lead clinician for disability care to be in place in even fewer cases: 31/133 (23.3%) (Tables 7.1 and 7.2).

Table 7.1 Details of the patient's usual lead clinician for their cerebral palsy management was documented in the case notes – children (under 18 years of age) - reviewers' opinion

	Admitted patients		Day case patients	
	n= %		n=	%
Yes - details recorded	162	66.1	78	57.8
No details recorded - no obvious usual lead clinician	56	22.9	36	26.7
Details not recorded	27	11.0	21	15.6
Subtotal	245		135	
Unable to answer	9		9	
Total	254		144	

Table 7.2 Details of the patient's usual lead clinician for their cerebral palsy management was documented in the case notes – adults (18 years of age or older) - reviewers' opinion

	Admitted patients	Day case patients
	n=	n=
Yes - details recorded	21	10
No details recorded - no obvious usual lead clinician	64	24
Details not recorded	10	4
Subtotal	95	38
Unable to answer	3	0
Total	98	38

CASE STUDY 7

A young adult with bilateral dystonic cerebral palsy, with motor function at GMFCS level IV, was admitted for a day case procedure, for which the patient gave consent and which was uneventful with same day discharge.

The case reviewer reported excellent coordination of care and well described health and care needs, by the neurorehabilitation consultant. This included ascertainment and recording of mental health needs and how these were being addressed. It was noted that comprehensive healthcare by specialists with the competencies to identify all unmet health needs and to draw up and implement a care plan to address these reflects good practice.

	Paediatric outpatient care	Community paediatric care	Allied health professional paediatric inpatient care	Adult outpatient care	Allied health professional adult inpatient care
	n=	n=	n=	n=	n=
Routinely available for disabled children/ young people and families	11	16	25	5	19
Only available for those with the most complex disabilities	46	44	21	20	13
Only available for pre-school children	4	11	NA	NA	NA
Not available	6	NA	15	16	15
Subtotal	61	71	46	25	32
Not answered	17	10	2	12	5
Total	84	81	63	53	52

Table7.3 Access to a key worker by healthcare service

The NICE guideline on cerebral palsy (NG62)¹⁹ recommends timely, expert multidisciplinary care for everyone with a cerebral palsy. Access to a key worker or lead professional was reported to be variable in different care settings, as shown by the different organisational questionnaires in Table 7.3.

Care pathways underpinning multidisciplinary care

An agreed, written care pathway for assessment, diagnosis and management of children and young people with cerebral palsies was reported not to be in place by 56/82 organisations for paediatric outpatient care, by 42/81 leads in the organisational questionnaire for community paediatric care, and by 42/48 respondents of the adult outpatient care questionnaire.

Where pathways were in place, variation was reported in where care pathways for children and young people with cerebral palsies were published. This did not offer ease of access to referrers and parents (Table 7.4).

Table 7.4 Availability of care pathways

	Paediatric outpatient care	Community care
	n=	n=
Local Offer (England)	4	6
Organisation website	7	10
Written referral guidance for GPs, health visitors etc.	6	8
Not published	7	19
Other (please specify)	12	18
Subtotal	23	39
Not answered	3	0
Total	26	39

*Answers may be multiple

Table 7.5 Content of care pathways

	General paediatric outpatient care	Community paediatric care	Adult outpatient care
	n=25	n=39	n=44
Hip surveillance	23	38	NA
Magnetic resonance imaging of the head +/- spine	19	25	NA
Anthropometric measurement and monitoring of growth and nutrition	23	25	NA
Spine monitoring and when to refer to spinal orthopaedic surgeon	23	25	NA
Pain identification and management	20	24	18



Table 7.6 Responsible clinician for hip and /or spine surveillance

	Hip surv	eillance	Spine surveillance		
	Paediatric Community outpatient care care		Paediatric outpatient care	Community care	
	n=	n=	n=	n=	
Physiotherapist	50	49	49	51	
General practitioner	3	2	1	2	
Community paediatrician	59	59	53	55	
General paediatrician	20	19	15	15	
Disability paediatrician	24	36	27	37	
Orthopaedic surgeon	46	45	43	40	
Ad hoc hip surveillance	5	5	8	6	
No standardised hip surveillance in place	7	6	8	2	
Subtotal	83	79	82	79	
Not answered	1	2	2	2	
Total	84	81	84	81	

*Answers may be multiple

The details of what was reported to be written in the care pathway for children and young people with cerebral palsies is shown in Table 7.5.

Hospitals were asked to indicate which professionals in their hospital were responsible for **hip surveillance and spine surveillance for those patients at GMFCS level III-V**, the responses are shown in Table 7.6.

The term 'hip surveillance' covers a spectrum of practice, including unstructured, variable reviews to high quality, standardised, structured surveillance programmes such as that embedded across much of Scandinavia and also now across Scotland: the Cerebral Palsy Integrated Programme Scotland (CPIPS).²⁸ In Sweden where this was first developed and adopted, hip dislocation rates have fallen from 11% to 0.4% through earlier detection and proactive surgical intervention where necessary. Orthopaedic surgery for contractures has also reduced from 40% to 15% since the programme started. The programme encourages collaborative working between the child or young person, their family and clinical team. CPIPS is a national programme across all of Scotland, started in 2013, based around a centrally stored website accessible from NHS terminals all over Scotland. Structured assessments and measurements are undertaken by paediatric physiotherapists who have all undergone the same training programme, x-rays ordered and assessed, then a standard dataset is recorded in the CPIPS database. To date 1963 children and young people with cerebral palsies in Scotland are registered on the CPIPS, believed to be more than 95% of the population of children and young people with cerebral palsies in Scotland. More than 6000 assessments have been documented and more than 5000 x-rays reported on. A similar structured surveillance programme is being adopted in Northern Ireland. NHS England is leading a working group aiming to seek funding to adopt the same database as in Scotland, for use across England.

Lead clinicians for disability care reported that the patient's hip status was not documented in the case notes for 55/207 (26.6%) patients. Where hip status was documented, both hips were reported to be in joint for 69/136 (50.7%) patients, one or more hips were migrating out of joint for 38/136 (27.9%) patients, one or both hips were completely dislocated in 29/136 (21.3%) patients and hip status was unknown in 8/152 patients. For those patients at GMFCS level III-V, before skeletal maturity was reached, lead clinicians for disability care reported hip status was not documented at least annually in 26/113 (23%) patients, it was unknown for 47/174 patients and the question was recorded as not applicable for 14/174 patients.

The NICE guideline on cerebral palsy (NG62) is clear about the care pathways that should be accessible for all children diagnosed with cerebral palsies, with emphasis on early referral to an expert team for urgent multidisciplinary assessment (Recommendation 1.5.1), the requirement for care to be delivered by multidisciplinary and integrated local teams (Recommendation 1.5.3) that can network other specialist services easily as required (Recommendation 1.5.4).

Spine surveillance

If a scoliosis was identified, a referral was made to the spinal orthopaedic surgeon as reported in 81/83 organisational questionnaires for general paediatric outpatient care, in 74/78 organisational questionnaires for disability or community care and in 34/43 organisational questionnaires for adult outpatient care.

Lead clinicians for disability care reported the patient's current spine status to be straight in 88/156 (56.4%) patients, curved in 68/156 (43.6%) patients and unknown in 65/221 patients. Where a curve was present, there was evidence of regular input from a spinal orthopaedic surgeon for only 36/61 patients. For patients with cerebral palsies at GMFCS level III-V there was evidence of documentation of the status of the spine at least annually in 55/88 patients, but not in 33 patients and unknown in 75 patients.

Clinical delivery models

There was variation in care pathways reported in the organisational questionnaires for paediatric outpatient care, community paediatric care and adult outpatient care as shown in Table 7.7.

Table 7.7 Care pathways for children and young people with a cerebral palsy

	Paediatric outpatient care	Paediatric community care	Adult outpatient care
	n=	n=	n=
Non-specialist - seen as part of general clinical caseload	48	54	41
Specialist uni-disciplinary, i.e. each specialist sees the child or young people separately	51	61	17
Multidisciplinary for postural management	46	45	14
Multidisciplinary for feeding management	38	47	5
Outreach clinics in special schools	56	69	11
Other	41	32	15
Subtotal	83	81	53
Not answered	1	0	0
Total	84	81	53

*Answers may be multiple

Quality of multidisciplinary care

The organisational data showed that whilst most organisations had access to physiotherapists and occupational therapists, some had no access at all to key multidisciplinary team members, including psychologists, continence practitioners, learning disability mental health teams and psychological support for patients and their families. NICE guideline NG62 is clear as to which practitioners should be involved in the expert multidisciplinary team for everyone with a diagnosis of a cerebral palsy.

Lead clinicians for disability care reported that the care of the patient was delivered by an appropriate multidisciplinary team in 205/215 (95.3%) patients. Where it was reported to not have been delivered appropriately, the specialty input that was reported to have been missing was learning disability in four patients, general medicine in three patients, trauma and orthopaedics in two patients, paediatric neurology in two patients, rehabilitation in two patients, general surgery pain management, child and adolescent psychiatry and respiratory medicine all one case.

CASE STUDY 8

A young child with bilateral spastic cerebral palsy was admitted as a day case for botulinum toxin injections which were completed with no documented complications.

The case reviewer found clear documentation in the acute admission notes that intensive physiotherapy was required in the community following the intervention, but there was no documentation of any communication from the acute care team to the community physiotherapist about this. Good practice would have been for there to have been advanced communication between the acute care team and community physiotherapist, giving notice of the date of intervention so that intensive physiotherapy could have been planned ahead in the therapist's busy schedule. As a minimum, there should be communication on discharge directly with the community physiotherapist, rather than leaving the communication for the patient/parent to arrange. Table 7.8 shows the variation by age in person-centred, developmentally appropriate goal setting which considered body structure and function as well as activity and participation, as reported by clinical leads for disability care.

	0-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Subtotal	Not answered	Total
	n=	n=	n=	n=	n=	n=	n=	n=
Yes	29	44	32	17	6	128	5	133
No	7	19	12	4	4	46	5	51
Subtotal	36	63	44	21	10	174	10	184
Unknown	8	13	6	5	3	35	2	37
Total	44	76	50	26	13	209	12	221

Table 7.8 Evidence of person-centred, age and developmentally appropriate goal setting

Access to physical therapies

Clinical leads for disability care considered that there was not timely and adequate adjunctive physical therapy after treatments involving botulinum toxin type A, continuous pump-administered intrathecal baclofen, orthopaedic surgery or selective dorsal rhizotomy (as per recommendation 1.2.15 of NICE Clinical Guideline 145: Spasticity in under 19's²⁹ in 13/113 (11.5%) patients. This question was not answered for 17/221 patients and not applicable in 91/221 patients. For those 13 patients, two children were 0-4 years old, three were 5-9 years old, four were 10-14 years old, one was 15-19 years old, and

two were 20-25 years old. The therapist case reviewers noted the high number of patients who were reported to have received timely therapies and reflected that this may have been differently reported by the therapy leads than by the doctors. Case note reviewers reported evidence of adequate post-operative physiotherapy in only 194/342 (56.7%) cases reviewed.

Case note reviewers reported evidence of regular physiotherapy to support and build function and prevent impairment in only 221/309 (71.5%) patients. This varied with age as evidenced in Table 7.9.

Table 7.9 Regula	r physiotherapy by age	e - reviewers	' opinion
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	0-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Total
	n=	n=	n=	n=	n=	n=
Yes	47	72	48	43	11	221
No	10	17	16	20	25	88
Subtotal	57	89	64	63	36	309
Unable to answer	6	8	7	7	10	38
Not answered	0	0	0	0	3	3
Total	63	97	71	70	49	350

Clinical management strategy

A clear, overall multidisciplinary clinical management strategy was reported to be in place by 179/215 (83.3%) lead clinicians and this was reported to have involved discussion with the patient and their family in all cases. For the 36/215 (16.7%) patients where the lead clinician reported no such strategy, six children were 0-4 years old, fourteen were 5-9 years old, five were 10-14 years old, two was 15-19 years old and seven were 20-25 years old. The age was not stated for two patients.

Leads for clinical inpatient care reported other teams to be involved in the daily care and management of the patient in 320/493 (64.9%) of cases. MDT meetings were reported to have occurred during the admission for only 77/453 (17%) patients. The results of these meetings were clearly documented in the shared notes during the admission in 62/73 patients and the patient and/or carer were made aware of the outcome of the discussions in 63 cases. This was not known for 14/77 patients.

The case reviewers assessed the quality of multidisciplinary care across four settings, and found room for improvement in all, with a marked increase in adult services (Figure 7.1). The overall quality of care of community and outpatient care is shown in Figure 7.2.

Data on primary care was not forthcoming from the organisational data and case review so the routine national data was used to build on the overall picture of care.







Figure 7.2 Overall assessment of care - community care - reviewers' opinion

General practice

Data to explore the interface between primary and secondary care for children and young people with cerebral palsies were available from CPRD for a sample of 6.9% of UK general practices, where data were linked to HES for an estimated 5.34% of GP practices in England. Overall consultation rates were calculated for all four countries within CPRD, with a more detailed analysis for England where the dataset was largest. In Wales, GP data were available from 70% of GP practices from WLGP linked to PEDW. The rate of General Practice consultations followed the same trend for each country across the age groups. The highest referral rates were in the 0-4 and 20-24 year age groups. There were significant differences between the countries within each age group but there was no overall consistent trend seen for one country over another (Figure 7.3).



Figure 7.3 Rate of GP consultations (per 100 person years at risk) for patients with a cerebral palsy identified in CPRD GP data by age group

The annual rate of GP consultations for children and young people with a cerebral palsy (Figure 7.4) was greater than for those without a cerebral palsy (Figure 7.5). The trend of consultations was similar across the age groups for

the two populations with the greatest rates for those of 0-4 and 20-25 years of age. The GP consultation rates remained relatively constant between 2004-2014 for both populations.



(CPRD: England HES Linked)

There was a small but steady increase in the consultation rate from the least to the most deprived quintile for children and young people without a cerebral palsy. This trend was not repeated for those with a cerebral palsy where there was no significant difference between the least deprived quintile and the two most deprived quintiles, the consultation rate dipped for the 2nd and 3rd quintile (Figure 7.6).



and young people with and without a cerebral palsy within each Index of Multiple Deprivation (IMD) quintile (CPRD: England HES Linked)

The median number and interquartile ranges of GP consultations per year are shown in Figure 7.7. Those with a cerebral palsy in all age groups having more consultations

per year than those without (Figure 7.8) the highest numbers of consultations per years were seen in those of 0-4 years of age (Figure 7.9).



Figure 7.7 Median and interquartile ranges for the number of GP consultations per year by cerebral palsy status and age group for England (CPRD: England HES Linked)









For the CPRD analysis 'consultations' were limited to 'GP consultation – surgery/clinic', 'home visit' and 'telephone consultation' whereas the WLGP data included patient administration, referrals and clinical intervention as well as GP contact. These data suggest that the activity within primary care over and above direct GP contact was considerable and significantly greater for children and young people with one of the cerebral palsies than for those without.



Figure 7.10 Reasons for consultation: Proportion of total GP consultations between 2004-2014 for children and young people aged 0-24 years with and without a cerebral palsy by Read codes mapped to ICD-10-CM Chapters (CPRD England)

The most common reasons for GP consultations among children and young people with and without cerebral palsies were respiratory conditions. Children and young people with cerebral palsies had a higher proportion of consultations for respiratory, neurological and mental health issues and a lower proportion of consultations for infections and musculoskeletal disorders than those without a cerebral palsy (Figure 7.10). The same analysis of WLGP data gave similar results with the exception of mental health where there was no clear difference between the two groups.

Rate of referrals from General Practice

The pattern of primary care referrals to external care centres (e.g. secondary care for inpatient or outpatient care) followed a similar age related trend for children and young people with (Figure 7.11) and without a cerebral palsy (Figure 7.12). The rate of referrals for children and young people with one of the cerebral palsies was appoximately twice that of those without one of the cerebral palsies across all age groups.



Figure 7.11 Rate of referrals from primary care to external care centres between 2004 and 2014 for children and young people with cerebral palsies by year and age group (CPRD: England HES Linked)



Figure 7.12 Rate of referrals from primary care to external care centres between 2004 and 2014 for children and young people without cerebral palsies by year and age group (CPRD: England HES Linked)

The rate of referrals for children and young people with one of cerebral palsies decreased with respect to increasing IMD quintiles of social deprivation. There was no significant difference between the rate of referrals for children and young people without one of cerebral palsies between IMD quintiles (Figure 7.13).





Outpatient appointments for children and young people with a cerebral palsy







Figure 7.15 Rate per 100 person years at risk of outpatient appointments between 2004 and 2014 for children and young people without a cerebral palsy by year and age group (CPRD: England HES Linked)

Children and young people with one of the cerebral palsies (Figure 7.14) had significantly more outpatient appointments than children and young people without (Figure 7.15). The rate for 0-4 year olds and 20-24 year olds with a cerebral palsy was approximately 10 times and 3 times greater respectively than for those without a cerebral palsy.

The rate of outpatient appointments decreased across the older age groups with the lowest appointment rate for those aged 20-24 years of age.

The rate of outpatient appointments increased between 2004 and 2014 for both populations, and approximately doubled for those with a cerebral palsy in all age groups.

The rate of outpatient appointments was greatest in the least deprived (quintiles 1 and 2) and the most deprived quintiles for children and young people with a cerebral palsy. There was no significant variation in the rate of outpatient appointments across the deprivation quintiles for those without a cerebral palsy (Figure 7.16).



Figure 7.16 Rate of outpatient appointments per 100 person years at risk for children and young people with and without a cerebral palsy aged 0-24 years between 2004 and 2014 by Index of Multiple Deprivation (IMD) quintile



by age group (CPRD: England HES Linked)

The median number of outpatient appointments per year decreased with age for children and young people with cerebral palsies but remained unchanged for those without.

The median number of outpatient appointments per year per child or young person with a cerebral palsy increased between 2004 and 2014 for those younger than 15 years. There was a small increase for those 15-20 years of age but none was evident for those between 20 and 24 years of age) (Figure 7.17).

Reasons for outpatient appointments were seldom coded with an ICD-10 diagnostic code, but could be grouped according to specialty attended (available on request). Data are presented for 2010-2014 when the specialty groups included in HES datasets were most recently revised. Overall 43% of outpatient attendances for children and young people with cerebral palsies were recorded as surgical specialties, 42% medical, 11% therapies and allied health professionals and 3.5% mental health specialties (NHS main specialty codes). The greatest proportion for both groups of children and young people was recorded as paediatric attendances followed by therapies (Figure 7.18).





Community paediatric outpatient attendances were greater for children and young people with the cerebral palsies. However, community based services were seldom recorded in the HES outpatient datasets, as activity occurring in community settings was not subject to routine data collection at the time of the study.

For children and young people with cerebral palsies, the proportion of all attendances for paediatric, therapy, nervous system, trauma and orthopaedics outpatient appointments was greater than that for children and young people without cerebral palsies. However, there were significantly fewer outpatient appointments for dental, pregnancy, dermatology, ENT, genitourinary and gynaecological and surgical attendances. There were few OPD attendances for respiratory conditions considering that this was the greatest cause of primary care attendance, emergency hospital admissions and mortality. However, these may have been recorded as paediatric attendances.

Figure 7.19 summarises the rate of outpatient involvement in children and young people with cerebral palsies which decreases with age. The rate of outpatient attendance drops dramatically for 20-24 year olds, where the rate of primary care consultations increased from the age of 15 onwards.



Figure 7.19 Rate of GP, Outpatient and Inpatient attendances for children and young people with and without a cerebral palsy between 2004 and 2014 by age group (CPRD: England HES Linked)

Key Findings – questionnaire, case note review and organisational data

- A lead clinician for disability care was reported to be in place in 351/403 (87.1%) hospitals
- Reviewers found documentation of a lead clinician for neurodisability care in only 31/133 (23.3%) case notes of young adults in comparison to 240/380 (63.2%) notes for children and young people
- Almost all lead clinicians responsible for providing the ongoing neurodisability care of the patient, reported that care was provided by an appropriate multidisciplinary team (205/215; 95.3%)
- Reviewers found there to be room for improvement in multidisciplinary paediatric inpatient care in 82/200 (41%) cases reviewed, in outpatient paediatric care in 62/150 (41.3%) cases, in adult inpatient care in 41/74 cases, and in adult outpatient care in 25/36 cases reviewed
- An agreed written care pathway for the assessment, diagnosis and management of children and young people with cerebral palsy was not in place in 56/82 organisations providing paediatric outpatient care; 42/81 organisations providing community paediatric care; and 42/48 organisations providing adult outpatient care. Where pathways were in place, a majority included arrangements for hip surveillance, MRI, pain identification and management, and anthropometric measurement and the monitoring of growth and nutrition.
- Evidence of adequate post-operative physiotherapy input was found in less than six out of every ten cases.

SEE RECOMMENDATIONS 4·7·16·20·22·23·24·26·27·28·30 31·32·33

Key Findings – routine national data

- Children and young people with cerebral palsies had a similar trend of 'consultation' at primary care to those without the condition. This was true for all four countries. 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. The consultation rates were greatest in 0-4 year olds and 20-24 year olds
- Analysis of the Wales General Practice Dataset suggests that activities that include, administration, referrals and clinical activities are considerably greater for children and young people with cerebral palsies than for those without
- The rate of referrals to secondary healthcare or specialist services for children and young people with cerebral palsies was twice that for those without a cerebral palsy and decreased across the quintiles for greater social deprivation. This may represent the least deprived families requesting more referral, or the most deprived failing or lacking confidence or the ability to proactively seek referrals. Professionals need to be aware of this difference and work towards more equal access to services and thus more equal outcome opportunities. This contrasts with the information from hospital admissions which suggests no clear link between rates of hospital admissions and deprivation index
- Children and young people with cerebral palsies had a higher proportion of primary care consultations for respiratory, neurological and mental health issues and a lower proportion of consultations for infections and musculoskeletal disorders than for children without
- The rate of outpatient attendances increased for children and young people with cerebral palsies between 2004-2014. The rate of attendance was approximately ten times greater for children aged 0-4 years of age with cerebral palsies than in children without and approximately three times greater at 20-24 years

- The rate of outpatient appointments decreased significantly with age for those with cerebral palsies whilst it remained relatively constant for children and young people without a cerebral palsy, (with the exception of 20-24 year olds)
- The proportions of all outpatient attendances were greater for paediatric, therapy, nervous system, trauma and orthopaedics specialties for children and young people with cerebral palsies than those without. However there were significantly fewer attendances for dental, pregnancy, dermatology, ENT, genitourinary and gynaecological and surgical specialties
- The data suggest that children and young people with cerebral palsies attend primary and secondary healthcare settings significantly more frequently than those without a cerebral palsy. Outpatient attendance rates decrease significantly with age whilst primary care attendance increased between 15-25 years of age.