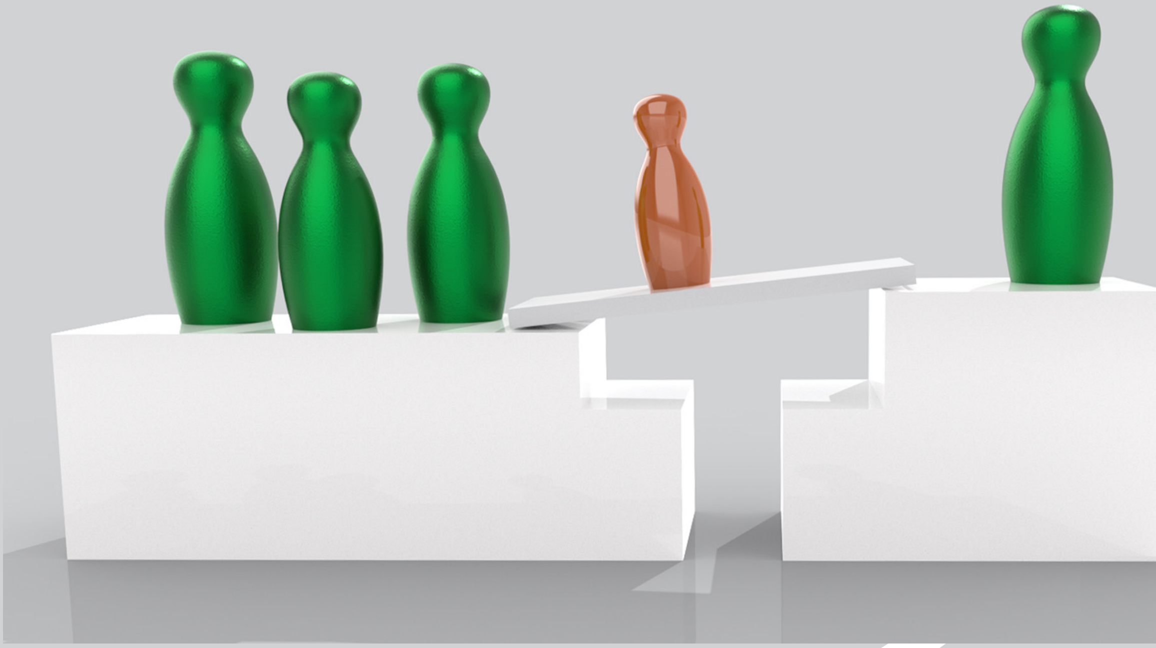
The Inbetweeners

A review of the barriers and facilitators in the process of the transition of children and young people with complex chronic health conditions into adult health services



NCEPOD

Improving the quality of healthcare

THE INBETWEENERS

A review of the barriers and facilitators in the process of the transition of children and young people with complex chronic health conditions into adult health services

A report published by the National Confidential Enquiry into Patient Outcome and Death (2023)

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FOREWORD

Designing and conducting a study which seeks to explore the quality of care for young people with complex conditions transitioning from child, through adolescent into adult health services was always going to be challenging. However, despite there being a plethora of authoritative reports, recommendations and edicts from bodies such as the National Institute for Health and Care Excellence (NICE) and the Care Quality Commission, the widely held view expressed by the community active in this area was that expected standards of care were going unmet. This report therefore set out to identify the barriers to effective developmentally appropriate care and what facilitates good care. In many ways the findings highlight both the good and the unsatisfactory elements of basic care which, although not necessarily specific to the transition process, can have a disproportionate impact during the transition from childhood into adulthood.

One of the striking report findings was the disparity between the assessment of the quality of care by the case reviewers, and the opinion of the treating clinicians. This perhaps suggests a lack of awareness of where the process of transition is not working, by many of those responsible for the care of young people who are transferring from paediatric into adult care. It may also reflect the lack of prioritisation of transition in the NHS, as it is not a commissioned service, it makes it more challenging for teams to deliver joined up care.

Most clinicians will not have experienced the move into adult health services as a patient, but if we cast our minds back far enough, we will all recall to a greater or lesser extent the stress of transitioning between schools, jobs, or different communities when moving home. Add into that equation dealing with a chronic illness and perhaps one can just start to appreciate how stressful that process must be. When young people disengage with healthcare provision their health conditions deteriorate with significant personal and socioeconomic costs, but if they feel included and are empowered to be involved in their own healthcare, good outcomes can and do occur.

There were many examples of good developmentally appropriate healthcare provision found when reviewing the case notes, but these tended to occur in units characterised by teams who had prioritised the care of children and young people with chronic health conditions moving into adult services. The case studies in this report aim to share this good practice more widely.

Some of the recommendations of the report potentially require allocation or diversion of resources which we fully appreciate will prove challenging in the present economic climate. However, many of the recommendations support the existing NICE guidelines, that have been available since 2016, and those around better communication and young person and parent/carer involvement should be happening already as a basic professional expectation.

As ever the trustees and I are enormously grateful to the members of the study advisory group, the case reviewers, healthcare professionals and local reporters who have given so generously of their time, particularly over the difficulties in recent times, and of course to the authors of the report for distilling such a large amount of data into such a concise report.

Ian C Martin, NCEPOD Chair

EXECUTIVE SUMMARY

To assess the barriers and facilitators for young people receiving a good transition to adult healthcare services, data were collected on children and young people with one of 12 complex conditions identified from a sample period between 1st October 2019 and 31st March 2021. Analysis was undertaken on questionnaires from 829 community/secondary/tertiary care clinicians, 167 primary care clinicians, 483 sets of case notes, 192 secondary/tertiary organisational questionnaires and 152 primary care organisational questionnaires, supported by qualitative data from young people, parent/carers, and health and social care professionals.

CONCLUSION

There is no clear pathway for the transition from healthcare services for children and young people to adult healthcare services. Moreover, the process of transition and the subsequent transfer is often fragmented, both within and across specialties. Often the adult services sit only with primary care. Developmentally appropriate healthcare needs to be everyone's responsibility and adequate resources need to be made available to allow this to happen.

1. MAKE DEVELOPMENTALLY APPROPRIATE HEALTHCARE CORE BUSINESS FOR ALL INVOLVED

This would ensure that transition and transfer planning is embedded into everyday healthcare by all the teams involved.

Only 16/167 (9.6%) organisations had transition included in the job descriptions of all healthcare staff involved in transition.

Mandatory training for staff in transition was found to be lacking, with only 37/169 (21.9%) organisations having such training in place.

2. INVOLVE YOUNG PEOPLE AND PARENT/CARERS IN TRANSITION PLANNING AND TRANSFER TO ADULT SERVICES

This would put young people at the centre of their own care, and they could support improvements in the transition service.

118/178 (66.3%) organisations had a policy stating that young people should be offered the opportunity to be involved in their own transition process.

20/136 (14.7%) organisations had a transition service that involved young people in the design of the service for all specialties.

3. IMPROVE COMMUNICATION AND CO-ORDINATION BETWEEN ALL SPECIALTIES

Clear communication between all specialties across multiple teams will stop the young person falling into a gap between services.

For 72/119 (60.5%) young people who were under the care of multiple teams the transition process was considered to be co-ordinated across the different teams.

Reviewers were unable to find evidence of co-ordination between teams in 165/242 (68.2%) cases reviewed.

4. ORGANISE HEALTHCARE SERVICES TO ENABLE YOUNG PEOPLE TO TRANSFER TO ADULT SERVICES EFFECTIVELY

This would ensure there is a direction for every young person moving to adult services and ensure receiving services/GPs are prepared.

Where the organisation had an overarching transition policy, that policy covered all young people with long-term conditions in just 76/98 organisations.

98/175 (56.0%) organisations had separate transition policies for different specialties.

5. PROVIDE STRONG LEADERSHIP AT BOARD AND SPECIALTY LEVEL AT ALL STAGES OF TRANSITION AND TRANSFER

Strong leadership is needed to implement a transition service that ensures every young person receives the care they should expect.

Only 74/157 (47.1%) organisations had a senior executive responsible for supporting the development and publication of transition strategies and policies.

Only 60/167 (35.9%) organisations had a member of the transition service supporting the executive board.

RECOMMENDATIONS

These recommendations have been formed by a consensus exercise involving all those listed in the acknowledgements. The recommendations have been independently edited by medical editors experienced in developing recommendations for healthcare audiences to act on.

The recommendations highlight areas that are suitable for regular local clinical audit and quality improvement initiatives by those providing care to this group of patients. The results of such work should be presented at quality or governance meetings and action plans to improve care should be shared with executive boards.

Executive boards are ultimately responsible for supporting the implementation of these recommendations. Suggested target audiences to action recommendations are listed in italics under each recommendation. At a local level the recommendations are aimed at all members of the multidisciplinary team involved in the care of a young person who will move from healthcare services for children and young people into adult services including doctors, nurses, occupational therapists, physiotherapists and speech and language therapists.

The recommendations in this report heavily support those that have been made previously by other organisations, and for added value should be read alongside:

- **NICE:** Transition from children’s to adults’ services for young people using health or social care services (NG43)
- **NICE:** Transition from children’s to adults’ services (QS140)
- **CQC:** From the pond into the sea
- **RCPCH:** Facing the Future: Standards for children with ongoing health needs
- **DHSC:** Quality criteria for young people friendly health services
- **Together for Short Lives**: Stepping Up. Transition to Adult Services Pathway
- **Welsh Government:** Transition and handover from children's to adult health services
- **Intensive Care Society:** Paediatric to adult critical care transition
- **WellChild:** 8 Principles for Transition

	LOCAL LEVEL
1.	Develop a personalised transition plan with each young person who will need to move from child into adult healthcare service. Give the young person and their parent/carer access to this plan.* **This should be developmentally appropriate and encourage independence in the transition process wherever possible. Language should be clear and understandable by all and accessible formats should be used.* ***Target audience:*** *All members of the multidisciplinary team caring for the young person in child health services and the adult health services that the young person will move to, supported by the trust/health board transition team*

2.	Copy young people and, where appropriate, their parent/carer into all correspondence regarding ongoing healthcare needs. The correspondence should: a. Be developmentally appropriate, allowing for a learning disability, autism or both, and mental capacity (e.g. easy read); b. Respect the young person's preferences (they may not want to receive it); c. Comply with the young person's consent for their parent/carer to be copied in; d. Be in a spoken language understood by those receiving it (e.g. in different languages); e. Be in an accessible format for those receiving it (e.g. Braille). ***Target audience:*** *All members of the multidisciplinary team caring for the young person in child health services and the adult health services that the young person will move to, supported by the trust/health board transition team*
3.	Hold joint transition clinics for young people moving from child into adult healthcare services, involving healthcare staff from the young person's paediatric team and the adult service(s) they will move to. ***Target audience:*** *All members of the multidisciplinary team caring for the young person in child health services and the adult health services that the young person will move to, supported by the trust/health board transition team and primary care*
4.	Request input into the multidisciplinary team (MDT) for young people with ongoing healthcare needs as needed from: a. Relevant healthcare professionals from physical, community and mental healthcare services, in the same or other locations b. Educational services, e.g. to share education and healthcare plans (EHCPs), subject to the young person's consent c. A representative of the social care team should always be included for looked after, or accommodated children or young people, and for care leavers. This is particularly important if the child and/or family are known to social care, have unmet social care needs and/or there are safeguarding or child protection concerns. ***Target audience:*** *All members of the multidisciplinary team caring for the young person in child health services and the adult health services that the young person will move to, supported by the trust/health board transition team*
5.	Involve primary care throughout the transition process from child into adult healthcare services to: a. Provide continuity of care for young people who are discharged to primary care if there is no equivalent healthcare professional in adult services b. Address any wider health concerns unrelated to the young person's long-term condition. ***Target audience:*** *Primary care and all members of the multidisciplinary team caring for the young person in child health services and the adult health services that the young person will move to, supported by the trust/health board transition team*
	TRUST/HEALTH BOARD LEVEL
6.	Convene an overarching trust/health board transition team to provide a 'one stop shop' model of holistic care for young people moving from child into adult healthcare services. The team should: a. Include a senior executive responsible for developing a transition policy and strategies b. Include a senior manager responsible for the implementation of the transition policy and strategies *(see recommendation 7)* c. Engage with young people and their parents/carers to be involved in the design of services d. Co-ordinate the age when transition starts

	e. Co-ordinate the transition if multiple specialties are involved within and across different provider organisations *(see recommendations 3, 4 and 5)* f. Provide access to a key worker before, during and after transfer into adult services g. Ensure each young person is transferred into adult services during a time of relative stability and that their readiness for transfer is assessed holistically. The young person should be supported in a developmentally appropriate way by the teams providing healthcare in both children’s and adult services h. Ensure adherence to best practice guidance. ***Target audience:*** *Executive boards and clinical leads of all trusts/health boards*
7.	Implement an overarching trust/health board transition policy for all young people with ongoing healthcare needs. This should ensure that: a. The young person is at the centre of their care and empowered to be involved in managing their own condition, including being copied into correspondence *(see recommendation 2)* b. Where possible, young people are seen during hours that are appropriate for them (e.g. after school) c. Where possible, young people are seen in an age-appropriate environment d. Appointments are of adequate duration to give sufficient time for detailed discussion, e.g. a double appointment e. Young people and their parents or carers have opportunities to be seen independently f. Wider conversations are undertaken with young people to address needs beyond their medical conditions. ***Target audience:*** *Executive boards and clinical leads of all trusts/health boards, with support from the transition team*
8.	Ensure transition from child into adult healthcare services is in the job plan for all members of the multidisciplinary team working in all child and adult specialties delivering clinical care to children and young people with ongoing healthcare needs. ***Target audience:*** *Executive boards and clinical leads of all trusts/health boards, with support from the transition team*
9.	Ensure staff in all organisations complete training in developmentally appropriate healthcare and the transition from child into adult healthcare services. The content should be tailored to the job role and the degree of involvement with children and young people. ***Target audience:*** *Executive boards and clinical leads of all trusts/health boards, with support from the transition team*
	NATIONAL LEVEL
10.	Ensure that all young people who may need to move from child into adult healthcare services can be identified as such on electronic patient systems, across all healthcare sectors*. **A standardised set of codes would support this.* ***Target audience:*** *NHS England, Digital Health and Care Wales and Northern Ireland Statistics and Research Agency with support from trust/health board executive committees and commissioners*
11.	Ensure that transition from child into adult services is specified in the service outcome measures and that the financial support for this reflects the additional clinical and administrative time needed. Appropriate quality and outcome measures should be included in both child and adult service specifications. ***Target audience:*** *Commissioners, Integrated Care Boards*

INTRODUCTION

The transition of a young person into adult health and social care services is defined as '*The purposeful, planned process of transferring a young person's healthcare from a child-centred to an adult-orientated care setting that comprehensively addresses the medical, psychosocial, educational and vocational needs of that young person.*'[1] It is widely recognised that this process does not always work well, numerous documents support this and have recommended where improvements are needed, e.g. the Royal College of Nursing in 2013, the Care Quality Commission in 2014, NICE in 2016, and the Royal College of Paediatrics and Child Health in 2018.[2-7] In fact, NCEPOD has also published three reports looking at the care of young people within very different clinical settings (chronic neurodisability, mental health, and long-term ventilation),[8-10] all of which highlighted issues with the transition planning and transfer into adult healthcare.

The process of transition is complex as the needs of each young person are not identical.[11] It is more challenging when a young person has multiple complex conditions, in settings where there may not be an adult team to transfer to.[12] or where children and young people's services end at age 16 and the adult service does not start until age 18.[3] In these cases the care often defaults to primary care. While all young people should be registered with a general practice (GP), there is evidence to suggest that young people with complex conditions often do not have an existing relationship with their GP.[13] This may result in them only seeking contact when in crisis,[14] or not at all. This could particularly impact on young people with a learning disability, autism or both, or poor mental health, who may find it more of a challenge to access primary care.

This NCEPOD report highlights a fundamental issue: transition from child into adult services is often perceived as the responsibility of the team the young person is leaving, instead of it being in the job plans of all healthcare professionals involved, including those in adult healthcare services. Good, developmentally appropriate care should not be an exception, it should be part of core business.

This report focuses on five main issues to highlight the barriers and facilitators to good developmentally appropriate healthcare:

1. *Developmentally appropriate healthcare*
2. *Involvement of children and young people and their parents/carers in their transition planning*
3. *Communication and co-ordination of care between all involved in the transfer into adult services*
4. *The organisation of transition services*
5. *Leadership*

As would be expected, the recommendations in this report support previous recommendations in this area, particularly the NICE guidelines which should be read in conjunction with this report.

This report highlights examples of good care as learning aids to support the existing initiatives, tools and guidelines, developed by local authorities, charities, trusts/health boards and individual clinicians to provide guidance on what service users should expect and how healthcare professionals can care for young people in a developmentally appropriate way.

WHAT ONE THING WOULD HAVE IMPROVED YOUR TRANSITION EXPERIENCE?

Young people and parent carers were asked what one thing would have improved their experience of the transition process into adult health services. The responses fell into broad categories:

THE AGE OF TRANSFER AND WHETHER IT IS DEVLOPMENTALLY APPROPRIATE

HAVING A TRANSPARENT TRANSITION

HAVING A KEY WORKER

BETTER COMMUNICATION

HAVING EQUIVALENT ADULT HEALTHCARE SERVICES

HELP AND SUPPORT FOR YOUNG PEOPLE

HELP AND SUPPORT FOR PARENT/CARERS

"A well thought out transition process which was person centred (not just age triggered at 16) with true involvement from young person and parent."

"Services working together instead of against each other, to work with and support the children and their families, not treating us like an inconvenience."

"My daughter had more than 30 specialist health professionals supporting her through childhood and very few of them knew who or how to transition us to the adult equivalent."

"A key worker to support the family through the process and to co-ordinate care, as no one took the lead and communication between teams was poor."

"Informed of what will happen by the healthcare provider and not having to do own research."

"Meeting new consultants beforehand and making sure all care in each speciality is carried on. We found some areas like respiratory just stopped."

"Adult care actually being provided."

"Parents being informed and advised what help there is out there for young adults 18+ and not for services to completely disappear with parents/carers not knowing where to turn for help."

"Make it more gradual, it's frustrating when I can't take telephone consultations because of school but I know my mum would be available to, this isn't an option anymore and it results in missed telephone consultations which slows down my healthcare."

"I was over 18 when I transitioned to adult services and the process was extremely quick. I was lost in communication between the two hospitals, so the adult services were unaware I was coming."

More detail can be found in a summary of the focus groups here.

CHAPTER 1: METHOD

Study Advisory Group

A multidisciplinary group was convened to define the objectives of the study and advise on the key questions to ask. The Study Advisory Group (SAG) comprised healthcare professionals, lay and patient representatives, and commissioners with a specialist interest in transition. This group steered the study from design to completion.

Focus groups and interviews

Young person and parent/carer focus groups and interviews were conducted to inform the direction of the study.

Study aim

To explore the barriers and facilitators in the process of the transition of children and young people with chronic health conditions into adult health services.

Objectives

The SAG identified organisational and clinical objectives that would address the primary aim of the study, including examples of good practice. These included:

Organisational review

- The use of policies and protocols for transition
- The organisation of, and access to, transition services where there is transfer to an equivalent service in the adult healthcare setting and where there is no equivalent adult specialty
- The commissioning and funding of transition services
- Communication both within and between organisations and healthcare professionals
- The delivery of staff training and education in adolescent and young adult health practice
- The use of benchmarks (including *You're Welcome* [15] standards)
- The role of executive and organisational leads (including members of the hospital board, transition co-ordinators, key workers, and youth workers)
- The use of formal networks of care both within and outside the organisation
- Multidisciplinary team (MDT) working including the use of virtual platforms for communication between MDT members and the young person/parent/carer
- The availability and use of peer support, mentoring or access to an integrated youth forum
- Access to support groups for parents/carers during the transition process
- The delivery of holistic developmentally appropriate care
- Quality improvement methodology and audit in transition

Clinical review

- The transition process (including developmentally appropriate care and the age at which preparation started)
- The use of transition documentation for young people and parents/carers, e.g. *Ready Steady Go* [16]
- The presence and funding of named key workers responsible for transition and support, before during and after transfer into adult services
- The role of the young person and parents/carers in the process of transition (including assessment of mental capacity, decision making and whether the process of transition was person centred)
- The role of primary care in transition
- The delivery of developmentally appropriate holistic care
- The follow up process (including support offered) once transfer into adult services has occurred (including the involvement of primary care)
- Communication between clinical teams, and between teams and the young person/parents/carers (including the co-ordination of care)
- Young people and parents/carers' experiences of transition
- Clinicians' experiences of the process of transition

Study population and case ascertainment

Inclusion criteria

This enquiry is about transition from health services for children and young people into adult health services. It does not investigate any single medical condition. The SAG decided that cases for review would be drawn from several conditions in order to encompass a breadth of health issues experienced by young people. The criteria were to include the following: a complex medical condition, a disabling condition, a condition that necessitated the involvement of both medical and surgical specialties, a condition resulting in significant cognitive impairment, a condition arising in adolescence, and finally, a condition requiring significant technological support. The SAG used online voting software to select 12 medical conditions that would encompass these issues. Young people aged between 13 and 25 years with one or more of the following 12 conditions were identified for a sample period between 1st October 2019 and 31st March 2021:

• Epilepsy • sickle cell disease • juvenile idiopathic arthritis • cerebral palsy • spina bifida • muscular dystrophy • solid organ post-transplant (heart, liver, or kidney) • a brain tumour • autism • Rett syndrome • type 2 diabetes in young people with obesity • chronic kidney disease.

Hospital participation

Data were included from providers of primary, community, physical and mental healthcare in England, Wales, and Northern Ireland.

Data collection - peer review

Identification of a sample population

A pre-set spreadsheet was sent to providers of community and physical healthcare to identify all young people who met the study criteria during the defined period. From this initial cohort up to five young people were sampled per organisation for inclusion in the study.

Questionnaires

Organisational questionnaires

Questionnaires were sent to all primary, community, physical and mental healthcare organisations, to collect data on the organisation of services, networks of care, MDT working, the commissioning of services, and the use of guidelines and protocols and training.

Clinician questionnaires

Questionnaires were sent to all teams identified as providing ongoing care to a young person included in the sample, across primary, community, physical and mental healthcare settings. Information was requested on the transition service, the transition pathway, communication with the young person and parents/carers, and MDT working and the co-ordination of care.

Case notes

To allow for the assessment of the pre, peri and post transition period, both electronic and paper case notes were requested from the age of 13 years (or the point of diagnosis) to the young person's 25th birthday or to the 31st March 2021. If a young person was identified and tracked across a number of care settings, case notes were requested from all organisations. If a young person was seen in multiple clinics, or by multiple specialties within the same organisation, case notes were requested from all services. Notes requested included:

- Clinic letters
- Discharge summaries
- Transition documentation (including *Ready Steady Go* [16] and transition plans)
- All MDT notes
- Education, health, and care pans (EHCPs)
- Moving on passport/transition passport
- Care plans
- Treatment escalation plans
- Any relevant primary care records as determined by the GP.

Peer review of the case notes and questionnaire data

A multidisciplinary group of case reviewers comprising transition co-ordinators, paediatricians, physicians and surgeons, nurses, general practitioners, physiotherapists, speech and language therapists, occupational therapists, and hospital-based youth workers working in primary, community, physical healthcare, and social care, were recruited to peer review the case notes and associated clinician questionnaires.

Data collection - young person and parent/carer surveys and focus groups

An open-access anonymous online survey collected the views of young people and parents/carers on the process of transition. The data were not linked to any other aspect of clinical data collection. Smaller focus groups were undertaken to gather more in-depth information.

Data collection - health and social care professional survey

An open-access anonymous online survey asked health and social care professionals for their views on the transition services available to them. The data were not linked to any other aspect of clinical data collection.

Information governance

All data received and handled by NCEPOD complied with relevant national requirements, including the General Data Protection Regulation 2016 (Z5442652), Section 251 of the NHS Act 2006 (21/CAG/0085, App No 1019), and the Code of Practice on Confidential Information.

Each young person was given a unique NCEPOD number. All electronic questionnaires were submitted through a dedicated online application. Prior to any analysis taking place, the data were cleaned to ensure that there were no duplicate records and that erroneous data had not been entered. Any fields that contained data that could not be validated were removed.

Data analysis

Following cleaning of the quantitative data, descriptive data summaries were produced.
Qualitative data collected from the case reviewers' opinions and free text answers in the clinician questionnaires were coded, where applicable, according to content to allow quantitative analysis.

As the methodology provides a snapshot of care over a set point in time, with data collected from several sources to build a picture, denominators will change depending on the data source, but each source is referenced throughout the document. This deep dive uses a qualitative method of peer review, and anonymised case studies, have been used throughout this report to illustrate themes. The sampling method of this enquiry, unlike an audit, means that data cannot be displayed at a hospital/trust/health board/regional level.

Data analysis rules

- Small numbers have been suppressed if they risked identifying an individual
- Any percentage under 1% has been presented in the report as <1%
- Percentages were not calculated if the denominator was less than 100
- There is variation in the denominator for different data sources and for each individual question as it is based on the number of answers given.

The findings of the report were reviewed by the SAG, case reviewers and the NCEPOD Steering Group which included clinical co-ordinators, trustees, and lay representatives prior to publication.

CHAPTER 2: DATA RETURNED AND STUDY SAMPLE

Data returns

Clinical data

In total 46,645 young people were identified as meeting the study inclusion criteria (Figure 2.1). Sampling was weighted to ensure that young people with a range of conditions were chosen, resulting in 1,076 young people being included in the initial sample.

Figure 2.1 summarises the data included. The clinician questionnaires were completed by a wide range of healthcare professionals, including doctors, nurses, occupational therapists, physiotherapists and speech and language therapists across all organisations identified as being involved in the ongoing care of the young person, including primary care, community care, physical and mental healthcare. The most common reason for cancelling a questionnaire was because no ongoing care could be identified by the team.

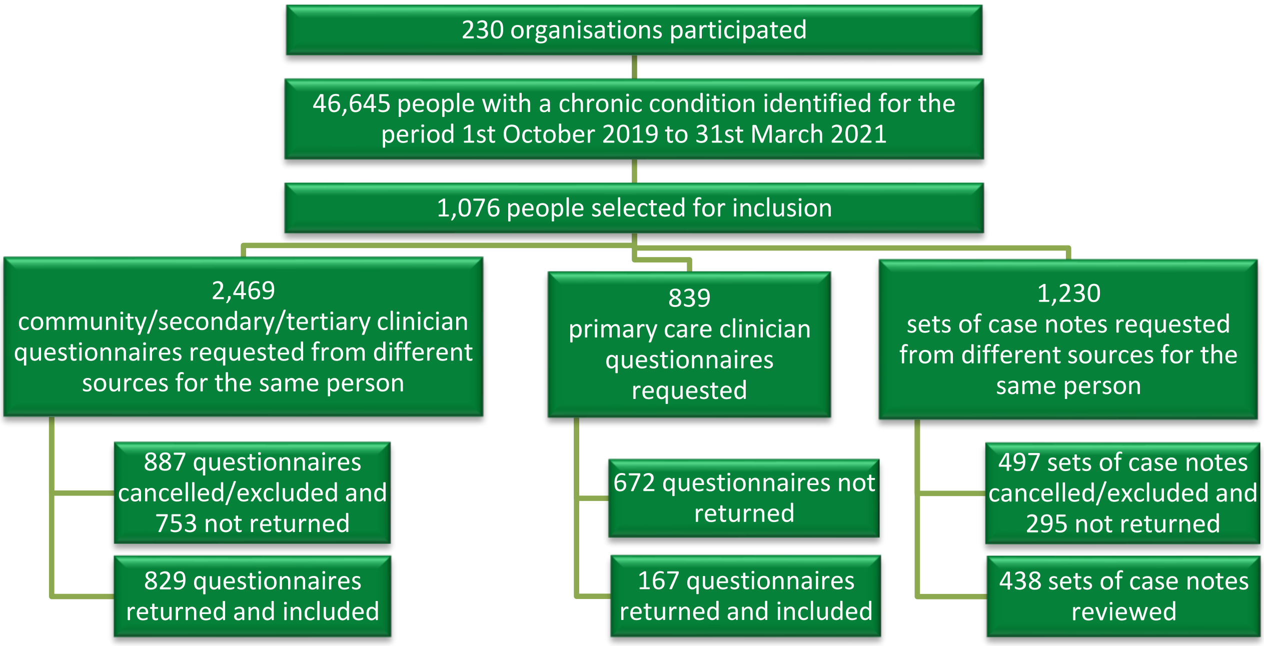

Figure 2.1 Clinical data returned

Organisational data

Organisational questionnaires were also received from 192/230 (83.5%) hospitals participating in the clinical data collection and a further 152 organisational questionnaires were received after contacting 6,786 primary care practices.

Survey data and focus groups

The health and social care professional survey was completed by 454 respondents. The young person and parent/carer survey was completed by 50 young people and 79 parent/carers. Four small focus groups were undertaken with two groups of four parent/carers and two groups of three. In addition, three young people were interviewed, representing a mix of physical and mental health conditions, and stages of transition.

Sample population

Underlying conditions

Young people were randomly selected for inclusion in the study based on the presence of at least one of the 12 identified conditions (Table 2.1).

Table 2.1 Underlying health condition

	Number of young people	%
Epilepsy	300	27.9
Cerebral palsy	187	17.4
Autism spectrum disorder and Rett syndrome	178	16.5
Type 2 diabetes and obesity	89	8.3
Juvenile idiopathic arthritis	87	8.1
Post-transplant - kidney, heart, or liver	86	8.0
Chronic kidney disease	81	7.5
Sickle cell anaemia	80	7.4
Duchenne muscular dystrophy	75	7.0
Brain tumours (medulloblastoma)	63	5.9
Spina bifida	49	4.6
Rett syndrome	16	1.5

Patient identification spreadsheet data; Answers may be multiple; n=1,076

Clinicians completing the clinician questionnaire considered that 462/829 (55.7%) young people had multiple conditions and that 105/254 (41.3%) young people who were preparing for, or transferring to, adult services had a life-limiting condition.[17] In addition, 191/254 (75.2%) young people approaching transfer or transferring into adult services were considered by the clinicians to have a disability which could add additional complexity to their care (Table 2.2 and Table 2.3).

Table 2.2 Concurrent disabilities in young people approaching transfer or transferring into adult services

	Number of young people	%
Both a physical and learning disability	121	48.4
No disability	59	23.6
A physical disability	54	21.6
A learning disability, autism or both	16	6.4
Subtotal	**250**	
Unknown	4	
Total	**254**	

Clinician questionnaire data

Stage of transition

Where transition had started, 112/542 (20.7%) young people were preparing to transfer; 142/542 (26.2%) were peri-transfer and 288/542 (53.1%) had fully transferred from health services for children and young people into adult health services. Transition had not started for 179/829 (21.6%) young people (Table 2.3). A total of 114/173 (65.9%) of these young people were under the age of 15; however, 36/173 (20.8%) were 16 years of age (Table 2.4).

Table 2.3 Stage of transition

	Number of young people	%
Fully transferred into adult health services	288	53.1
Peri-transfer into adult health services	142	26.2
Preparing for transfer	112	20.7
Subtotal	**542**	
Transition not started	179	
Not applicable - diagnosed when under adult health services	64	
Unknown	44	
Total	**829**	

Clinician questionnaire data

Table 2.4 Age of young person where transition not started

	Number of young people	%
13	16	9.2
14	43	24.9
15	55	31.8
16 -17	56	32.4
18 - 20	3	1.7
Subtotal	**173**	
Unknown	6	
Total	**179**	

Clinician questionnaire data

The main reasons given for transition not starting were the structure of the transition service and the absence of a transition service at the organisation (Table 2.5). For 8/145 (5.5%) young people transition was not started because they had a life-limiting condition. However, as the date of death in people with life-limiting conditions is anticipated rather than known it may be beneficial to start transition in young people who could live beyond 16 -19 years of age, as adult-based end of life care input may be required.

Table 2.5 Reason transition had not started

	Number of young people	%
Structure of service/too early to transition	38	26.2
No transition service at this hospital	26	17.9
Life-limiting condition	8	5.5
Severity of condition	4	2.8
Care to be transferred to the general practitioner	4	2.8
Young person would not engage with the transition process	2	1.4
Parents/carers would not engage with the transition process	2	1.4
Other	61	42.1
Subtotal	**145**	
Unknown	34	
Total	**179**	

Clinician questionnaire data

CHAPTER 3: DEVELOPMENTALLY APPROPRIATE HEALTHCARE AS 'CORE BUSINESS'

The concept of developmentally appropriate healthcare acknowledges young people as a distinct group and works to empower young people to slowly take responsibility for their healthcare needs. The healthcare provision should be based on development, taking account of cognitive abilities of young people with a learning disability, autism or both, for example, not just taking age as a number. It should be holistic, recognising how changes in biology, psychology, social interactions, and education all impact on health. Transition from health services for children and young people into adult health services is not a separate entity but is part of this developmentally appropriate healthcare and the transfer into adult services is only one episode in a gradual process that crosses disciplinary and organisational boundaries.[18,19]

Training in developmentally appropriate healthcare

If the quality of transition is to meet published national standards, health professionals, young people and their parents/carers need have a good understanding of what developmentally appropriate healthcare is and what they can expect from it.[20]

Mandatory training for staff in this area was found to be lacking, with only 37/169 (21.9%) organisations having such training in place. This is despite the wide availability of free e-learning in adolescent health, including modules on transition.[21] A total of 81/169 (47.9%) organisations did have training which was non-mandatory, while 51/169 (30.2%) provided no training (unknown for 23).

Many young people with long term conditions do not have a single 'receiving specialty service' to take transfer of their care, which often means that the general practitioner (GP) has to be the main co-ordinator of care and effectively manage the transition and transfer to other specialties. A similar proportion of GPs had training for staff regarding developmentally appropriate/adolescent healthcare (72/134; 53.7%). Only 24/139 (17.3%) practices provided mandatory training that specifically covered taking over the care of young people with long-term conditions (unknown for 18).

Knowing the law on consent and mental capacity

Education regarding consent and mental capacity during teenage years is key in ensuring not only safe care but also that young people understand their own health needs and the ability to make the right decisions regarding their healthcare. In total, it was reported from 146/175 (83.4%) organisations that staff received specific training on taking consent (unknown for 17).

The number of organisations providing training in mental capacity (150/173; 86.7%), was similar to the number providing training in consent to treatment (unknown for 19). However, these figures may be falsely elevated as mental capacity training for adults is taught in mandatory training for all staff, so staff who do not look after young people may be included here. Knowledge of the Mental Capacity Act 2005[22] is crucial in evaluating whether a young person has the capacity to make specific decisions about their health.

The health and social care professional survey asked about training in several areas of care for young people. Use of the Mental Capacity Act 2005,[22] confidentiality and consent were the three most frequently taught areas. Less than half of staff had received training in developmentally appropriate healthcare and/or transition. Seventy professionals had no training in any of these areas (Figure 3.1).

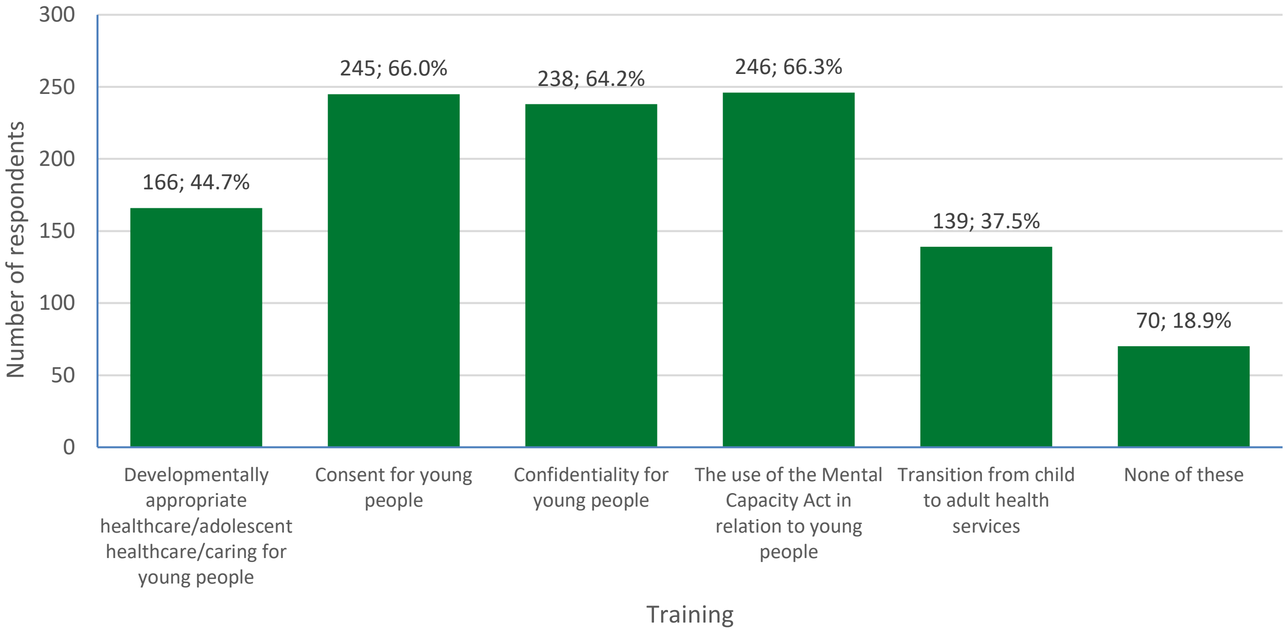

Figure 3.1 Training received by health and social care professionals
Health and social care professional survey data; answers may be multiple; n=371 (unknown for 83)

The quality of the training delivered was mostly rated by respondents to the health and social care professionals survey as reasonable, with a small percentage rated as excellent in most areas (Figure 3.2). This was a subjective observation.

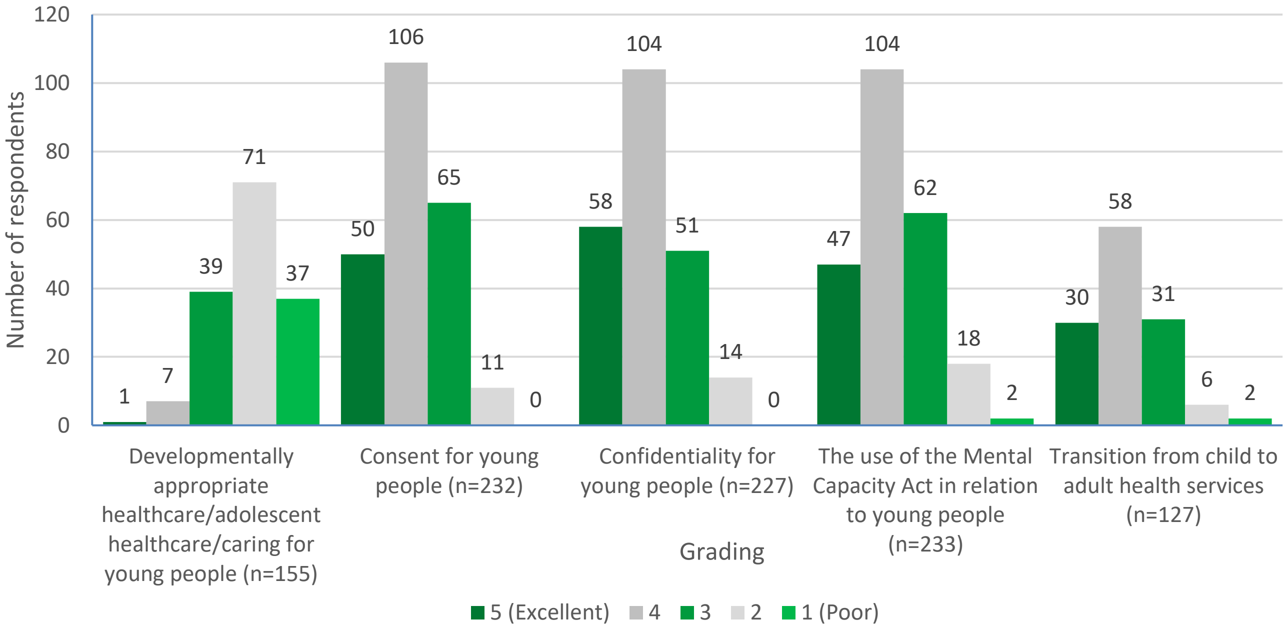

Figure 3.2 Grading of the quality of the training received by health and social care professionals
Health and social care professional survey data

Job planning

Staff will be unable to put what they have learned into effective practice if they do not have allotted time for it. Young people are living longer with chronic disease, meaning that the cohort transferring into adult services is growing and there is even more reason for job plans to include sufficient time to support them effectively. Two-thirds of organisations did have some specialties with transitional care included in the job description but only 16/167 (9.6%) organisations had transition included in the job descriptions of all healthcare staff involved in transition (Table 3.1).

Table 3.1 Transitional care is included in the job descriptions of healthcare staff involved in transition

	Number of organisations	%
Yes - for all specialties	16	9.6
Yes - for some specialties	92	55.1
No	59	35.3
Subtotal	**167**	
Unknown	25	
Total	**192**	

Organisational data

Organisation of facilities to provide developmentally appropriate healthcare

Without appropriate training and dedicated staff time, organisations may find it difficult to provide the right environment and resources to support proper care for young people through transition. The 'one-stop shop model', where health and wellbeing are addressed during one hospital visit, has been cited as a good model of care in the community.[23] This model allows the patient to see the wider team on the same day. For transition planning this would bring together the teams supporting children and adults on the same day, preparing the young person for adult care and reducing the need to travel to multiple appointments.

Only 19/192 (9.9%) organisations had this model in place for all specialties, and 72/192 (37.5%) had it in place for some specialties. These appointments will take more time than a routine disease related visit but only 23/165 (13.9%) organisations offered longer appointments for young people during transition (unknown for 27). The impact of chronic disease and its therapy means young people are already likely to miss out on educational opportunities; despite this, only 39/192 (20.3%) organisations offered appointments outside school or college hours. However, it was noted by many of the healthcare professionals involved in this study that often special needs schools and colleges have clinic appointments at the place of education, therefore bringing the team around the young person in this setting, although these data were not captured in this study.

Only 27/192 (14.1%) organisations had an age-appropriate environment to deliver such care for all specialties, and 79/192 (41.1%) for some specialties. The organisational data showed that when an organisation provided an age-appropriate space, young people were being signposted to key areas of adolescent health such as sexual health, information around drug use and education (Table 3.2).

Table 3.2 Resources available for young people within an age-appropriate environment

	Number of organisations
Educational resources	51
Sexual health resources	49
Resources regarding drugs	42
Other	40
Subtotal	**83**
Unknown	23
Total	**106**

Organisational data; answers may be multiple; n=83 (unknown for 23)

Clinicians reported that 82/156 (52.6%) young people were signposted to holistic services when attending appointments, with the majority being signposted to mental health services and for nutritional advice (Figure 3.3) (unknown for 98).

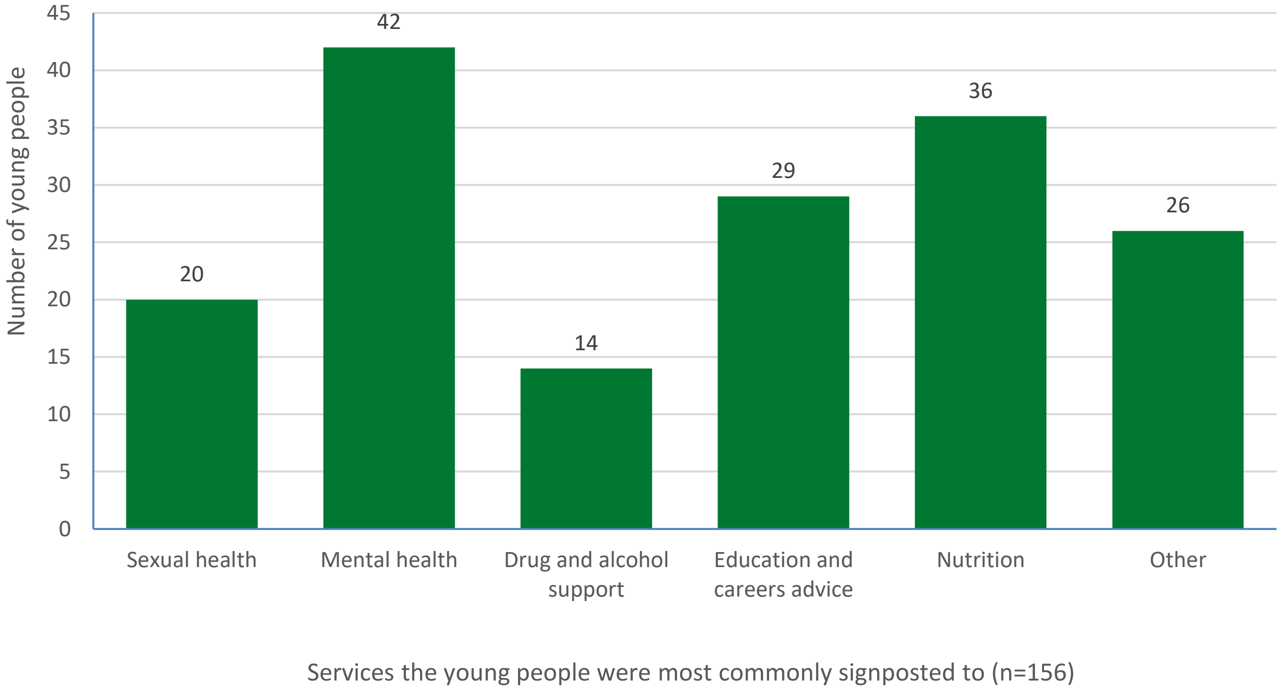

Figure 3.3 Services available to young people approaching transfer into adult services
Clinician questionnaire data

Supporting ownership of holistic healthcare needs

As well as providing or signposting to wider holistic services, developmentally appropriate healthcare encourages young people to take ownership of their own healthcare needs. Reviewers found that most young people were not being given the opportunity to develop skills for self-management of their health needs, with evidence in just 172/363 (47.4%) cases reviewed (unknown for 75).

Young people are more likely to be involved in their own healthcare and to be empowered to take ownership if they are included in discussions around their own healthcare. The survey of young people and parents/carers highlighted that parents were more likely to be invited to attend meetings around transition and transfer into adult services (27/79) than the young people themselves (8/50). Only 71/298 (23.8%) young people knew who to contact if transition was not going well (unknown for 140). Overall, these results highlight the lack of support for young people to become empowered in managing their own health.

GPs signposted young people to a wide range of services, with the majority prioritising mental health, and many also referring to alcohol and drug use services, sexual health, and smoking cessation services. Many practices used social prescribing when organising the care for young people (Figure 3.4). Although not captured in these data, it must also be noted that GPs promote self-management in a variety of other, softer ways, such as ongoing discussion at appointments, and not simply by signposting to holistic services. However, only 30/128 (23.4%) GP practices had resources to specifically develop young people's self-management of their health needs (unknown for 24).

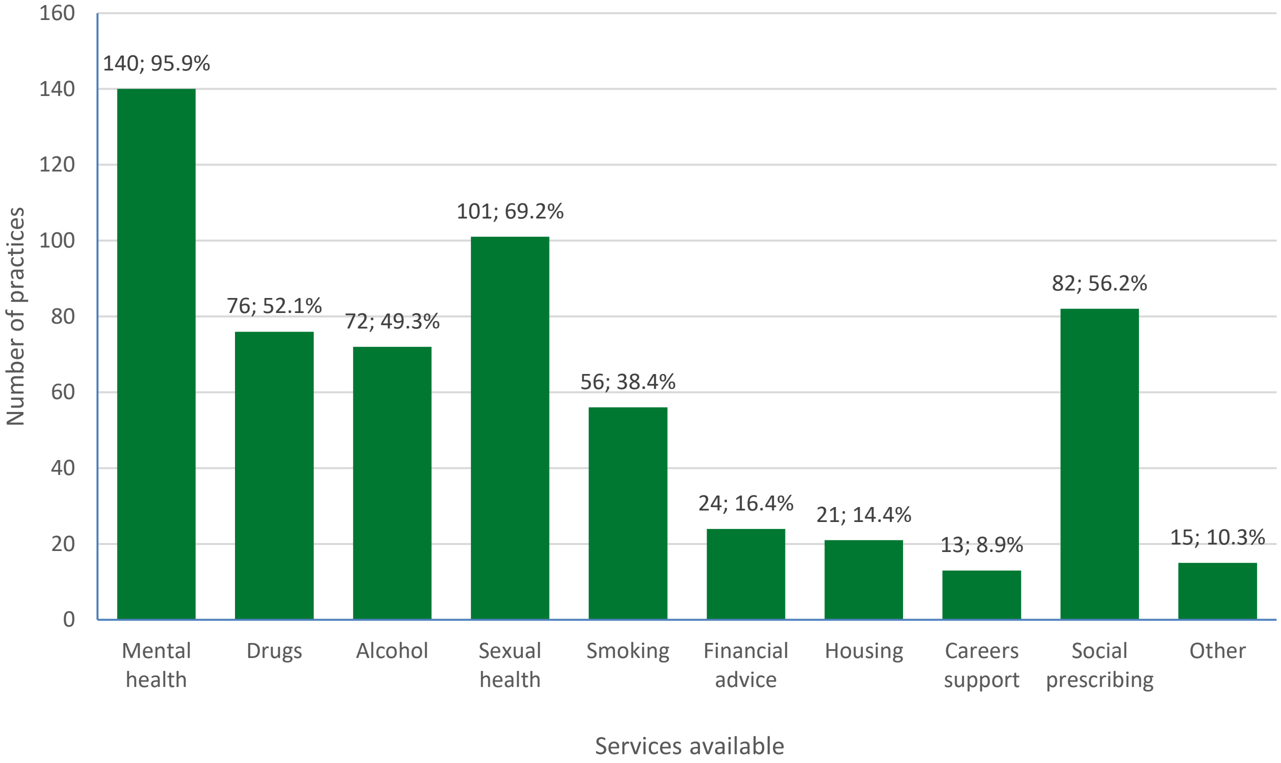

Figure 3.4 Services available for GPs to refer young people to
Primary care organisational data; answers may be multiple; n=146 (unknown for 6)

Young people reported that wider holistic care was not always discussed during transition (Figure 3.5). Despite providers feeling mental health was a strong topic of signposting and discussion, the survey of young people and their carers found that education was the most frequently discussed area and more commonly, no holistic discussion happened at all.

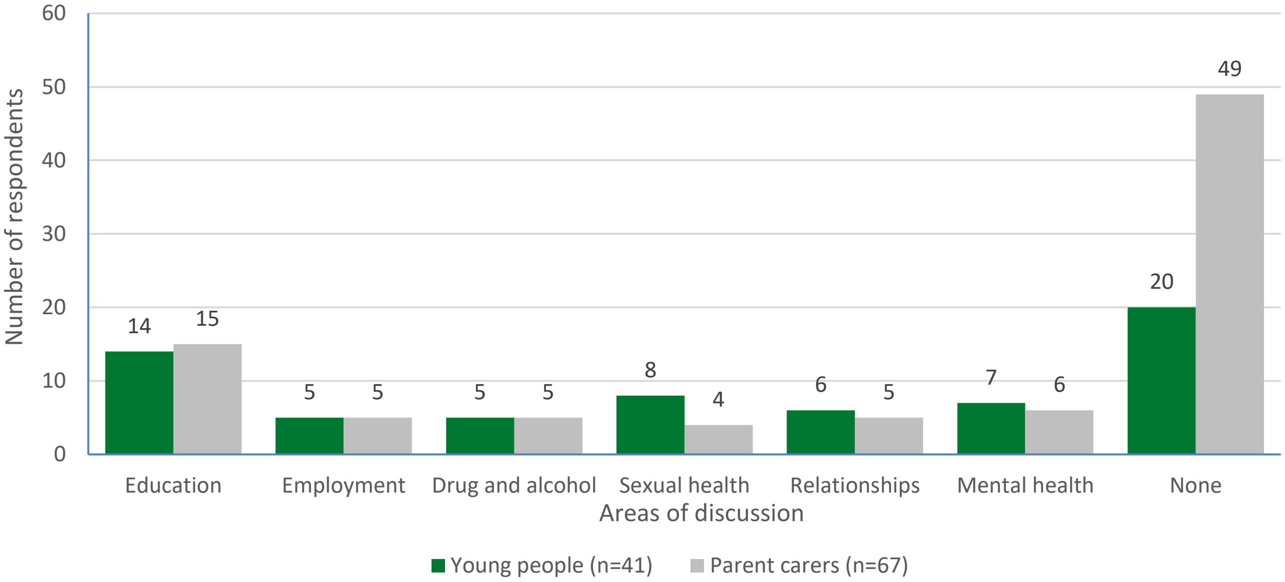

Figure 3.5 Areas that were discussed with young people and parents/carers by a healthcare professional during the transition period
Young person and parent/carer survey data; answers may be multiple; young people n=41 (unknown for 9); parents/carers n=67 (unknown for 12)

Age at which transition was discussed with young person

It is recommended that transition begins at the age of 13.[4,5,19] However, the reviewers found that it was more commonly mentioned in the case notes around the ages of 17 or 18, the time at which transfer into adult services generally takes place (Figure 3.6). Where it could be assessed, reviewers stated that transition was started at the appropriate age for only 91/280 (32.5%) young people by all services and 72/280 (25.7%) by some services (Table 3.3). These data clearly illustrate that for the majority of young people, acknowledgement of transition and initiation of developmentally appropriate healthcare is happening too late, and mostly at the time of transfer into adult services.

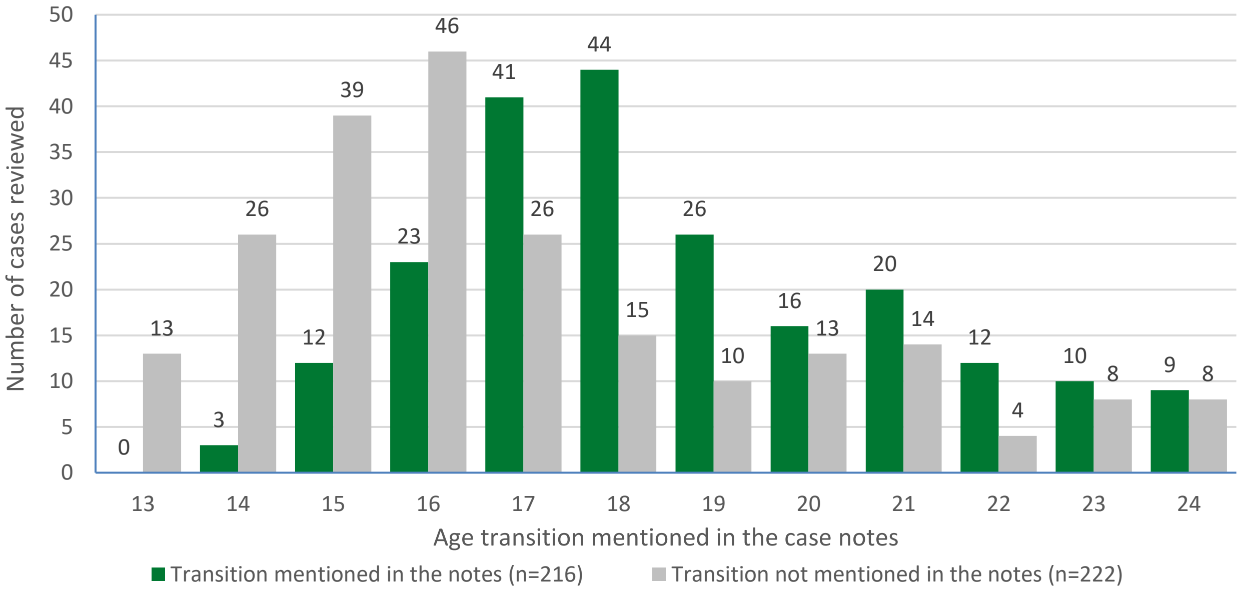

Figure 3.6 Age at which transition from health services for children and young people into adult health services was explicitly mentioned in the case notes
Reviewer assessment form data

Table 3.3 The transition process started at a developmentally appropriate age for this young person

	Number of young people	%
Yes - for all services	91	32.5
Yes - for some services	72	25.7
No	117	41.8
Subtotal	**280**	
Unable to answer	158	
Total	**438**	

Reviewer assessment form data

Missed opportunities

Young people are less likely to seek healthcare and for this reason it makes sense that any contact with healthcare professionals is used as an opportunity to educate and inform. Reviewers found missed opportunities in 219/322 (68.0%) cases reviewed, when transition and developmentally appropriate healthcare could have been addressed but was not (unknown for 116).

CASE STUDY 1 - MISSED OPPORTUNITIES

An 18-year-old patient with epilepsy and mental health concerns attended outpatient appointments with the neurology team every 4-6 months. Case reviewers found that for almost two years the clinic letters included a ‘cut and paste’ outline of the patient’s medical condition and current situation. The letters were never addressed to the patient and there was no mention of any other aspects of the patient’s life, despite their history of poor mental health.

Given that the patient always attended appointments, the reviewers stated that there were many ‘missed opportunities’ to address wider aspects of wellbeing and to deliver developmentally appropriate healthcare.

LEARNING EXAMPLE

TRANSITION AS CORE BUSINESS

- A 19-year-old patient with sickle cell disease, a learning disability, arteriovenous malformation and one total hip replacement had regular appointments to discuss transition and plan the transfer into adult services.
- A transition lead was identified for the patient’s care, who acted as an overarching co-ordinator and made arrangements for the patient to visit the adult services site.
- The patient had a transition plan, which was vital at times of crisis during emergency department attendance.
- The patient was seen in the paediatric emergency department until transfer to adult services had taken place at the age of 17, at which point they were seen in the adult emergency department.
- The patient was fully informed of this process, as were the parents, so expectations were appropriately managed.

CHAPTER 4: PATIENT AND PARENT/CARER INVOLVEMENT IN HEALTHCARE PLANNING

Developmentally appropriate healthcare sets out a conceptual framework for what constitutes appropriate intervention.[24] This can then be translated into practice with the focus on the young person and their involvement in their own care. This involvement should be in the young person's individual healthcare plans as well as in shaping the design of the system in the organisation in which they are being treated.

Young people's involvement in their own healthcare planning

NICE recommends that individual plans regarding transition are co-produced with the young person.[4,5] Our study revealed a difference in the perception of how well this was done between those who delivered the service (organisational and clinician questionnaires), and those reviewing or experiencing the service (case reviewers and the views of the young people).

Organisational data showed that 118/192 (61.5%) organisations had a policy stating that the young person should be offered the opportunity to be actively involved in their own transition process. In 86/118 (72.9%) organisations this took the form of jointly developing care plans. The clinician questionnaire data showed that on approaching transfer 141/187 (75.4%) young people were involved in their transition process (unknown for 67). These were both much higher that the view of the reviewers, who on reviewing case notes found that only 56/290 (19.3%) young people were involved in their transition process for all specialities and 89/290 (30.7%) for some specialties (unknown for 148).

Barriers to a young person's own involvement in transition (such as lack of mental capacity) could be identified in the notes of 104/285 (36.5%) young people (unknown for 153). Overall, reviewers rated involvement of young people in their transition process as poor (Figure 4.1).

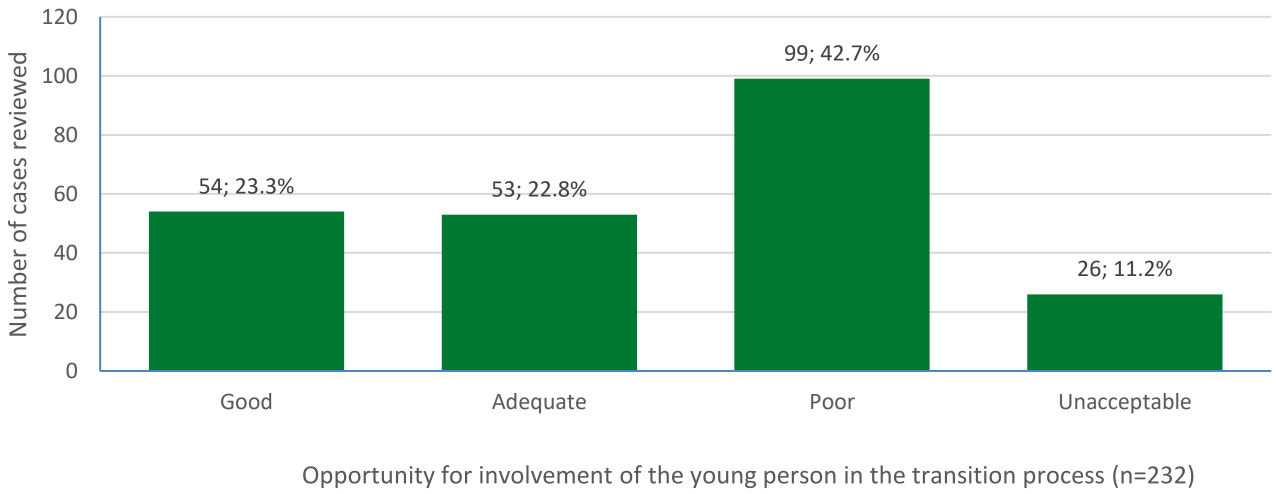

Figure 4.1 Appropriate involvement of the young person in the transition process
Reviewer assessment form data

When young people were asked about their involvement in transition planning, only 5/46 stated that they were fully involved, while 20/46 said that they were not involved at all (Figure 4.2).

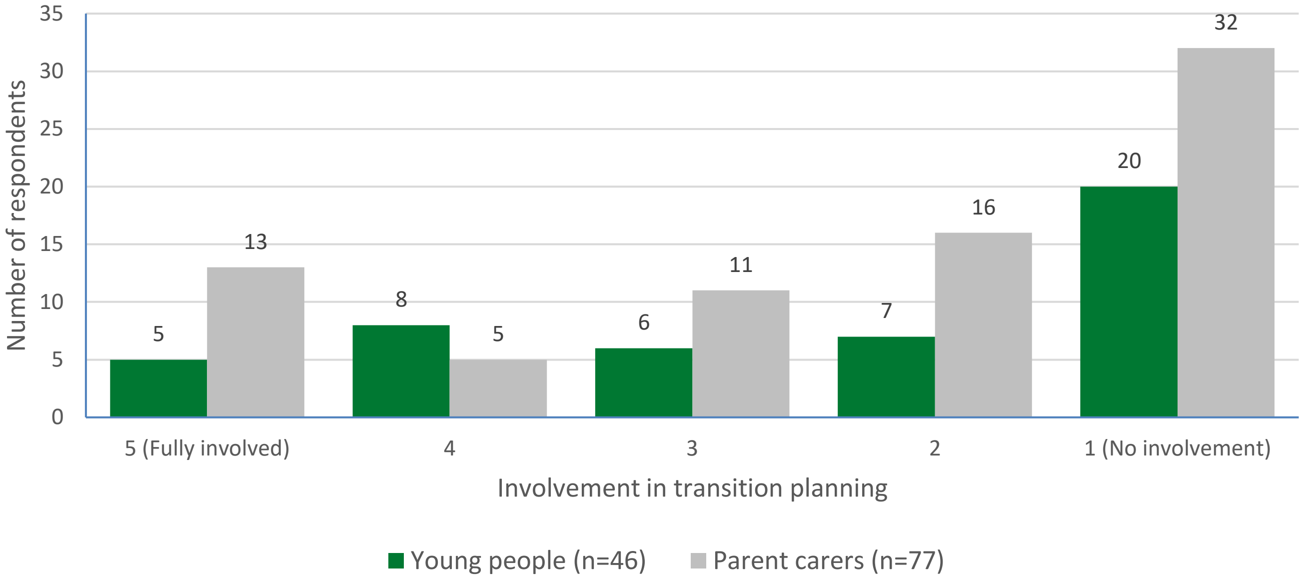

Figure 4.2 How involved young people and parents/carers were in transition planning
Young person and parent/carer survey data; young people (unknown for 4); parents/carers (unknown for 2)

One explanation for this discrepancy may be that the concept of transition is poorly understood with a lack of education for young people, parents, and healthcare professionals around the distinction between transition and transfer as well as what developmentally appropriate healthcare means. This was clearly reflected in the response from young people and carers when asked about their understanding of the transition process (Figure 4.3).

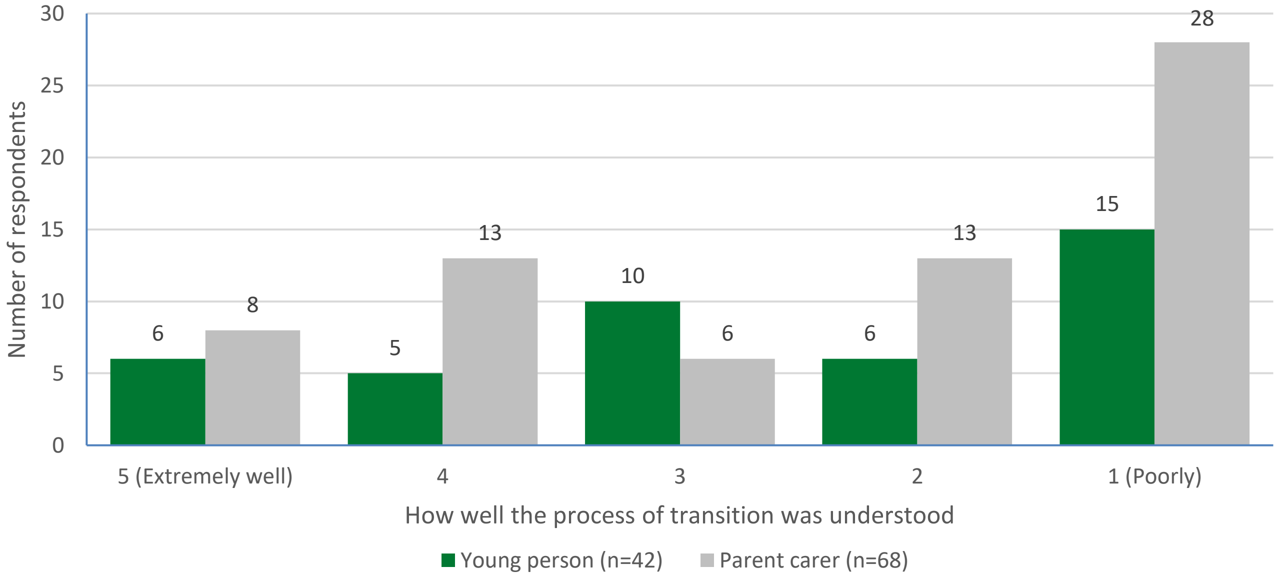

Figure 4.3 How well the process of transition was understood by young people and parents/carers
Young person and parent/carer survey data; young people (unknown for 6); parents/carers (unknown for 11)

It is important for professionals to manage expectations so that the differences between health services for children and young people and adult healthcare provision are understood. However, many young people and parents/carers did not feel that these differences had been well communicated (Figure 4.4).

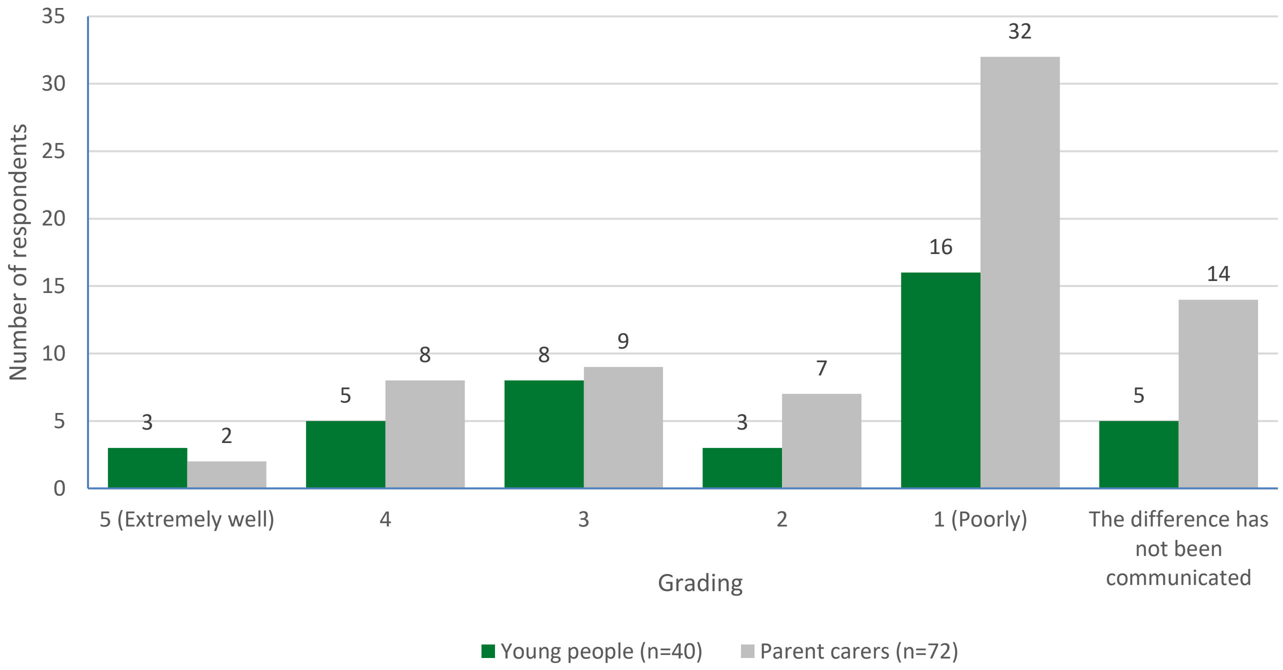

Figure 4.4 Grading of how well the differences between health services for children and young people and adults were communicated
Young person and parent/carer survey data; young people (unknown for 10); parents/carers (unknown for 7)

CASE STUDY 2 - TRANSFER NOT TRANSITION

A 17-year-old patient with a diagnosis of sickle cell disease came to the UK at the age of 15 and was seen in the children and young person's sickle cell clinic. There was no mention of, or discussion about, the patient's future healthcare. The patient was not seen by adult haematology services in any clinic appointment. Clinic letters were not addressed to the patient; there was no transition plan nor documentation such as Ready Steady Go in the patient's case notes. There was mention in the notes that the patient was morbidly obese and had mental health problems. Aged 17, the patient had an acute sickle cell crisis necessitating hospital admission and was initially seen in the adult emergency department before being admitted to the adult ward. On discharge, the patient was followed up in the adult sickle cell clinic. The clinic letter stated that the patient had '… been transitioned to adult services'.

The reviewers highlighted the lack of understanding between transition - a process which is inclusive of providing developmentally appropriate healthcare, and transfer - the physical move from child into adult services.

Involvement of parents/carers

In 62/113 (54.9%) organisations there was a policy that included consideration of how a young person would like their parent/carer to be involved in their care (unknown for 79). It was reported from a further 91/172 (52.9%) organisations that there was a policy stating that parents/carers should be offered the opportunity to be actively involved in transition (unknown for 20). Only 43/91 of these organisations were able to state how the parent/carer involvement should be undertaken.

Clinicians responded more positively regarding parent/carer involvement in care, with 200/254 (78.7%) commenting that parents/carers had been involved in the transition process . However, reviewers were only able to identify parent/carer involvement with all services in 56/290 (19.3%) cases reviewed, and with some services for 89/290 (30.7%) cases (unknown for 148). Overall, reviewers rated the involvement of parents/carers in their transition process as being poor (Figure 4.5).

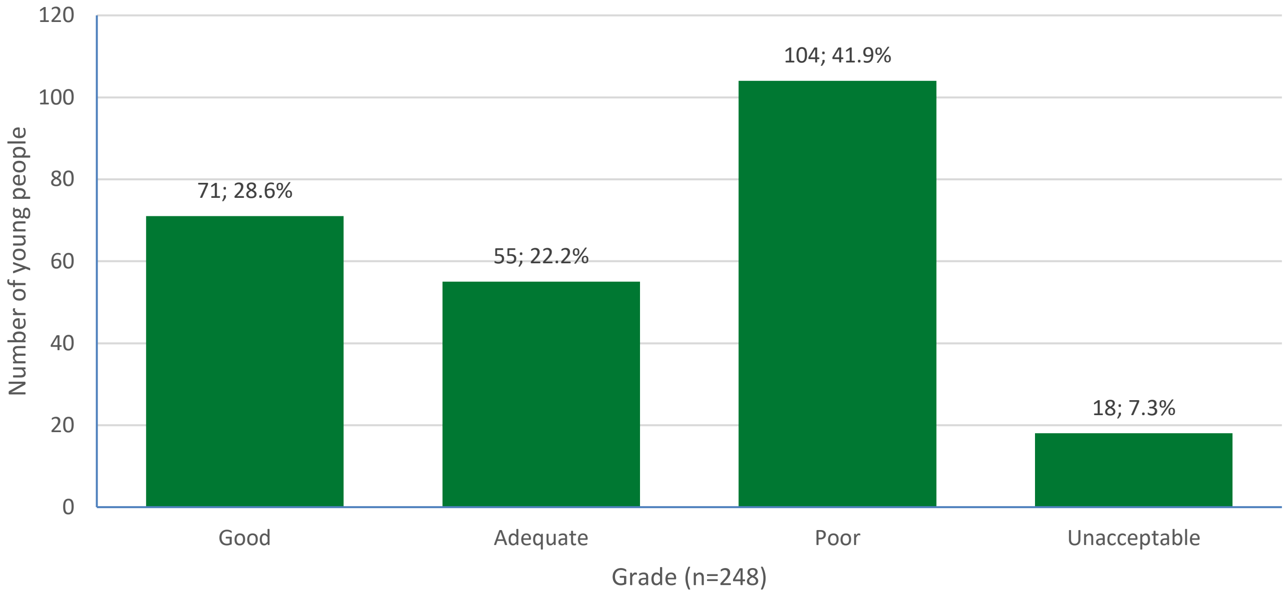

Figure 4.5 Grading of the involvement of parents/carers in the transition process
Reviewer assessment form data

Opportunities for young people and their parents/carers to be seen alone

As a young person develops, adjustment of healthcare is encouraged by giving the opportunity for young people to be seen alone during appointments. In total, 70/181 (38.7%) organisations acknowledged that young people were given the opportunity to be seen alone in clinic appointments by all specialties, and 107/181 (59.1%) for some specialties. Similar figures were seen for parents/carers being given the opportunity to be seen alone: 58/171 (33.9%) for all specialties and 96/171 (56.1%) for some specialties (Table 4.1).

Table 4.1 Young people and parents/carers were given the opportunity to be seen alone

	Young people given the opportunity to be seen alone		Parents/carers given the opportunity to be seen alone	
	Number of organisations	%	Number of organisations	%
Yes - for all specialties	70	38.7	58	33.9
Yes - for some specialties	107	59.1	96	56.1
No	4	2.2	17	9.9
Subtotal	**181**		**171**	
Unknown	11		21	
Total	**192**		**192**	

Organisational data

GPs responded very positively with 146/152 (96.1%) giving young people the opportunity to be seen alone. It should be noted that GPs will often see young people in a different context, about a problem not necessarily related to their chronic condition. This may mean they are more likely to attend without a parent/carer.

Involvement in the design of the transition service

There were 20/136 (14.7%) organisations, where a transition service was in place, and young people were involved in the design of the service for all specialties and 84/136 (61.8%) for some specialties (unknown for 56). Involvement was mostly in the form of informal discussions (68/104; 80.9%) rather than a structured process.

In the opinion of health and social care professionals, the involvement of young people in the transition process ranged from poor for 35/328 (10.7%) organisations to excellent for 21/328 (6.4%); and the involvement of parents/carers from poor for 36/327 (11.0%) organisations to excellent for 25/327 (7.6%) (Figure 4.6).

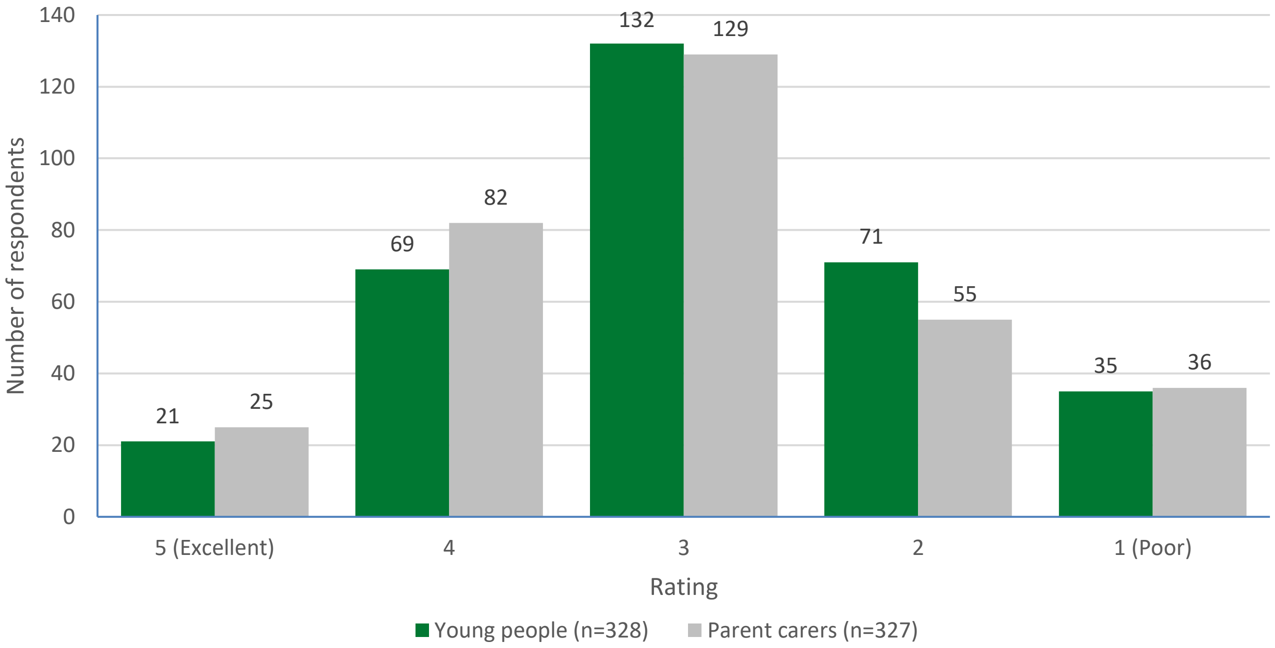

Figure 4.6 Rating of the involvement of young people and parents/carers in the transition process

Health and social care professional survey data

Youth forums are an excellent way of ensuring young people are involved in service design as advocated by NICE guidance and *You're Welcome* standards of care.[4,5,15] However, only 63/192 (32.8%) organisations had their own youth forum.

LEARNING EXAMPLE

GOOD YOUNG PERSON INVOLVEMENT

- An 18-year-old patient with beta thalassaemia attended the hospital for regular transfusions.
- The young person attended a teenage clinic where there were specialists for children and young people and adults.
- There were regular mixed multidisciplinary meetings to discuss different aspects of the patient's medical care, but also to talk about their general wellbeing and developmental stage.
- During the COVID-19 pandemic the patient had to attend appointments on their own, allowed them to gain further independence and to manage the disease, which was empowering, and gave them more confidence.

CHAPTER 5: COMMUNICATION AND CARE CO-ORDINATION

NICE guidance recommends a person-centred approach that involves the young person, their family or carers, primary care clinicians and colleagues in education services.[4,5] To achieve this there needs to be excellent communication between everyone involved to ensure co-ordination across the pathway.

Communication with the young person

Transition plans

One of the key elements of developmentally appropriate healthcare is the adjustment of care as a young person develops. Ideally this would be done with the healthcare provider routinely exploring with the approach to transition together with the young person and personalising their clinical needs via a transition plan.

It was reported from 99/192 (51.6%) organisations that there was an overarching transition policy and within this policy, 84/99 stated that all young people going through transition planning have a transition plan in place from early adolescence. However, reviewers only found evidence in the notes for a transition plan being in place for all specialties involved in a young person's care in 58/398 (14.6%) cases reviewed, for some specialties in 84/398 (21.1%) and not at all in 256/398 (64.3%) cases (unknown for 40). When there were transition plans in place, reviewers found evidence that these were individualised and not just a 'tick box' exercise for 101/142 (71.1%) young people.

Data from the surveys showed that only 7/50 young people said they had a transition plan and just 9/79 parents/carers were aware that a transition plan was being used. Sharing of the transition plan was predominantly via a paper copy or mentioned in clinic letters, with a very clear absence of any more age-appropriate use of technologies. Notably, only 7/50 young people responding to the survey reported using technology while going through transition, which seems like a missed opportunity given the heavy use of social media and technology platforms among this age group.

Ready Steady Go and *Hello to Adult Services* are examples of transition tools that can be used as an aid to create a transition plan. Originally developed in rheumatology services as part of a research project[25] and then adopted by the Transition Steering Group at Southampton Children's Hospital,[26] *Ready Steady Go* [16] is the most widely used and recognised transition tool within the NHS.

There are other less well-known transition plans (tools) in use, and some organisations develop their own. A total of 47/83 organisations with an overarching transition policy had developed bespoke transition plans, and 15/29 organisations with no overarching policy but with separate, specialty-based, transition policies had developed their own transition plans rather than using well-recognised models (Table 5.1). The presence of any transition tool is an encouraging indication that organisations have acknowledged the need for developmentally appropriate healthcare.

Table 5.1 Transition plans used

	Overarching transition policy	Separate policies
	Number of organisations	Number of organisations
Ready Steady Go	70	23
Local transition plan	47	15
HEADSSS	20	3
Education, health, and care plan model - Council for Disabled Children	16	8
Stepping Up - Together for short lives	10	3
10 step programme - Alder Hey	9	5
Making healthcare work for young people - Northumbria Healthcare Foundation Trust	2	0
Other	9	6
Subtotal	**83**	**29**

Organisational data; answers may be multiple; overarching policy n=83, separate policies n=29

Where it could be determined, only 27/83 organisations had an overarching policy stating that the use of a plan should be audited for all young people, with just 6/29 organisations with separate policies saying they had audited the use of such plans.

Communication with young people and their parents/carers

Effective self-management of healthcare should be encouraged by health professionals, corresponding directly with the young person whenever possible. In total, 57/124 (46.0%) organisations had a policy stating that young people should be copied into correspondence both pre- and post-transfer into adult services, with 28/124 (22.6%) only copying young people into letters after transfer into adult services (unknown for 68). Although some policies stated young people should be copied into correspondence, reviewers found evidence that only 51/373 (13.7%) young people were copied in for all specialities and 98/373 (26.3%) for some services (unknown for 65). Many young people and parents/carers did not rate the communication by healthcare professionals as good (Figures 5.1 and 5.2).

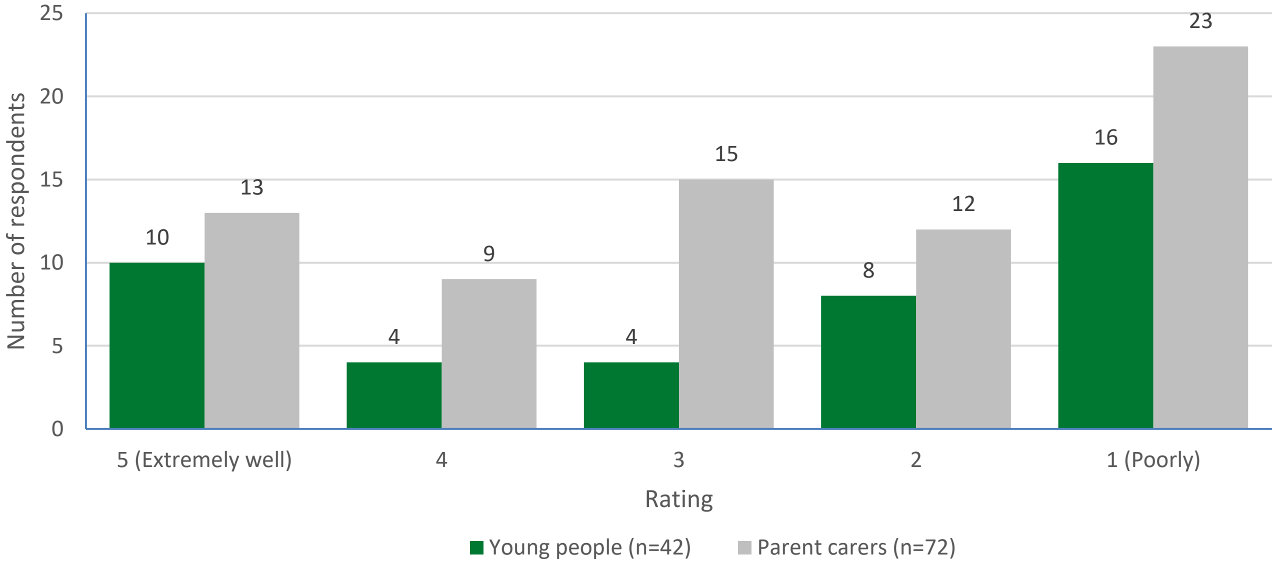

Figure 5.1 Rating of the communication by healthcare professionals in children and young people's services

Young person and parent/carer survey data: young people (unknown for 8); parents/carers (unknown for 7)

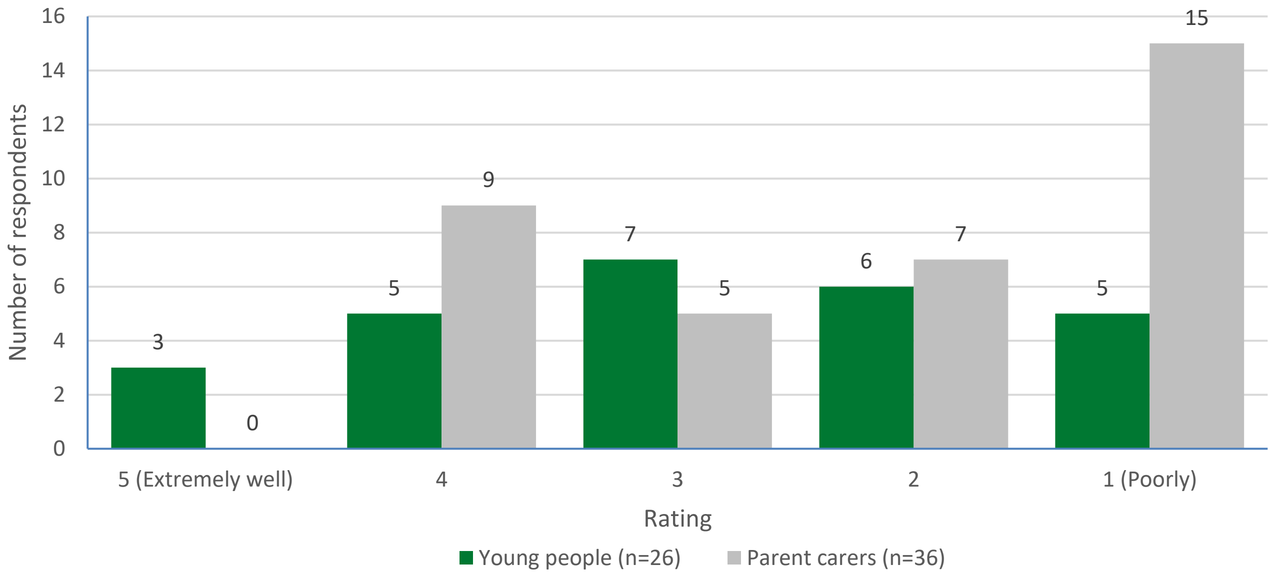

Figure 5.2 Rating of the communication by healthcare professionals in adult services
Young person and parent/carer survey data (all young people 17+ years)

There was evidence in the case noes that 188/438 (42.9%) young people had a learning disability. Data from the clinician questionnaire indicated that where the young person had a learning disability (137/254; 53.9%), and where it could be determined, the ability to make independent decisions regarding their healthcare been considered as part of transition planning for 70/95 young people. Conversely, where the reviewers had identified that the young person had a learning disability, there was evidence in the case notes that mental capacity has been discussed with parents/carers for only 59/188 (31.4%) young people.

Although it was reported that 129/163 (79.1%) organisations had a policy regarding reasonable adjustments for young people with a learning disability (unknown for 29), reviewers considered there were barriers to communication with the young person evident in 132/312 (42.3%) cases reviewed (unknown for 126).

Reviewers raised concerns that the voice of the young person with a learning disability or neurodivergence was not being heard. One example was the *'limited communication ability of a young person with a vocabulary of few words'* and another was that *'communication very limited and dependent on eye movement communication'.*

The challenge of multiple teams and split site care

Multiple teams

Reviewers found evidence that 346/438 (79.0%) young people were under the care of multiple specialties and in 92/346 (26.6%) cases this was within the same trust/health board, and in 254/346 (73.4%) this involved multiple teams across two or more trusts/health boards. Similar data extracted from the clinician questionnaire found that the number of teams ranged from one to 23, with 97/128 (75.8%) young people under the care of two, three or four teams (unknown for 35).

For the young people who had fully transferred into adult services, 136/217 (62.7%) were under the care of multiple teams provided by adult and/or children and young people's teams in both secondary and tertiary trusts/health boards at the point of transfer (Table 5.2) (unknown for 71). It was of note that primary care was only considered as part of the wider team for 67 young people. This seemed low and perhaps demonstrates a disconnect between acute and community services.

Table 5.2 The young person was under the care of multiple clinical teams at the point of being fully transferred from health services for children and young people into adult health services

	Number of young people	%
Secondary care children and young person's team	69	51.9
Primary care	67	50.4
Hospital-based children and young person's team - tertiary care	64	48.1
Secondary care adult team - secondary care	55	41.4
Hospital-based adult team - tertiary care	53	39.8
Community team - children and young person's team	47	35.3
Community team - adults	30	22.6
Social care	23	17.3
Other	14	10.5
Subtotal	**136**	
Unknown	81	
Total	**217**	

Clinician questionnaire data; answers may be multiple; n=136

Membership of the teams

NICE recommends that health and social care managers in child and adult services should work together in an integrated way to ensure a '*smooth and gradual transition*' and states that '*poor communication will impact on the ability of teams to collaborate and to co-ordinate care*'.[4,5] As many young people had multiple teams involved in their care, this often resulted in a broad membership of the transition team. However, only three organisations included GPs or primary care colleagues as regular members of the team (Table 5.3).

Table 5.3 The regular members of the transition team responsible for transition

	Number of organisations
Paediatric clinicians	17
Clinical nurse specialists	17
Management	15
Nurses	15
Adult clinicians	14
Community team clinicians	8
Community team nurses	7
Young people	6
Key workers	5
Physiotherapists	4
Peer support	4
Parents/carers	4
Occupational therapists	3
Youth workers	3
General practitioners/primary care	3
Unknown	1
Other	15

Organisational questionnaire data; answers may be multiple; n=29 (unknown for 1)

Co-ordination and communication between teams

When a young person is under the care of multiple teams, there should be co-ordination to enable person centred care and support a smooth transfer. For 72/119 (60.5%) young people who were under the care of multiple teams the transition process was considered to be co-ordinated across the different teams, while for 47/119 (39.5%) it was not (unknown for 44). However, reviewers were unable to find evidence of co-ordination between teams in 165/242 (68.2%) cases reviewed (unknown for 104) and they rated co-ordination of multidisciplinary team care during transition as good for 65/270 (24.1%) young people, and poor for 117/270 (43.3%) (Figure 5.3) (unknown for 76).

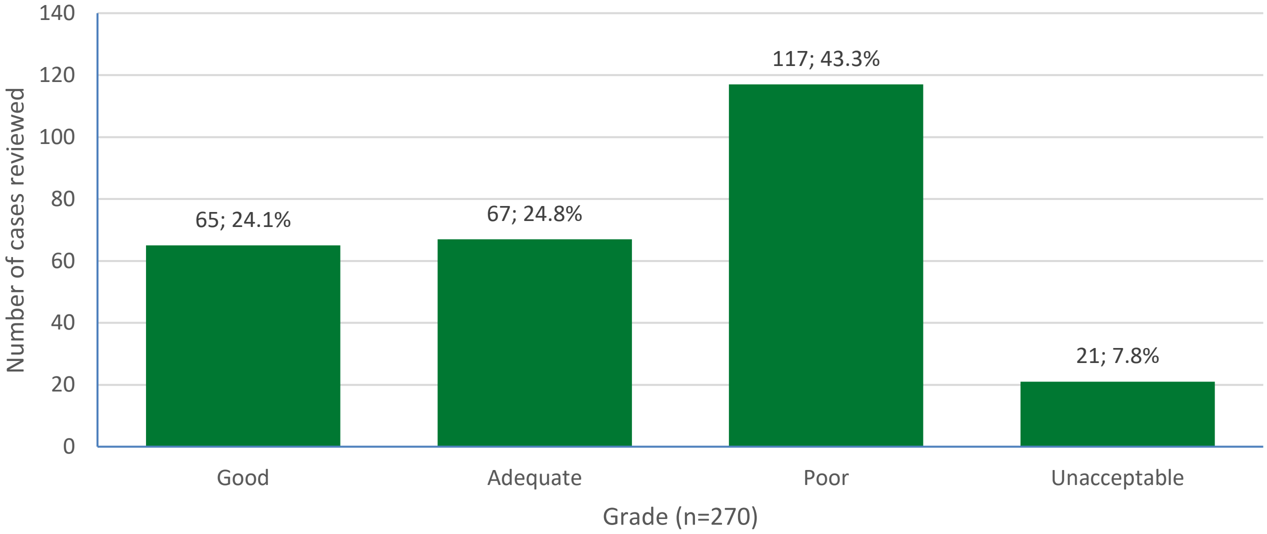

Figure 5.3 Grading of the co-ordination of multidisciplinary team care during the transition process
Reviewer assessment form data; (unknown for 76)

Where answered, only 128/301 (42.5%) health and social care professionals considered that care was well co-ordinated across multiple clinical teams, and 58/324 (17.9%) rated it as poor (Figure 5.4).

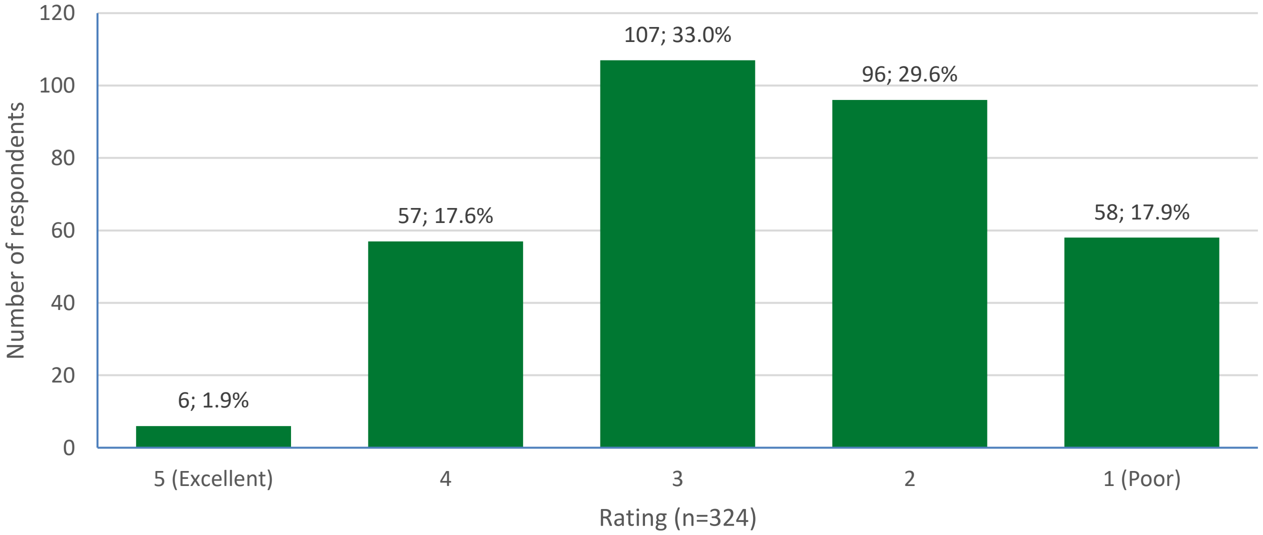

Figure 5.4 Rating of the co-ordination of care across multiple clinical teams
Health and social care professional survey data; (unknown for 130)

Good communication is fundamental to the co-ordination of care but where the young person was under the care of multiple specialties communication between the teams was found to be variable (Table 5.4).

Table 5.4 Evidence in the case notes that there had been communication about transition between multiple teams during the process of transition

	Number of young people	%
Yes - between all teams	44	16.3
Yes - between some teams	71	26.3
No	155	57.4
Subtotal	**270**	
Unable to answer	76	
Total	**346**	

Reviewer assessment form data

In most cases, young people and parents/carers also considered communication between teams to be poor (Figure 5.5).

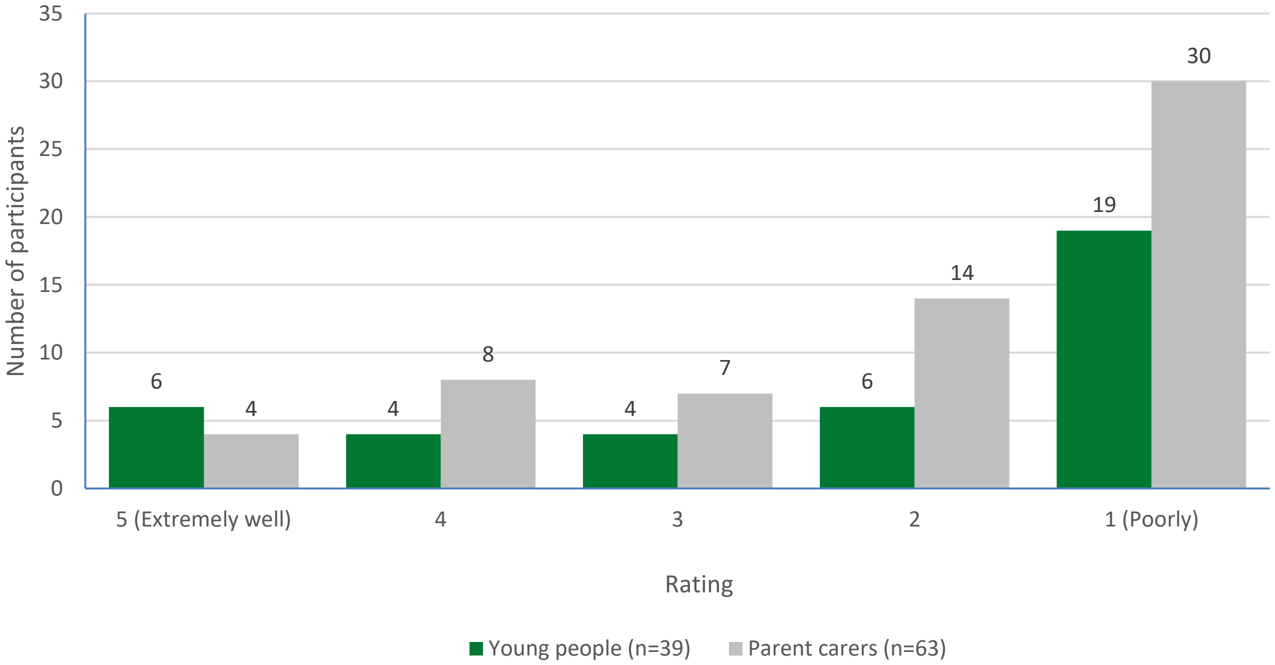

Figure 5.5 Rating of how well the teams providing healthcare to the young person communicated with each other
Young person and parent/carer survey data; young people (unknown for 11); parents/carers (unknown for 16)

Communication with primary care

The Care Quality Commission (CQC) 2014 report on children's transition into adult services states that "*General practice has a crucial role as the single service that does not change as the result of reaching adulthood.*"[3]

A total of 100/151 (66.2%) organisations had a pathway to liaise with primary care for young people transitioning into adult services, 106/151 (70.2%) had information for young people on how to contact their GP and 49/151 (32.5%) had a policy to encourage young people to access primary care for their other health needs (unknown for 41). Clinician questionnaire data indicated all young people (254/254; 100.0%) were registered with a GP and these details were recorded in the hospital records. Clinicians who responded said that young people were encouraged to access primary care for their other health needs in 163/182 (89.6%) instances (unknown for 72).

There were 123/147 (83.7%) organisations where there was no receiving adult specialty, and therefore young people would be discharged back to their GP for ongoing care (Table 5.5).

Table 5.5 Arrangements when there is no equivalent adult specialty for the young person to transfer to

	Number of organisations	%
The young person is discharged to the GP	123	83.1
Young person is seen in a specialty clinic for main subspecialty only	85	57.4
Young person is seen in a general adult clinic	49	33.1
Other	42	28.4
Subtotal	**147**	
Unknown	45	
Total	**192**	

Organisational data; answers may be multiple; n=147

Based on the 152 primary care organisational questionnaires, although 100/131 (76.3%) clinicians working in primary care communicated with other organisations arranging transfer from child into adult services, very few (17/112; 15.2%) stated that they were involved with the transition for the young person registered with their practice. Furthermore, only 8/123 (6.5%) GPs had been invited to join transition team meetings with other organisations as needed, and only 4/122 (3.3%) GPs looking after young people in the study had been invited to attend transition meetings.

This disconnect between clinicians working in hospitals and those working in primary care is apparent in one clinician's observation that "*We use an ad hoc approach if there is no clear route for transition - usually this involves handing over care to the GP.*" This was also noted in the finding that only 10/33 young people and 4/69 parents/carers said that the young person's GP was involved in the transition process.

The CQC also recommends that "*All information about the healthcare of a child or young person should be shared with their GP to enable them to promptly and best respond to complex and ever-evolving health needs as the young person reaches and moves to adult services.*"[3] However, reviewers found limited evidence of communication between the hospital teams and healthcare teams in other settings and primary care (Table 5.6).

Table 5.6 Evidence in the case notes of communication about transition between the team(s) in the physical, community and mental healthcare settings and primary care

	Physical healthcare		Community healthcare		Mental healthcare	
	Number of young people	%	Number of young people	%	Number of young people	%
Yes - for all services	86	23.2	30	10.9	12	7.1
Yes - for some services	90	24.3	49	17.9	17	10.0
No	195	52.6	195	71.2	141	82.9
Subtotal	**371**		**274**		**170**	
Unable to answer	56		55		44	
Not applicable	9		73		186	
Notes not available	2		36		38	
Total	**438**		**438**		**438**	

Reviewer assessment form data

Communication with the education sector

The CQC 2014 report found that *"In most areas, it was the local authority and educational establishments who are the key drivers in the preparation and planning of transition. This may or may not include the health arrangements."*[3]

Education, health, and care plans (EHCPs) are legal documents for children who require additional support to enable them to access education.[27] EHCPs could therefore provide an opportunity for shared planning and to improve communication about all aspects of care the young person needs, not just related to transition.[7,28] There was evidence in 121/335 (36.1%) sets of notes that the young person had an EHCP (unknown for 103). Reviewers observed that if EHCPs had formed part of the clinical records this could have greatly supported communication between education, health and social care as recommended by NICE.[4,5] In Wales and in Northern Ireland the individual development plan or statement of special educational needs serves a similar function.[29,30]

Communication with social care

Many young people with complex conditions will need additional support from social work teams. In total, 90/165 (54.5%) organisations reported that they had a pathway to liaise with social care for young people transitioning (unknown for 27). Of the 66/173 (38.2%) young people with whom there had been liaison with social care, 51/66 were known to have a social worker.

There was evidence in the case notes that 142/438 (32.4%) young people had received social care involvement, but even where reviewers found evidence of this involvement, it was included in the transition plans of only 40/81 young people. One clinician observed *"There is often no mention of social care and it is not clear if this care was not needed or just not considered. Balance this with the value that actively involved social workers can contribute to transition."*

A particularly vulnerable group of young people are those who are 'looked after' as they are more likely to move, change clinical teams and consequently lack continuity of care and support.[31,32] In total, 25/244 (10.2%) young people approaching transition were 'looked after'. Reviewers noted that a young person who is in the care of the local authority may often move and therefore lose contact with healthcare teams. However, with the right support, continuity can be maintained.

Quality of communication and co-ordination

High quality communication is essential for excellent co-ordination of care, however, it was considered to be poor or unacceptable in many cases both by those who completed the health and social care professionals survey (Figure 5.6) and by the reviewers (Figure 5.7).

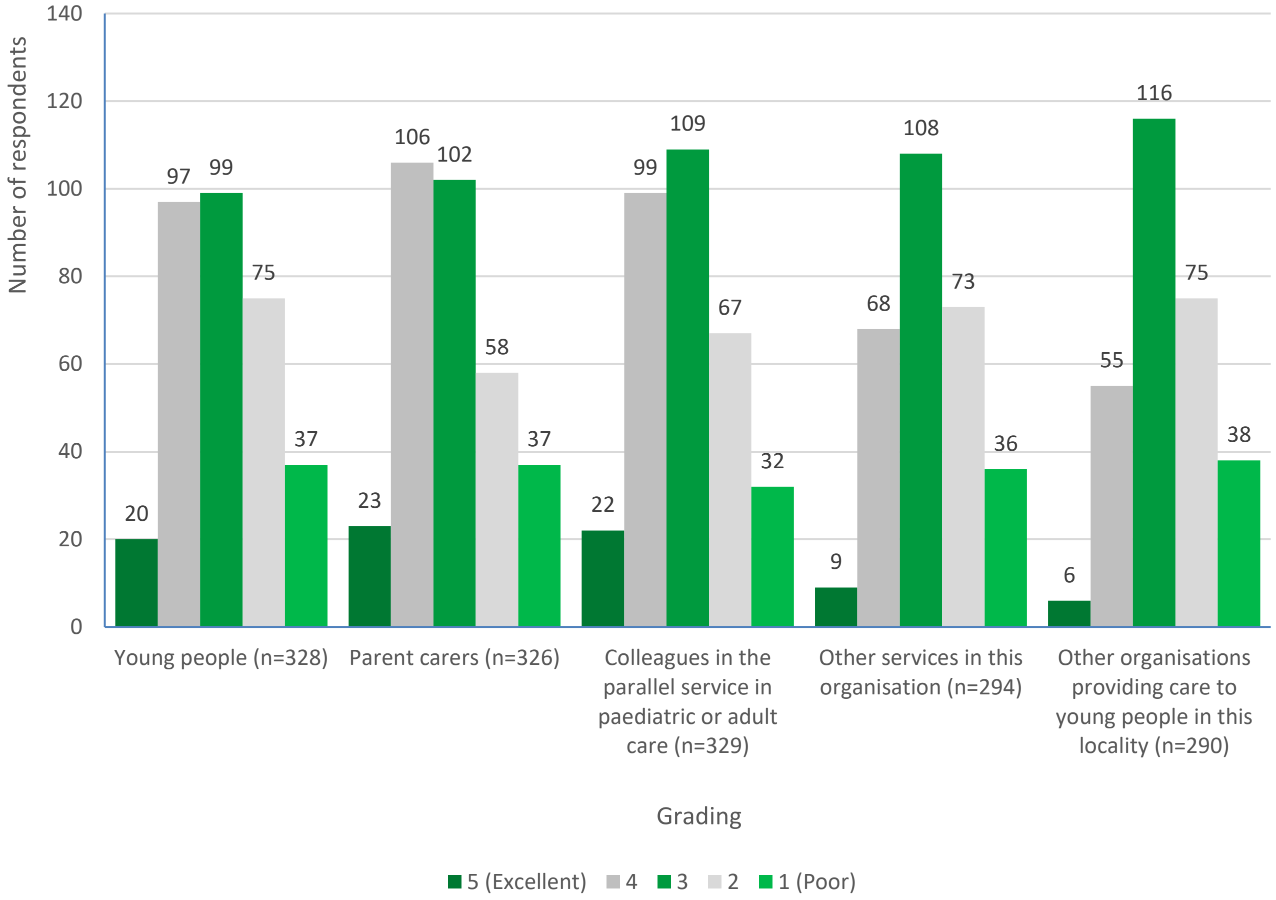

Figure 5.6 Grading of the quality of communication with regards to the transition process
Health and social care professional survey data

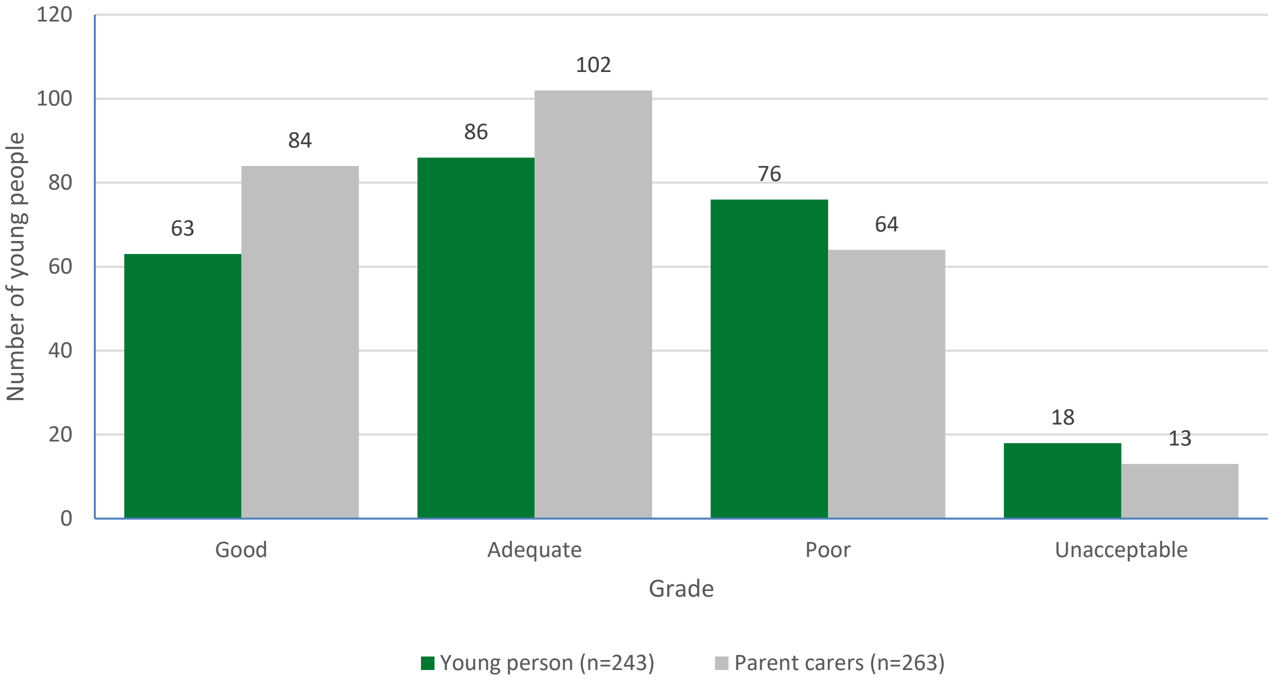

Figure 5.7 Grading of the communication with young people and parents/carers during the transition process
Review assessment form data

CASE STUDY 3 - EDUCATION, HEALTH, AND CARE PLANNING

An 18-year-old young person with epilepsy and many complex needs was under regular review by various specialties, including a complex movement disorder clinic. The education, health, and care plan (EHCP) showed that there was excellent communication and transition planning between education and social care, but limited planning in healthcare, with only one line regarding the transfer of the young person from paediatric into adult neurology.

Reviewers considered this to be an example of teams not working together and the fragmented planning that can occur.

LEARNING EXAMPLE

GOOD CO-ORDINATED PATIENT-CENTRED CARE

- A 22-year-old patient with diabetes and obesity who required non-invasive ventilation was under the care of numerous teams at a regional centre.
- Much of the patient's care was provided in an adolescent endocrine clinic and transition was regularly discussed.
- The patient was asked if they would prefer to have ongoing care delivered at the regional centre or at the local district general hospital.
- Once the patient and their family had decided what worked best for them, direct introductions were made to the adult teams.
- One of the consultants wrote to the patient to welcome them to the adult services while also checking where they would want to be cared for if they were to become acutely unwell.
- The GP was involved throughout, enabling any wider health issues to be addressed.

CHAPTER 6: THE ORGANISATION OF SERVICES

The facilities available to young people and the way that these are organised have a substantial impact on the quality of the care that can be delivered.

Place

Of the 192 hospitals from which an organisational questionnaire was returned, 111/192 (57.8%) provided child, adolescent, and adult services, and 46/192 (24.0%) provided child and adult services (Table 6.1).

Table 6.1 Services provided by age group

	Number of organisations	%
Paediatric, adolescent and adult services	111	57.8
Paediatric and adult services	46	24.0
Adolescent and adult services	11	5.7
Paediatric services	9	4.7
Paediatric and adolescent services	7	3.6
Adult services	6	3.1
Adolescent services	2	1.0
Total	**192**	

Organisational data

Although a total of 131/192 (68.2%) organisations reported that there were adolescent services, only 47/192 (24.5%) had an adolescent ward and only 60/186 (32.3%) had an adolescent clinic.

The age at which health services for children and young people end and adult services begin varied as shown in Table 6.2.[33]

Table 6.2 The age at which services started and ended

	Age that children and young people's services end		Age that adult services start	
	Number of organisations	%	Number of organisations	%
<16 years	4	2.3	0	0.0
16 years	70	40.9	71	41.0
17 years	12	7.0	12	6.9
18 years	68	39.8	89	51.4
19 years	15	8.8	1	<1
25 years	2	1.2	0	<1
Subtotal	**171**		**173**	
Unknown	21		19	
Total	**192**		**192**	

Organisational data

It was of note that the age ranges for transfer into adult services varied by specialty within a given organisation (Table 6.3). The impact of this is that co-ordinating transition for a young person whose care is under multiple specialties becomes very difficult.

Table 6.3 Ages for which services apply varied by specialty

	Children and young people's services end		Adult services start	
	Number of organisations	%	Number of organisations	%
Yes	136	80.5	124	75.2
No	33	19.5	41	24.8
Subtotal	**169**		**165**	
Unknown	23		27	
Total	**192**		**192**	

Organisational data

In order to offer transition services to young people, they need to be easily identified within hospital systems. However, only 34/192 (17.7%) organisations and 6/152 (3.9%) general practices had a flagging system in their electronic patient records that allowed them to identify this group of young people. This issue is particularly important for those who are vulnerable. Health inequalities impact the care received by many people for many reasons. In this study 54/290 (18.6%) of young people were identified as having at least one recognised health inequality that impacted on the care that they received (Table 6.4). The most cited reasons for impact were a learning disability (33), a physical disability (16), socioeconomic status (11) English not being a first language (8), being part of an inclusion health group (5) and severe mental illness (3). It has been noted already in this report that a higher-than-expected number of young people with a learning disability were identified in the sample; these factors may also influence how flagging on electronic patient records is best utilised.[34-36]

Table 6.4 Evidence in the notes of one or more health inequality or bias that impacted on the care provided

	Number of young people	%
Yes	54	18.6
No	236	81.4
Subtotal	**290**	
Not answered	148	
Total	**438**	

Reviewer assessment form data

The transition service

When answered, 202/365 (55.3%) clinicians completing the health and social care professional survey stated that their organisation had a transition service, but only 42/184 (22.8%) had a transition page on their website. Giving young people and their carers information about the transition service would help them understand what was available to them.

To ensure that each specialty within a trust/health board approaches transition in the same way would require a single team to be responsible for setting the parameters in which the specialties work. The team would co-ordinate the age at which transition starts, integration of transition if multiple services are involved, the age of transfer and provide best practice guidance. However, only 30/192 (15.6%) organisations that submitted data had such a team with 134/192 (69.8%) organisations having multiple teams involved. Similarly, only 17/129 (13.2%) organisations had a named individual responsible for transition (unknown for 63).

CASE STUDY 4 – NO JOINED-UP CARE

A 19-year-old patient with spastic quadriplegia (due to cerebral palsy), cortical blindness, epilepsy and a learning disability was transferred into adult services. However, the patient's mother (who had power of attorney for health and welfare) was not allowed to stay with them on admission to an adult ward despite the fact that they were not able to communicate with medical staff about their needs. The patient was therefore referred back to the children and young person's team for any inpatient stay, including for top-up baclofen infusions for spasticity, yet remained under the care of an adult neurologist in a different trust.

The reviewers considered that this was an example of how the organisation of transition between adult and children and young people's services led to fragmentation of clinical care.

Joint transition clinics with adult and children and young people's services

Giving the young person the opportunity to meet the team who will be looking after them in adult life is recommended by NICE[4,5] and it has found it to be associated with positive outcomes.[1] However, the provision of 'transition clinics' in which staff from both child and adult services attend was offered for all specialties in only 16/192 (8.3%) organisations, and 21/187 (10.9%) organisations did not offer these clinics at all. The remaining 150/187 (78.1%) organisations offered transition clinics for some specialties only.

Of the organisations that did run clinics where young people could meet the adult team (166/192; 86.5%), both teams were part of the same organisation alone in 67/166 (40.4%). Other organisations had a number of different pathways both in and out or their organisations presumably reflecting the fact that different specialties liaise with counterparts that may or may not be located in the same adult organisation. This adds to the complexity of transition pathways in young people with complex health needs.

Over half (84/151; 55.6%) of organisations were a member of a network of care for transition (unknown for 41). However, these networks were usually specialty based which may result in a young person with complex care needs being under multiple networks or having only some aspects of their care addressed (Table 6.5).

Table 6.5 Networks of care for transition

	Number of organisations
Specialty based	40
Trust/health board based	20
Other	19
Subtotal	**79**
Unknown	5
Total	**84**

Organisational data

In 20/192 (10.4%) organisations the staff caring for children and young people stopped being involved with the young person at transfer into adult services, while a further 38/192 (19.8%) remained involved until after the first visit to adult services. In 69/184 (35.9%) it varied by specialty, and the remaining 45/192 (23.4%) organisations did not offer a joint transition service. One letter from a children and young person's team to their adult counterpart about the transfer of care stated: "*She is now under your care; at our last visit I said goodbye and wished her good luck*."

Key/named workers

Navigating a complex medical pathway can be a challenge and multiple reports have recommended that each young person has access to a key worker.[3-5] It was reported from 74/192 (38.5%) organisations that young people did have key workers, and the health and social care professionals found similar numbers pre-transfer

(127/327; 38.8%) with a lower percentage of young people (65/271; 24.0%) having access to a key worker for transition advice after their transfer into adult services (Table 6.6).

Table 6.6 All young people have a key worker

	Pre-transfer		Post transfer	
	Number of respondents	%	Number of respondents	%
Yes	127	38.8	65	24.0
No	200	61.2	206	76.0
Subtotal	**327**		**271**	
Unknown	110		166	
Not answered	17		17	
Total	**454**		**454**	

Health and social care professional survey data

The survey of young people and parents/carers showed low numbers having an assigned key worker with 26/45 young people never having had access and 43/63 parents/carers having no access to a key worker (Table 6.7).

Table 6.7 The young person/parent/carer had an assigned key worker/named worker

	Young people	Parents/carers
No key worker involvement	27	43
Before transfer into adult services	8	12
During transfer into adult services	3	9
After transfer into adult services	3	5

Young person and parent/carer survey data; answers may be multiple; young people n=37 (unknown for 10); parents/carers n=63 (unknown for 9)

What a key worker can achieve depends on their remit and case load. There was considerable variation reported in the case load of key workers, ranging from eight to 420 young people per worker, with some being responsible for over 400 young people at a given time (Table 6.8).

Table 6.8 How many young people approaching transition the key/named worker was responsible for

	Number of young people
<50	15
50-99	11
100-199	10
200-299	2
≥400	2
Other	9
Subtotal	**49**
Unknown	26
Total	**75**

Clinician questionnaire data

CASE STUDY 5 - NO ONGOING SUPPORT

A 22-year-old patient had a second kidney transplant at the age of 17 and had been fully transferred into adult services. Reviewers stated that the transition clinics were good, with adult and paediatric nephrologists present and good involvement of a young adult specialist nurse. The clinician's questionnaire stated that the involvement of the nurse was invaluable but there was only one nurse and no ongoing contact post transfer into adult services. Post transfer the patient missed several hospital appointments and took their medication less regularly resulting in a rejection episode and failure of the graft. The patient cited low mood and a lack of support as reasons for the suboptimal engagement with their healthcare needs.

The reviewers commented that the absence of a key worker to follow up this young adult led to a potentially avoidable outcome, which was of particular note as the transition planning and transfer had been undertaken well.

Youth workers can be a useful point of contact in triaging young people to services that are available for them and in providing a non-medical perspective on care but only 10/192 (5.2%) organisations had youth workers for all specialties and 129/192 (67.2%) had none.

Some form of key worker, youth worker or advocate support is important. There were 62/173 (35.8%) organisations from which it was reported that they had a register of young people with a chronic condition currently in the process of transition (unknown for 19), while only 26/62 organisations reported that there was a method of assessing where young people were on the transition pathway.

The survey of young people and their carers showed that only a minority of young people (8/42) and parents/carers (27/78) were invited to attend any specific meetings regarding the transition from child into adult services.

LEARNING EXAMPLE

GOOD COMMUNICATION

- A 19-year-old patient with muscular dystrophy was initially under the care of paediatric neurology and cardiology but lived a long way from a tertiary centre
- Once fully transferred into adult care, the patient benefited from excellent communication over a 4-year period and very good interaction between tertiary children and young people's and adult services.
- Local adult secondary care services were involved and acted as a local back-up for their care.
- The patient's GP was very involved and ensured any broader healthcare needs were being met.

CHAPTER 7: LEADERSHIP

To run any successful transition service, those leading the organisation must have decided what it needs to do, how they will do it, who will do it and when. There will need to be sufficient funds for infrastructure and sufficient time in the job plans of staff with the relevant skills. The service will need to be audited to ensure that it is running optimally and should actively seek the views of its users to change and develop. All of this requires strong leadership.

Executive board representation

Only 87/192 (45.3%) organisations had at least one clinical lead for transition and in primary care only 3/152 (2.0%) practices reported having a lead for transition. Primary care encompasses all age groups, and it could be said that transition happens 'seamlessly' but within a given practice or primary care network there should be a clinician who leads on the provision of healthcare for adolescents and young people.[37]

NICE recommends that there should be a senior executive responsible for supporting the development and publication of transition strategies and policies, yet only 74/157 (47.1%) organisations had such a role (unknown for 35).[4,5] NICE also recommends that organisations have a senior manager responsible for implementing those strategies, but only 78/166 (47.0%) organisations reported that there was input at this level.[4,5] Only 60/166 (36.1%) organisations had a member of the transition service supporting the executive board (unknown for 26).

Policies

Where the organisation had an overarching transition policy, that policy covered all young people with long-term conditions in just 76/98 organisations (Table 7.1).

Table 7.1 What the overarching transition policy covered

	Number of organisations
All long-term conditions	76
Specific long-term conditions	22
Subtotal	**98**
Unknown	1
Total	**99**

Organisational data

The transition policies varied in what they included, with most stating at what age transition should start (95/98) but only 79/98 stating that young people should be given support to learn how to self-manage their condition(s), 62/98 stating that care should be delivered in a developmentally appropriate setting and only 42/98 recommending the use of a personal passport of relevant information for each young person transitioning. The age at which organisations recommended transition planning should start varied with 21/94 organisations recommending ages later than that recommended by NICE.[4,5]

To maximise the chance of a single transition pathway for a young person with multiple health needs the policies should be consistent within a given organisation. However, 98/175 (56.0%) organisations had separate transition policies for different specialties (Table 7.2).

Table 7.2 Different specialties had separate policies for transition

	Number of organisations	%
Yes - for all specialties	14	8.0
Yes - for some specialties	84	48.0
No	77	44.0
Subtotal	**175**	
Unknown	17	
Total	**192**	

Organisational data

Commissioning

No healthcare system can function without appropriate funding, and commissioning is a powerful tool for ensuring services are both funded and delivered.[38] Of those organisations which had transition clinics staffed by both children and young people's and adult services (166/192; 86.5%), only 40/132 (30.3%) had any formal commissioning or funding for them (Table 7.3). In fact, only 57/138 (41.3%) funding arrangements/contracts specified transition at all (Table 7.4).

Table 7.3 Transition clinics were formally commissioned/funded

	Number of organisations	%
Yes - for all specialties	5	3.8
Yes - for some specialties	35	26.5
No	92	69.7
Subtotal	**132**	
Unknown	34	
Total	**166**	

Organisational data

Table 7.4 Transition care was included in funding arrangements/contracts

	Number of organisations	%
Yes - for all specialties	8	5.8
Yes - for some specialties	49	35.5
No	81	58.7
Subtotal	**138**	
Unknown	54	
Total	**192**	

Organisational data

These data were supported by the health and social care professional survey which showed that the perception of the quality of commissioning arrangements for transition was poor (Figure 7.1).

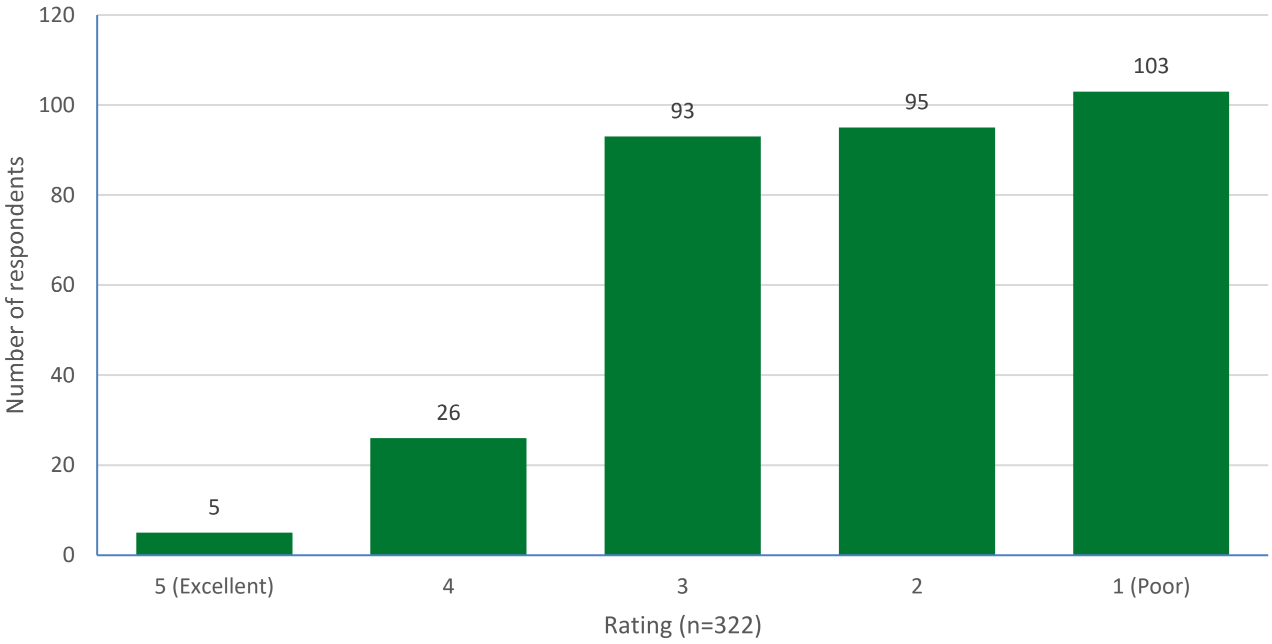

Figure 7.1 Rating of the overall commissioning arrangements for transition services in the area the health and social care professionals worked

Health and social care professional survey data; (unknown for 132)

Audit

All organisations should audit the effectiveness of the care they deliver. An audit helps to identify areas of risk that can be mitigated and recommends analysis of gaps in care. Audits of transition strategies and polices were carried out for all specialties in only 21/166 (12.7%) organisations, and not at all in 79/166 (47.6%) organisations (unknown for 26). When audits were carried out, they were annual or more frequent in 48/68 organisations (Table 7.5).

Table 7.5 How often audits of transition strategies and policies were carried out

	Number of organisations
Annually	40
Six-monthly	5
Quarterly	3
Other	20
Subtotal	**68**
Unknown	19
Total	**87**

Organisational data

Most organisations (131/156; 84.0%) did not undertake a gap analysis to identify young people who were under children and young people’s services but could not access support from adult services (Table 7.6). It was reported that a gap analysis against NICE guidelines on transition was not undertaken in 64/163 (39.3%) organisations, with only 59/163 (36.2%) performing the gap analysis for all specialties (Table 7.7). Although the *You’re Welcome* standards are readily accessible and well-respected, 97/133 (72.9%) organisations did not perform a gap analysis to assess compliance with them.

Table 7.6 An organisational gap analysis was undertaken to identify young people who were under children and young people’s services but could not access support from adult services

	Number of organisations	%
Yes - for all specialties	6	3.8
Yes - for some specialties	19	12.2
No	131	84.0
Subtotal	**156**	
Unknown	36	
Total	**192**	

Organisational data

Table 7.7 An organisational gap analysis was undertaken to assess compliance with NICE guidelines on transition

	Number of organisations	%
Yes - for all specialties	59	36.2
Yes - for some specialties	40	24.5
No	64	39.3
Subtotal	**163**	
Unknown	29	
Total	**192**	

Organisational data

LEARNING EXAMPLE

GOOD TRANSITION ARRANGEMENTS

- An 18-year-old patient had received a kidney transplant for end stage kidney failure.
- The patient had a complex medical history with a learning disability and motor problems.
- An excellent transition into adult services was made with use of *Ready Steady Go* documentation.
- There was good evidence of ongoing involvement of parents and patient in their care.
- The trust had developed the role of a ‘complex care’ specialist nurse who knew all the relevant services in the local area and ensured that appropriate transition arrangements were in place for all aspects of the patient’s care.
- Letters from adult specialists were copied to the children and young person’s team for a year afterwards to ensure that no aspects of care had been missed or misinterpreted.
- The unit routinely sent out a survey to young people and their parents/carers after transfer to provide a rolling audit of quality of care.

CHAPTER 8: OVERALL QUALITY OF THE TRANSITION

In this study there was a noticeable contrast between the views of clinicians and reviewers on the overall quality of transition of young people from health services for children and young people into adult health services.

The case reviewers graded the overall process of transition as good for just 66/293 (22.5%) young people, adequate for 75/293 (25.6%), poor for 123/293 (42.0%) and unacceptable for 29/293 (9.9%) (Figure 8.1) (unknown for 55). Conversely, clinicians who completed the clinician questionnaire thought that the process of transition worked well for 322/401 (80.3%) young people, where the stage of transition was known, and those who completed the primary care clinician questionnaire thought transition worked well for 32/48 young people (and was unknown for 119/167 (71.3%) young people).

It may be that good work on transition was happening but was not recorded in the case notes, however, data from surveys of young people and their carers did not support this. This discrepancy may suggest that clinicians are unaware of the quality of transitional care that is provided and know to improve it. It was also of note that in the case notes reviewed, 'transition' was only mentioned in 216/438 (49.3%) sets.

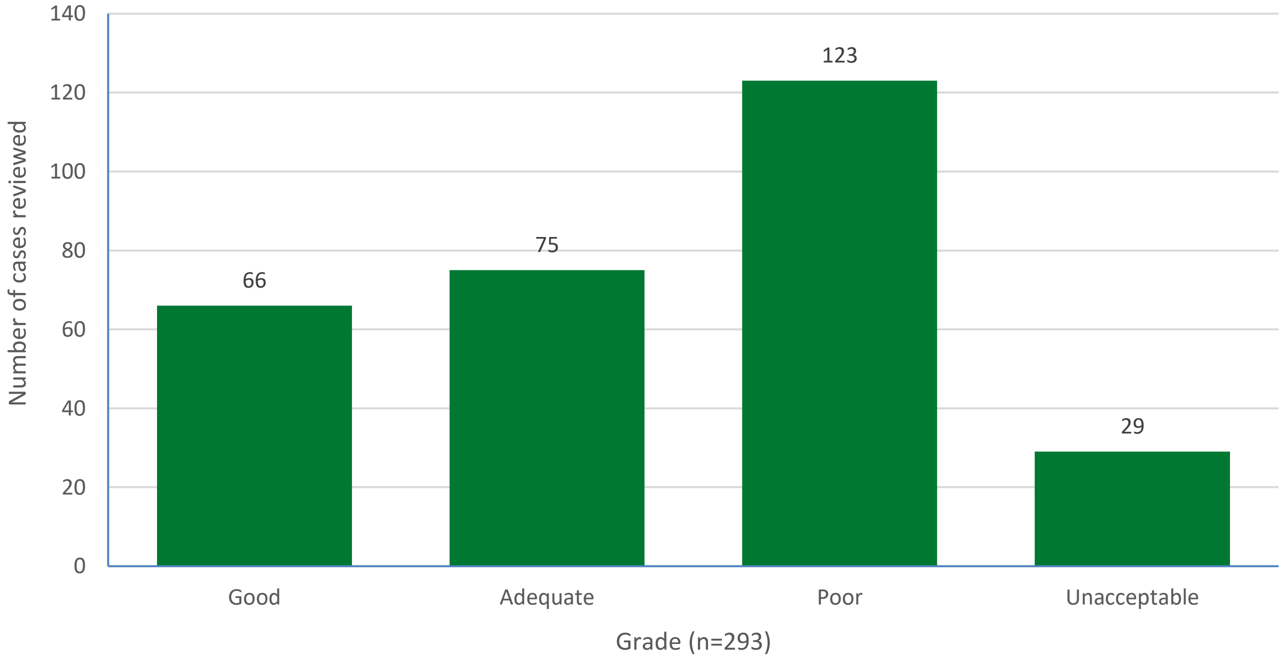

Figure 8.1 Grading of the overall process of transition into adult health services.
Reviewer assessment form data

LEARNING EXAMPLE

A GOOD QUALITY TRANSFER INTO ADULT HEALTH SERVICES

- A 19-year-old patient with a complex metabolic condition requiring a liver transplant, was under the care of multiple specialists.
- The gastro-hepatology team started discussing transfer into adult services when the patient was 14 years old.
- They liaised with the child and adolescent mental health services team. The clinic letters addressed wider issues of the patient’s healthcare needs, including diet and exercise as well as sexual health.
- The patient was signposted to other resources including various apps to help them self-manage their care.
- At the age of 16 years the patient was transferred to the adult hepatology team where they were seen in an adolescent and young adult clinic in evening hours.
- At the appointment, they could meet with the wider multidisciplinary team to discuss education and mental health, as well as exercise and general wellbeing.

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GLOSSARY

DEVELOPMENTALLY APPROPRIATE HEALTHCARE	Developmentally appropriate healthcare for young people is care that acknowledges the dynamic impact on health and ill-health of the biological, psychological, social and vocational development of young people.
HOLISTIC SERVICES	Services that are person centred, coordinated and tailored to the needs of individuals, which put the needs and experience of people at the centre of how services are organised and delivered. https://www.england.nhs.uk/ourwork/part-rel/transformation-fund/
KEY WORKER	A care professional who takes a key role in co-ordinating the care of the patient and promoting continuity, ensuring the patient knows who to access for information and advice. https://datadictionary.nhs.uk/nhs_business_definitions/key_worker.html
LEARNING DISABILITY	A learning disability is defined as meeting three core criteria: • Lower intellectual ability (usually an IQ of less than 70) • Significant impairment of social or adaptive functioning • Onset in childhood A learning disability may be described as mild, moderate, severe or profound. NICE guideline [NG93]. https://www.nice.org.uk/guidance/ng93
LIFE-LIMITING CONDITION	A condition for which there is no cure and death is inevitable, either in childhood or early adulthood. http://www.icpcn.org/faq/
LOOKED AFTER CHILDREN	A child who has been in the care of their local authority for more than 24 hours, including: • Living with foster parents • Living in a residential children's home • Living in residential settings like schools or secure units https://learning.nspcc.org.uk/children-and-families-at-risk/looked-after-children
SOCIAL PRESCRIBING	Social prescribing – sometimes referred to as community referral – is a means of enabling GPs, nurses and other health and care professionals to refer people to a range of local, non-clinical services. https://www.gov.uk/government/publications/social-prescribing-applying-all-our-health/social-prescribing-applying-all-our-health
STAGE OF TRANSITION/TRANSITION PERIOD	**Preparing for adulthood:** The process of planning and preparing a young person with chronic disease and their carer for the transfer from paediatric to adult services. **Peri-transfer from child to adult health services:** Ensuring young people and their carers who are about to move to adult services are prepared for transfer by introducing them to the adult services while being supported by paediatric services. Empowering Young People to understand their disease in preparation to be independently managing their own healthcare needs. **Fully transferred from child to adult health services:** The stage at which care has been taken over by adult services and the young person (or parent carer) is managing their own condition
TRANSITION SERVICE/TEAM	A team of people, or person, who facilitate and coordinate the transition process from child to adult services within an organisation. In many organisations the transition team coordinates transition for the Trust as a whole, while specialty-based teams coordinate the transition of individual patients.

USEFUL LINKS

NICE National Institute for Health and Care Excellence	NICE Guideline 43 NICE Quality Standard 140
Royal College of Nursing The voice of nursing	Lost in Transition
CareQuality Commission	From the Pond into the Sea
Ready Steady Go programme	Transition programme
RCPCH Royal College of Paediatrics and Child Health Leading the way in Children's Health	Transition resources
together for short lives	Family resources Transition pathway
TRANSITION	The Transition Research Programme, Newcastle
yphsig young peoples health special interest group	HEEADSSS app

ayph	Association for Young People's Health
Royal College of Physicians	Young Adults and Adolescents Steering Group (YAASG)
elfh elearning for healthcare	Adolescent health programme
10 STEPS Transition To Adult Services	Transition programme
COUNCIL FOR DISABLED CHILDREN	Developmentally appropriate healthcare
NHS Great Ormond Street Hospital for Children NHS Foundation Trust	Great Ormond Street Hospital for Children
NHS Nottinghamshire Healthcare NHS Foundation Trust	Preparing for adulthood
Scottish Transitions Forum	Scottish Transitions Forum
Intensive Care Society	Paediatric to adult critical care transition
WellChild the national charity for sick children	8 Principles for Transition