12

12 – Transition to adult services

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Study Advisory Group question: *Is transition planning managed effectively?*

Why is this important? *The transition between paediatric and adult service is a crucial time for a young person with a neurodisability. It often means that all the systems and support and people they were used to have changed. To ensure that this process is managed well, it must start in plenty of time, without causing undue stress to the patient or their family.*

Transition for young people with chronic health needs describes the process of moving from children's to adult healthcare and encompasses the initial planning, the actual transfer between services, and any support provided throughout.[10,68] There is variation in the chronological age at which this journey begins, and best practice suggests that there should be flexibility according to the needs of an individual patient. When not well managed the changes and challenges that young people encounter at transition may be associated with deterioration in their overall health and function. Planning effectively to bridge the gap between child and adult services can reduce and even eliminate the loss of wellbeing.[69,70,71]

Dependent on classification it has been estimated that there are between one in five to 10 children in the UK that have a chronic condition.[72] The greater need for planned transition of care to adult services has in part arisen because of improved health outcomes in the paediatric age group. Whilst there are well described pathways from child to adult services for conditions such as diabetes, cystic fibrosis and congenital heart disease, there is a relative paucity of multidisciplinary teams which provide parallel/equivalent services for young adults with chronic neurodisability and they are likely to be particularly disadvantaged.[73] This study has also found evidence that young people and young adults with a cerebral palsy encounter particular challenges in navigating to adult services as there are often no lead professionals or teams available for neurodisability care which mirror those which now exist in many parts of the UK within paediatrics. The alternatives for young adults with a cerebral palsy encounter variable quality of care in many instances, with lack of leadership, substantial gaps in services and increased reliance on GP services. This is exemplified well in chapter 7 with few leads for adult neurodisability (Table 7.2).

Overall a lead clinician for disability care was reported to be in place in 351/403 (87.1%) hospitals by admitting clinicians. Reviewers found documentation of a lead clinician for neurodisability care in only 31/133 (23.3%) case notes of young adults compared with 240/380 (63.2%) notes for children and young people.

This chapter will discuss the evidence of success or otherwise of the following for young people with a cerebral palsy

- The overall transition process
- Age appropriate care
- Decision making

The transition process

In patients with chronic long term health needs, transition from paediatric to adult based health services should be proactively managed in a similar way to all young people with long term health needs. Ideally planning begins by at least the age of 14 years and provides a progressive and well delineated transfer of care to a team that is able to continue to assess and manage the patient's individual needs.[10,68] All aspects of the transition process may not move at the same speed and at the same time, and this requires leadership and care co-ordination. There is a bountiful amount of guidance available, much of which has already been referenced and which can stimulate and guide practice. Fundamental to transition at an organisational level is whether there is a written pathway. Only 33/90 respondent organisations dealing with paediatric inpatient care had this in place.

Organisational leads for paediatric inpatient care responded to the question as to where young people with a cerebral palsy were cared for when leaving children's services. Patients mainly transferred to general adult medical and surgical services and many (50/84) were those without specific pathways or adjustments for neurodisability care. Only 19/84 organisations mentioned that specialist services for disabled adults would be involved (Table 12.1).

Table 12.1 To what services do young people with cerebral palsies transfer when leaving children's medical/surgical services, when inpatient care is required?

	n=
Specialist service for disabled young adults	19
General medical/surgical/orthopaedic services with pathways/protocols in place for adjustments in view of disability	29
General medical/surgical/orthopaedic services, no specific pathways/protocols for adjustments	50
Other (please specify)	15
Subtotal	**84**
Not answered	6
Total	**90**

**Answers may be multiple*

NICE Guidance suggests that by age 14 the process of transition should have been considered and planning commenced.[10] Leads for neurodisability care might be best placed to understand where their patients were in the process of transition and were asked to comment. They identified just 52 patients who were aged 14 years or older during the study period who were undergoing transition or might have done so. Seventeen patients had not yet transitioned, 19 were currently transitioning and nine had done so within the previous three years (Table 12.2).

Table 12.2 Stage of transition from paediatric to adult services

	n=
Patient has not yet transitioned from paediatric to adult services	17
Patient is currently transitioning from paediatric to adult services or transitioned less than three years ago prior to the stated admission	19
Patient transitioned more than three years ago prior to the stated admission	9
Subtotal	**45**
Not answered	7
Total	**52**

Transition was evident in just over half of 15 to 19 year olds (33/60) in the cases reviewed, and in a third of patients reviewed in the 20-25 age range. (Table 12.3).

Table 12.3 Evidence in the case notes the patient was or had transitioned from paediatric to adult services - reviewers' opinion

	10-14 years	15-19 years	20-25 years	Total
	n=	n=	n=	n=
Yes	1	33	28	**62**
No	49	27	13	**89**
Subtotal	**50**	**60**	**41**	**151**
Unable to answer	4	5	5	**14**
Not answered	17	5	3	**25**
Total	**71**	**70**	**49**	**190**

Leadership of transition

Guidance stresses that for transition to adult care to be successful leadership with a named professional and strong multiagency involvement is important. Reviewers reported that in only just over half the cases reviewed, where transition was occurring/had occurred (12/21), there was evidence of an identified lead worker, and in a third (7/20) there was evidence of multiagency involvement.

NICE guidance (2016)[10] also emphasises the need for primary care involvement in care after transition for young people in the form of a lead general practitioner (GP). Patients with complex neurodisability are often under the care of a very comprehensive multidisciplinary team of professionals during childhood years and may not have much contact with their GP. Once in adult care the GP may be expected to provide a vital hub for support and co-ordination, in part because neurodisability services for patients with a cerebral palsy are rarely replicated in the same way across adult based community and hospital services. Recognition of this pivotal role is particularly important and has recently emerged in national guidance on re-organisation of GP services into Federations, Networks or Clusters.[82-84] Within these larger networks there is improved potential for GPs to specialise in particular areas of care such as paediatrics and neurodisability.

Case reviewers found that for patients who were undergoing transition there was evidence of a lead GP in 39/53 (Table 12.4).

Table 12.4 Evidence in the case notes of a lead GP for this patient - reviewers' opinion

	n=
Yes	39
No	14
Subtotal	**53**
Unable to answer	9
Total	**62**

Routine national data evidence provided within this report points to the fact that young people and young adults with a cerebral palsy are more likely to use GP services than children, young people or young adults without neurodisability. The greatest number of annual GP consultations was seen in the 0-4 year olds and those of 20-24 years. ⑦

CASE STUDY 27

A young adult with a cerebral palsy was admitted with their first major seizure. The patient's GMFCS level was not recorded but they were able to walk unaided and most of their notes related to a complex congenital heart problem which was soon to be managed by adult cardiologists. The letter to the patient's GP stated that the patient "does have significant problems" but makes no explicit mention of a transition plan or their previous neurodisability care which has been considerable over several years.

Reviewers comment that it seemed likely that the GP would now be leading the overall neurodisability care but that a clear management plan had not emerged even though the patient appeared to have 'graduated' from paediatric care.

There were a few examples of good transition planning.

CASE STUDY 28

A young adult patient with complex needs including a tracheostomy, chronic respiratory disease and oxygen therapy was admitted to a large paediatric centre for eight days with acute on chronic abdominal pain. No specific diagnosis was made but the symptoms were well managed with input from a dedicated paediatric pain team. However, during admission the patient's GMFCS level was not documented, and neither was their level of learning ability. Whilst no discharge summary was evident to case reviewers there was a very well documented transition plan in place with evidence of meetings of a supportive multidisciplinary team.

The reviewers commented that it was unusual to find such a good example of transition care in place with co-leadership, in this case, from the patient's paediatric neurodisability lead and an adult respiratory clinician but also involvement of the patient's GP and other professionals in primary care.

Case note review reviewers were asked whether in their opinion they felt there was evidence that there had been difficulty or delay in agreeing a transition pathway for patients. Whilst numbers are very small, in half the cases reviewed (7/14) where it was possible to comment there was evidence that there had been difficulty.

Age appropriate care

Age descriptors

The most relevant groups with regard to transition of care were those in the 10-14 and 15-19 year age ranges. Most clinical leads for inpatient care stated that their hospital would regard a 10-14 year old as a child and a 15-19 year old was an "adolescent or young person" but there was variation (Table 12.5). Defining how a particular age group is described in healthcare terms often underpins decisions about location and organisation of care and this was inconsistent across organisations. For example 24/122 organisations defined 15-19 year olds as an 'adult', 11/315 as a 'child' and 55/87 as an 'adolescent/young person'. This is not unique to care of patients with a cerebral palsy, and transition matters across all diagnoses.

It was of note that the majority of acute inpatient leads stated that age 16 years was the 'usual' upper age limit for paediatric care (51/90) if the patient did not have a neurodisability. Sixteen years was also the most common age which adult unit leads used to describe when adult care began (37/65) but there was more variation here. If the patient had neurodisability, the general trend was for organisations to deliver paediatric care to those with disability until the patient was somewhat older. The upper limit was 18 years for paediatric care in 44/90 cases with 19 stating that 19 years was 'the norm' (Table 12.6) where as for routine

Table 12.5 Definition of the patient by age

	0-9 years	10-14 years	15-19 years	20-25 years	Subtotal	Not answered	Total
	n=	n=	n=	n=	n=	n=	n=
Child	228	76	11	0	**315**	3	**318**
Adolescent/ Young person	0	23	55	9	**87**	1	**88**
Adult	0	0	24	98	**122**	1	**123**
Subtotal	**228**	**99**	**90**	**107**	**524**	**5**	**529**
Not answered	0	1	1	0	**2**	5	**7**
Total	**228**	**100**	**91**	**107**	**526**	**10**	**536**

Table 12.6 Age limits for providing paediatric and adult care

	Up to what age does this hospital provide:		From what age does this hospital provide:	
	Acute paediatric care	Acute paediatric care for disabled	Acute adult care	Acute adult care for disabled
	n=	n=	n=	n=
14 years	2	1	0	0
15 years	1	0	2	2
16 years	51	14	37	37
17 years	8	9	5	4
18 years	26	44	21	21
19 years	2	19	0	0
Other	0	3	0	1
Subtotal	**90**	**90**	**65**	**65**
Not answered	0	0	1	1
Total	**90**	**90**	**66**	**66**

paediatric care in just 28/90 organisations, 18 or 19 was the upper limit. This finding was not mirrored by adult care leads where very little difference was noted. The lag in transition to adult services for young people with a cerebral palsy in secondary care was consistent with national routine data.

Case reviewers highlighted several examples of young people still being cared for in children's services that they might have expected to have been well outside the usual paediatric age limits (Case study 29).

Whilst there is a need for both flexibility and patient choice in location of care and overall delivery of services, these data may also highlight the underlying confusion in healthcare providers around ensuring best age appropriate facilities for older young people with neurodisability as they approach adulthood. This mirrors the considerable professional uncertainty around the best/most appropriate location of care when very few patients transition to have care led by adult neurodisability leads.[74]

CASE STUDY 29

A young adult patient with a GMFCS level III cerebral palsy as determined by paediatricians was using a wheelchair to aid mobility at school. The patient was about to go to university 50 miles away and needed to continue their healthcare support in their new location. The last letter from the consultant paediatrician stated that she has tried to identify an adult neurodisability lead to supervise the patient's care in future but that this had proved impossible.

The reviewers agreed that even where there were adult neurodisability leads in post their involvement in patients with a cerebral palsy may be limited to spasticity management. Generally after transition it was then up to the patient's GP, and on occasion interested surgeons, to offer care leadership. Patients and families often felt abandoned as a consequence and clinicians gave examples that physical and mental health of their patients deteriorated as a consequence.

Organisation of age appropriate care

A 2001 UK survey of 12-19 year olds demonstrated a significant number of "adolescents" using both inpatient and day case beds in acute general hospitals and recommended that more dedicated provision be considered for this age group even in smaller District General Hospitals (DGHs).[75] Young people have very distinct needs compared to children and these are not the same as for most adults. A host of additional recommendations have strongly re-enforced these needs.[68,76-80]

In this study only 37/90 leads for paediatric inpatient care reported that their hospital had a specific ward or ward area for adolescents/young people.

Young people and adults with physical and/or learning disability may have particular additional needs over and above their normally able peers of the same age. In the context of access to hospital services, those with a high level of motor disability (GMFCS levels III,IV,V) are more likely to be dependent on additional technology which requires the space to accommodate them in a ward area. It is particularly important to consider and prioritise these specific individual needs to help maintain both dignity and independence in young people and so that a stay in hospital does not result in regression of confidence, skills and function. ⑨

Leads for adult inpatient care reported variation in type of accommodation and environmental adjustments available for young adults with cerebral palsies admitted for routine procedures or surgery. Single room accommodation (21/42), en suite toilet facilities (18/42), and space for special equipment (32/42) was available in only two thirds of ward areas. However almost half the organisations surveyed did not provide a response to these questions.

UK and European recommendations on best practice for child inpatients suggest that parents should be routinely able to stay on-site when their child requires inpatient care.[81] Young people with neurodisability may be particularly vulnerable when admitted to adult wards but parental accommodation was less likely to be provided according to organisational leads whilst leads for adult inpatient care reported that for 32/42 patients a facility was available, a relatively large number (24/66) did not respond to this question.

CASE STUDY 30

A teenage non ambulant young person with a cerebral palsy at GMFCS level III was admitted to a general paediatric ward as an emergency from clinic with a fracture to their mid thigh bone after accidental trauma whilst being moved at school. The patient underwent surgery after a short period in traction and had excellent analgesia from an epidural anaesthetic. There were several entries in the medical and nursing notes of the patient's parent carers being concerned for their child's privacy as they were being nursed alongside a baby with bronchiolitis and a large attendant family in a (paediatric) high dependency area.

Case reviewers commented that physical space in ward areas is often particularly limited for young people with complex needs and that privacy and dignity may be difficult to ensure in all circumstance but should be considered with high importance.

Whilst the organisational data demonstrates that facilities in adult acute inpatient wards may be unsatisfactory for young people with neurodisability, there may also be problems in delivery of care for this age group in a paediatric ward area. Accommodating young people in a ward where the physical space, layout and processes are much more often employed to deliver care to babies and young children (which make up the larger number of total acute admissions in paediatrics) may be equally unsatisfactory. Patient privacy is also more often an issue as this case study demonstrates. ⑥ ⑨

Leadership and care pathways for young people and young adults

Leadership in care for young people is fundamental to providing appropriate standards and services in all healthcare settings. There has been increased recognition of this need in guidance from several organisations.[80,85] Clinical leads in acute paediatrics stated that in only a fifth (19/88) of their organisations there was an identified lead clinician or team for adolescent care. The paucity of recorded adult leads for neurodisability has also already been noted in the introduction to this chapter and in chapter 7. ⑦

Specific healthcare pathways for care of young people can also provide support for this cohort of patients and promote good practice. These provide age and developmentally appropriate adjustments which are embedded in the wider healthcare plan for young people, and where relevant include consideration of wider educational and social needs. They do not necessarily require large resources in terms of additional staffing or funding.

In only 21/89 organisations was the care of adolescents provided as part of a specific care pathway (Table 12.7) and in most patients care fell within paediatric pathways. This finding coupled with the lack of leadership has highlighted a substantial gap.

Table 12.7 Who the care of adolescents fell under

	n=
Paediatric pathway	79
Adult pathway	28
Specific adolescent pathway	21

**Answers may be multiple*

This study has found evidence of less than good diagnostic precision and description of needs in young adult patients with a cerebral palsy. GMFCS level was poorly recorded throughout, and even in care by lead clinicians for neurodisability this was relatively poorly/inconsistently done. ⑧

In the 15-24 age range GMFCS was particularly poorly recorded. In part this may be a reflection of the fact that older patients may have not benefitted from the same diagnostic rigour as those born more recently. However GMFCS level is not a new descriptive tool[86] and it would have been expected that it would have been applied to ongoing care and needs. Similarly the older patients in this study were less likely to have a more specific diagnosis made. ⑤

These factors, together with the very different pattern of delivery of care for young adults with neurodisability and alongside a relative lack of appropriate services may have led to young people and young adults receiving less good access to certain essential services. This was demonstrated in relation to physiotherapy which was less likely to be in place for older patients – 54.5% (54/99) in the 15-25 age group vs. 71.3% overall. ⑦

CASE STUDY 31

A young adult patient with a cerebral palsy at GMFCS level III who had an intrathecal baclofen pump to manage their spasticity was admitted for a minor revision to their delivery pump. The patient was noted by their consultant neurosurgeon to not be functioning as well as usual and that the patient was having issues with independence at work. The patient was often using a chair to get around. The patient's mother was at the consultation and stated that she was concerned that her child was no longer receiving any physiotherapy support despite requests to adult services to help.

Reviewers comment that it is likely that there also needs to be a full workplace assessment for this young patient and that their regression in terms of motor ability is very common at this age and when as a young adult they are trying to get to grips with life in the workplace. This may well result in other important issues arising with both mental and physical health and wellbeing.

Routinely collected national data

Where possible medical and surgical specialties were categorised as paediatric or adult services. Generic treatment specialties without a corresponding paediatric designation were categorised as 'other'. These include therapies, psychiatry, radiology and pathology specialties and were excluded from the analysis.

Figures 12.1 and 12.2 show that in England a greater proportion of children and young people with a cerebral palsy over the age of 13 years used paediatric services and continued to do so for longer than those without a cerebral palsy, thus transitioning to adult services later than children and young people without a cerebral palsy. The transition for inpatient care appears to be slower than for outpatient appointments.

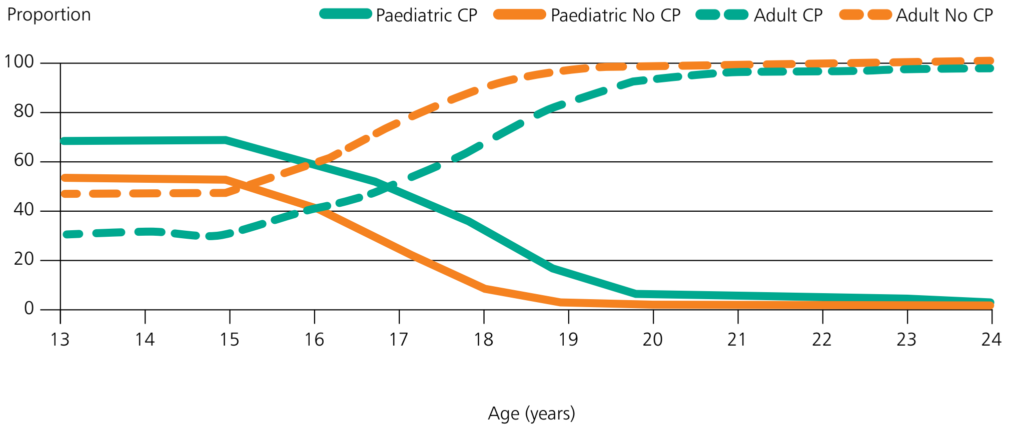

Figure 12.1 Proportion of outpatient appointments between 2007 and 2014 for children and young people with and without a cerebral palsy by age (CPRD HES Linked England)

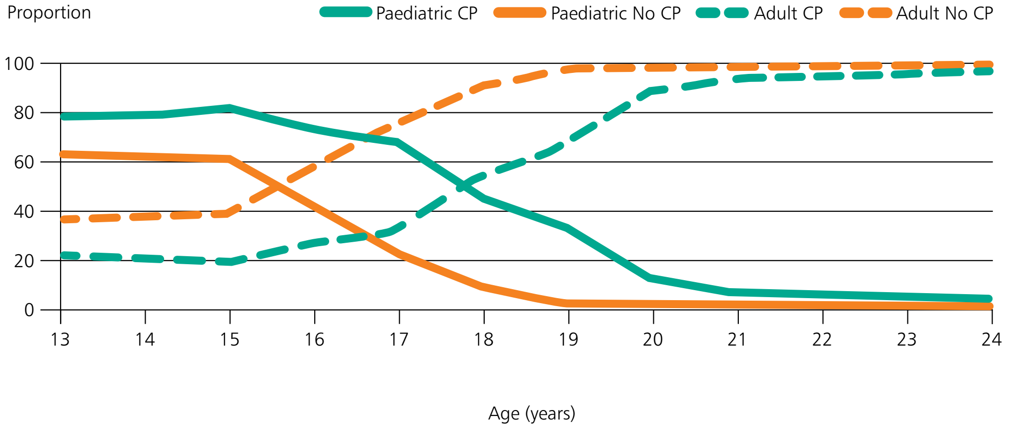

Figure 12.2 Proportion of paediatric and adult hospital admissions between 2007 and 2014 for children and young people with and without a cerebral palsy by age (CPRD: HES Linked England)

Nearly all (99%) of children without a cerebral palsy had transitioned to adult services by 19 years of age; this was extended to at least 21years of age for those with a cerebral palsy.

In Wales (Figure 12.3) the transition to adult outpatient services appeared to start later than in England at around the age of fifteen years. The transition to adult inpatient services appears to happen more slowly (Figure 12.4).

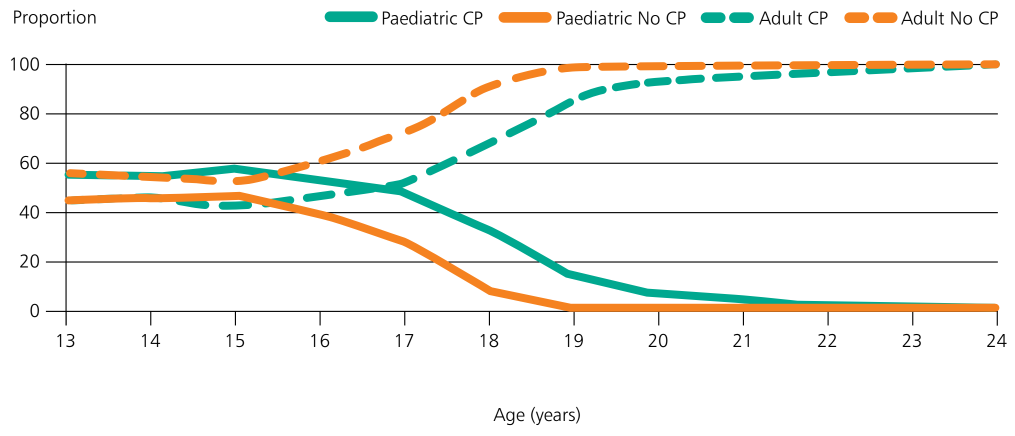

Figure 12.3 Proportion of paediatric and adult outpatient appointments for children and young people with and without a cerebral palsy children and young people with and without a cerebral palsy by age. (OPDW)

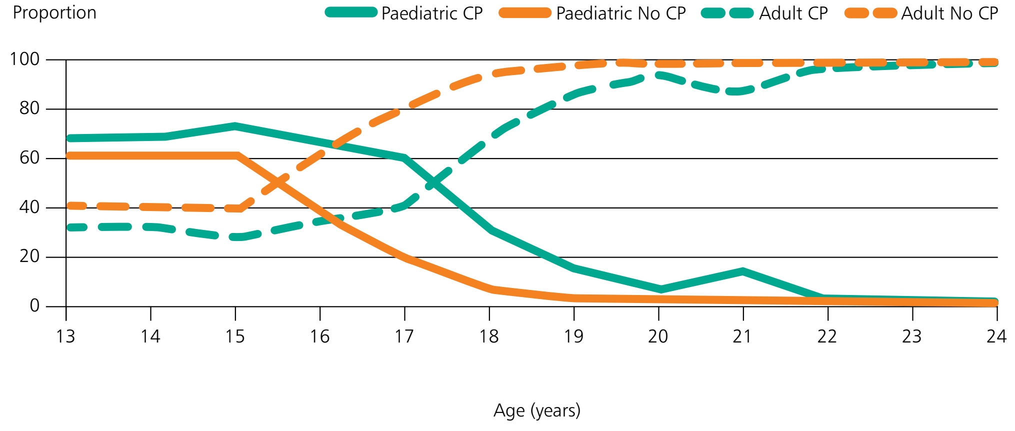

Figure 12.4 Proportion of total hospital admissions for children and young people with and without a cerebral palsy by age and specialty type (PEDW; 2004-2014) Note - 'other' and 'unknown' specialties excluded

Inpatient hospital admissions – CPRD HES linked

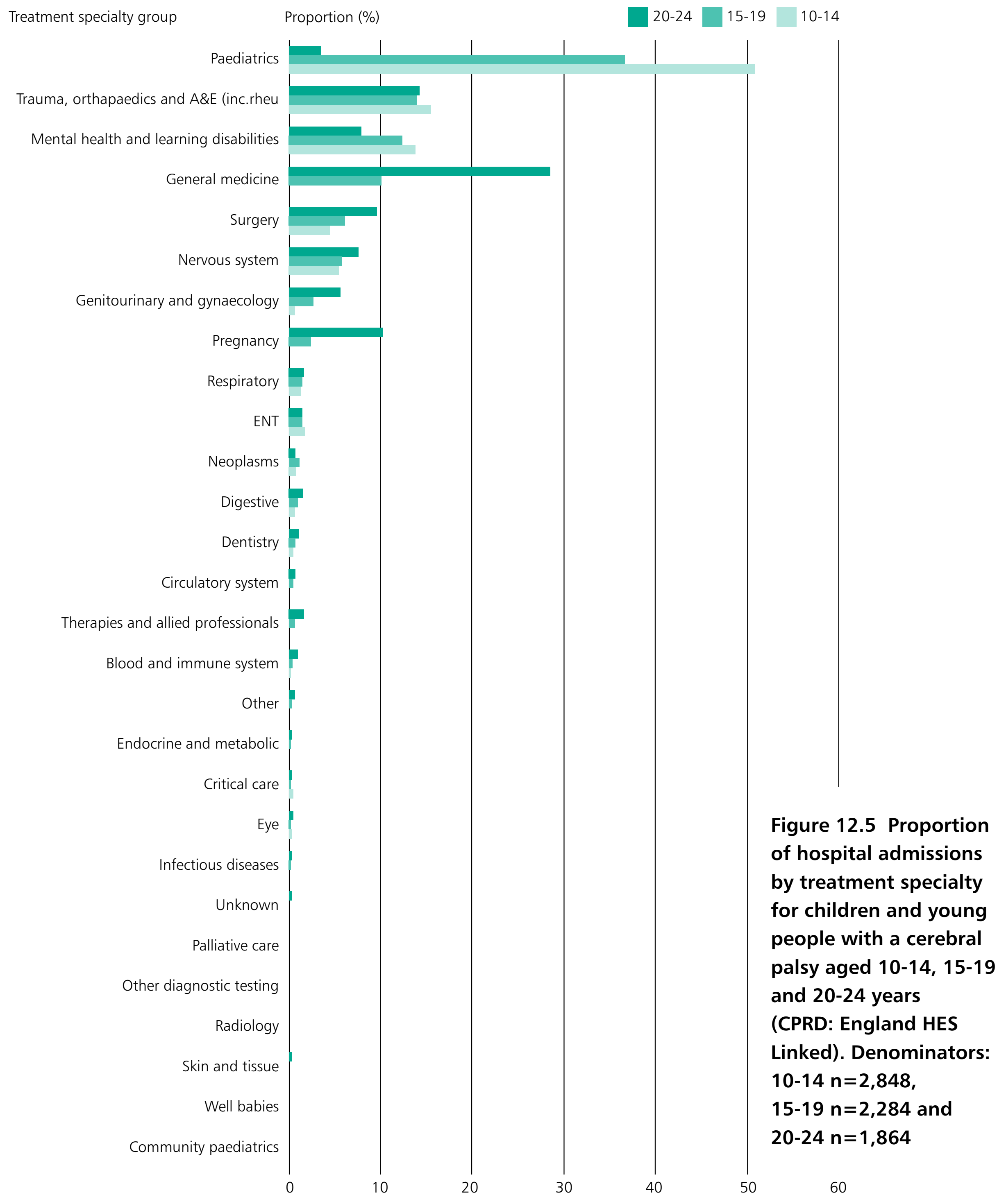

Figure 12.5 Proportion of hospital admissions by treatment specialty for children and young people with a cerebral palsy aged 10-14, 15-19 and 20-24 years (CPRD: England HES Linked). Denominators: 10-14 n=2,848, 15-19 n=2,284 and 20-24 n=1,864

The burden of hospital admissions changed between the ages of 10 and 24. The proportion of paediatric admissions fell dramatically for children and young people with (Figure 12.5) and without a cerebral palsy (Figure 12.6) but less quickly for those with a cerebral palsy. General medicine admissions increased significantly between 14 and 24 years of age.

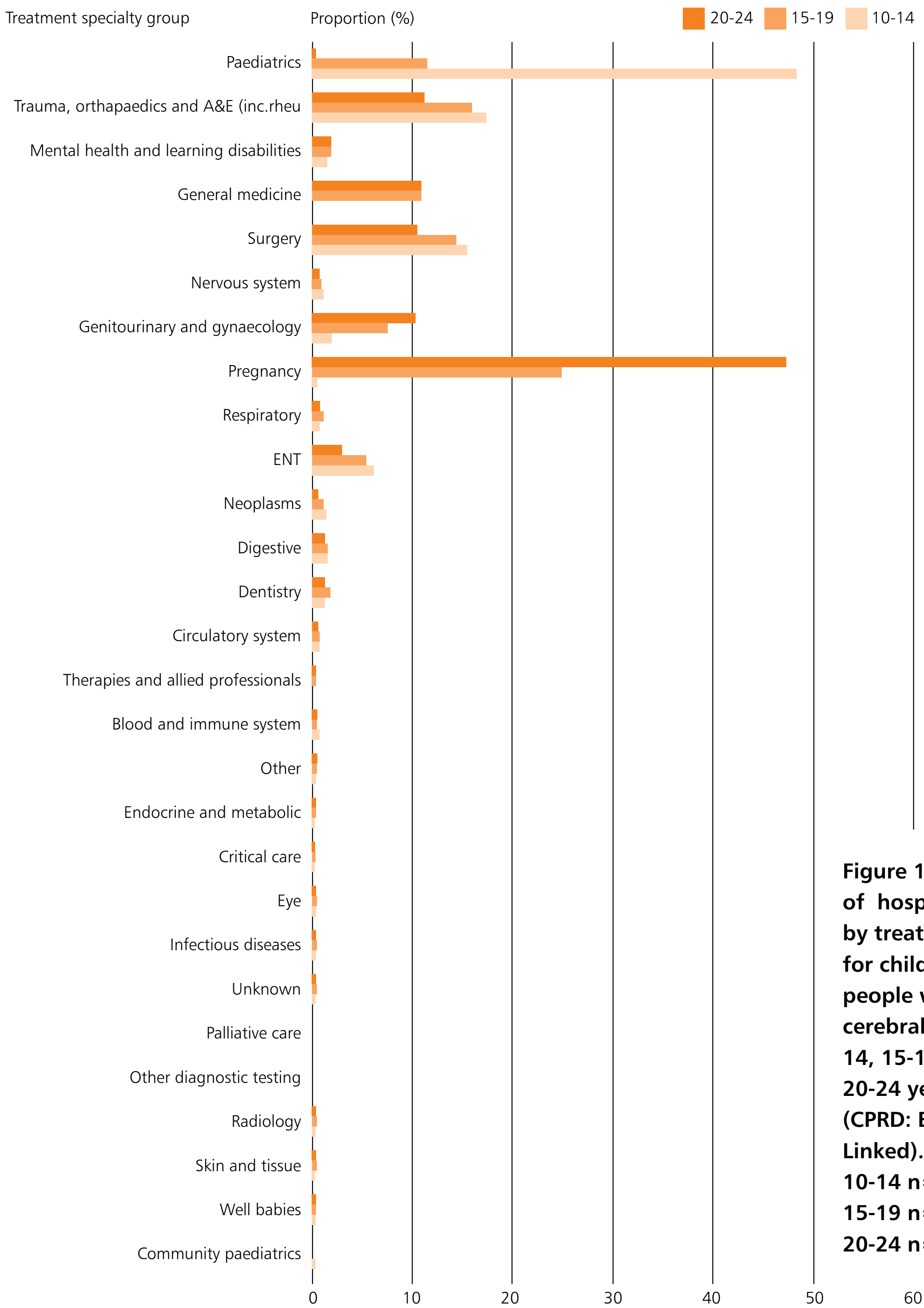

Figure 12.6 Proportion of hospital admissions by treatment specialty for children and young people without a cerebral palsy aged 10-14, 15-19 and 20-24 years (CPRD: England HES Linked). Denominators: 10-14 n=53,950, 15-19 n=93,656, and 20-24 n=154,937

A greater proportion of children and young people with a cerebral palsy had admissions to mental health and learning disability specialists than for those without a cerebral palsy, the latter fell between the ages of 10-24 years.

The proportion of surgical admissions increased with age for children and young people with a cerebral palsy but decreased for those without a cerebral palsy where the greatest change was seen for obstetrics.

Outpatient appointments – CPRD HES linked

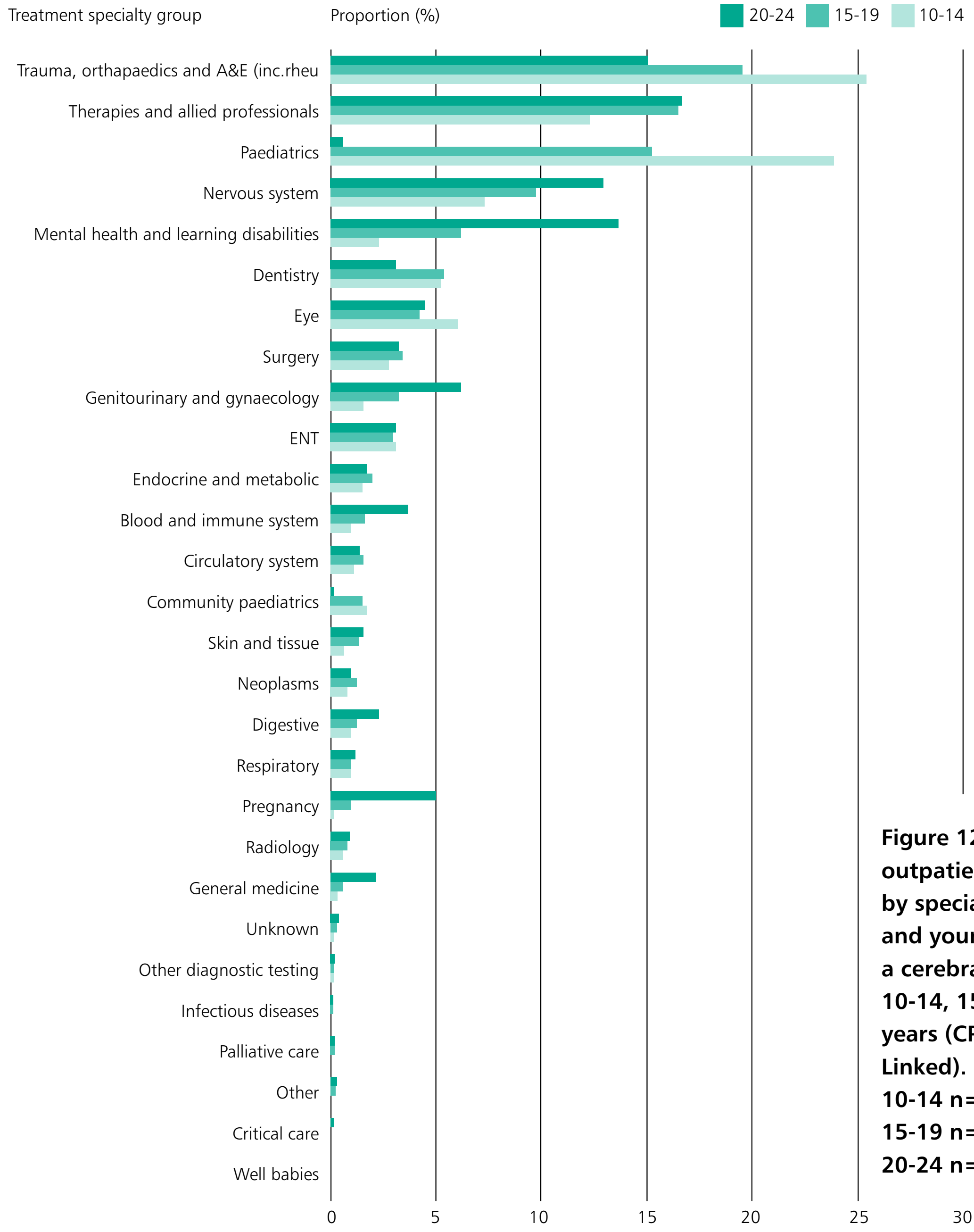

Figure 12.7 Proportion of outpatient appointments by specialty for children and young people with a cerebral palsy aged 10-14, 15-19 and 20-24 years (CPRD: England HES Linked). Denominators: 10-14 n=24,691, 15-19 n=18,802 and 20-24 n=14,972

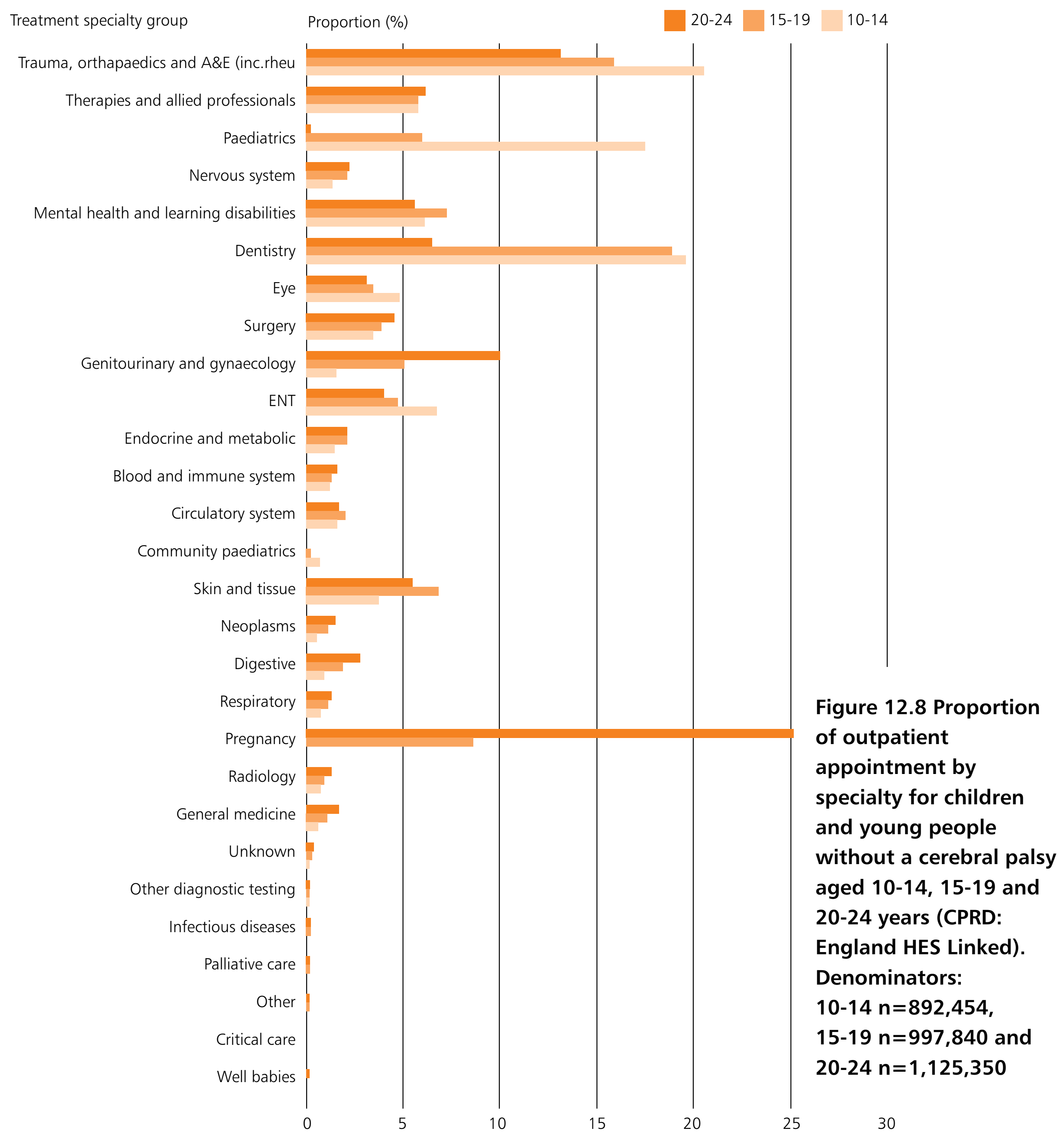

Figure 12.8 Proportion of outpatient appointment by specialty for children and young people without a cerebral palsy aged 10-14, 15-19 and 20-24 years (CPRD: England HES Linked). Denominators: 10-14 n=892,454, 15-19 n=997,840 and 20-24 n=1,125,350

The proportions of outpatient appointments for therapies and allied health professional, neurological services and mental health and learning difficulties increased with age and were significantly greater for children and young people with a cerebral palsy (Figure 12.7) than those without a cerebral palsy (Figure 12.8). The proportion of paediatric outpatients decreased in both groups but remained higher for children and young people with a cerebral palsy than those without.

The proportion of dentistry outpatient appointments decreased with age but was significantly fewer than for children and young people without a cerebral palsy.

Communication and decision making

Communication and decision making for young people with neurodisability can provide particular challenges some of which have been discussed in chapter 6. 6

Inpatient care ward rounds can be an intimidating situation for young people, and it may be difficult to express views and ask questions openly in the time provided, especially if there is no provision for confidential discussion and parent carers are routinely present. Joint RCP/RCN guidance from 2012 outlined good practice in the conduct of ward rounds but made no specific reference to young people or young adults.[87] In this study leads for inpatient care of children and young people were asked whether young people were given an opportunity to be seen separately e.g. in medical and surgical ward rounds, and in one in four organisations stated that this was not offered (Table 12.8).

Admitting clinicians were also asked whether the patient was given a choice as to whether a parent was present in all discussions and as appropriate for their age, and for 15/101 patients they stated that this did not occur.

Table 12.8 Young people were offered the opportunity to be seen separately from their parent/carer in the acute medicine and surgical service, e.g. on ward rounds

	Acute medicine service	Acute surgical service
	n=	**n=**
Yes	71	61
No	16	19
Subtotal	**87**	**80**
Not answered	3	10
Total	**90**	**90**

Capacity and best interests

Children and young people should be encouraged to be involved in decisions about their care.[61] When a young person has no obvious disability of mind or body, their competence and capacity are often assumed without formal testing. Specific legislation in different parts of the UK guides what to do when there is doubt.[62,88] In practice capacity tends to be considered at points in time where key decisions such as e.g. consent for a procedure or surgery are required.

Organisational data from leads in emergency departments, child and adult inpatient areas and from adult outpatient facilities were asked whether capacity was routinely assessed. The most likely place for assessment to take place seems to have been in emergency departments where it was a routine in 69/86 organisations and adult inpatient units 43/47. In contrast, assessment took place in only half the organisations providing paediatric inpatient care (Table 12.9).

In just 50/88 inpatient paediatric units and 43/47 adult units it was reported to be routine practice to assess mental capacity of young people 16 years and over and who were thought to have an impaired ability to make decisions. Case note reviewers were also asked whether mental capacity assessment was recorded where the patient was over the age of 16 years and there was a documented learning disability, and this occurred in only one in three cases (42/135).

Chapter 11 discussed specific issues with regard to approved consent procedures in young people undergoing a surgery or a procedure, and where it was clear that in some instances there were cases where parent carers had been asked to be the sole people to consent for older young people/young adults without capacity. 11

Leads for different aspects of service reported whether (or not) a best interests decision-making process was embedded for young people aged 16 years and over who had been assessed as not having capacity to make a specific decision at a specific time and in a specific circumstance. Adult services within organisations were more likely to have this in place. Since many young people with neurodisability over the age of 16 years are still under the umbrella of paediatric services, it is of particular note that only 44/77 paediatric community leads reported that their organisations had a process (Table 12.10).

Table 12.9 The extent to which capacity was reported to be routinely assessed according to local legislation

	Emergency department care	Paediatric inpatient care	Adult inpatient care	Adult outpatient care
Yes	69	50	43	30
No	17	38	4	12
Subtotal	**86**	**88**	**47**	**42**
Not answered	6	2	19	11
Total	**92**	**90**	**66**	**53**

Table 12.10 Organisational arrangements for best interest decision making in patients without capacity

	Paediatric outpatient care	Community paediatric care	Paediatric inpatient care	Adult outpatient care	Adult inpatient care	Emergency department care
Yes	47	44	57	34	40	68
No	30	33	27	9	8	16
Subtotal	**77**	**77**	**84**	**43**	**48**	**84**
Not answered	7	4	6	10	18	8
Total	**84**	**81**	**90**	**53**	**66**	**92**

It has already been noted that case reviewers felt that there was poor evidence of documentation of inclusion in all age groups. There was little difference between patients under or over 16 years (Table 12.11). However, it was particularly unusual that evidence was not stronger in an older age group. ⑥

Inclusion was more of an issue in children and young people with more profound motor disability, and particularly in those patients over 16s where just 13/40 patients at GMFCS level V seemed to be included. This compared with 11/13 young people at GMFCS level I, and 7/9 at GMFCS level II. Some patients with GMFCS level V motor disability may well have profound difficulties with hearing, vision and understanding. However this must never be assumed and communication aids may be necessary. Documentation of the level of ability together with what is communicated to the young person and parent carer is essential.

Table 12.11 Room for improvement in the documentation of inclusion of the patient in discussions and decision-making – reviewers' opinion

	Admitted patients		**Day case patients**	
	n=	**%**	**n=**	**%**
Yes	120	40.0	59	39.9
No	180	60.0	89	60.1
Subtotal	**300**		**148**	
Unable to answer	37		21	
Not answered	15		13	
Total	**352**		**182**	

Key Findings – questionnaire, case note review and organisational data

- 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
- Only one third (33/90) of organisations providing paediatric inpatient care had a written transition pathway
- In 50/84 inpatient organisations stated that they transferred patients to adult general medical, surgical and orthopaedic services with no specific pathways or adjustments in place for neurodisability
- There were 62 cases where there was evidence in the notes that the patient was transitioning or had transitioned from paediatric to adult services
- There was evidence in the case notes that a transition plan was in place in 17/46 of these cases
- Reviewers identified 12/21 sets of case notes where there was evidence of an identified lead worker in the records of neurodisability patients who were undergoing transition to adult care. In 7/20 cases there was evidence of multiagency involvement
- Reviewers found evidence in the case notes that if a patient was undergoing or had undergone transition to adult healthcare they had a lead GP in 39/53 cases
- There was considerable variation/inconsistency in the definitions for age that inpatient health organisations used for children and adults. 24/122 organisations defined 15-19 year olds as an "adult", 11/315 as a "child" and 55/87 as an "adolescent/young person"
- The upper age limit for paediatric inpatient care was higher in many organisations for patients with neurodisability with 63/90 organisations using 18 or 19 years as an upper limit as compared with 28/90 in relation to general paediatric patients

SEE RECOMMENDATIONS
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- Clinical leads in acute paediatrics stated just 37/90 had a ward or ward areas for adolescent/young people and that in only a fifth (19/88) of their organisations was there an identified lead clinician or team for adolescent care. 21/89 stated that they had specific adolescent care pathways
- Responses from the adult inpatient care questionnaire indicated there was single room accommodation in 21/42 sites; en suite toilet facilities in 18/42 sites; and space for special equipment in 32/42 sites
- Leads for inpatient care of children and young people stated that young people were not routinely given an opportunity to be seen separately e.g. in medical and surgical ward rounds. In 15/101 inpatient organisations patients were not given a choice as to whether a parent was present in all discussions and as appropriate for their age
- Case note reviewers noted that mental capacity assessment was recorded in case notes where the patient was over the age of 16 years and there was a documented learning disability, in only 1 in 3 cases (42/135).

Key Findings – routine national data

- Transition to adult services takes significantly longer for children and young people with a cerebral palsy than for those without
- Transition from paediatric to adult services takes longer for inpatient admissions than outpatient services
- The proportion of outpatient appointments for specialties managing mental health and learning difficulties increased significantly between 10 and 24 years of age but hospital admissions for the same specialty decreased with age
- The proportion of outpatient appointments for therapies and allied professionals and neurological services increased with age and were significantly greater for children and young people with a cerebral palsy than without.