



Transition from child to adult health services

What is this study about?

NCEPOD are exploring the process of the transition of young people with complex chronic conditions from child to adult health services.

The aim of the study is to explore the barriers and facilitators in the process of the transition of young people with complex chronic conditions from child to adult health services.

Information is being collected from primary, community, physical and mental healthcare settings

Data collection methods include:

- Young person and parent care views (questionnaires and focus groups)
- Clinician views (questionnaires and interviews)
- Case note review

Who should complete this survey?

Please complete this survey if you are or could be involved with this group of young people. We are hoping to collect data from health and social care providers across a range settings, including primary care, community care (including school nursing and hospices), physical healthcare, mental healthcare, commissioning and social care.

Please answer the questions in this survey based on your current role and organisation, based on your day-to-day practice.

All responses given as part of this study are confidential

Questions or help

If you have any queries about this study or this questionnaire, please contact: transition@ncepod.org.uk or telephone 020 7251 9060.

This study was commissioned by The Healthcare Quality Improvement Partnership (HQIP) as part of the Clinical Outcome Review Programme into Child Health.

Clinician details

1. What is your job role?

- Doctor
- Nurse
- Physiotherapist
- Occupational therapist
- Speech & Language therapist
- Manangement
- Key worker
- Youth worker
- Peer support worker
- Commissioner
- Social care provider
- Other (please specify)

2. Which type of setting do you work in? (Please tick all that apply)

- Primary care
- Physical healthcare - acute setting
- Physical healthcare - community setting
- Physical healthcare - independent setting
- Mental healthcare - acute setting
- Mental healthcare - community setting
- Mental healthcare - independent setting
- Social care
- Hospice or respite care
- Commissioning organisation
- Other (please specify)

3. Does your organisation provide: (Please tick all that apply)

- Paediatric services
- Adolescent services
- Adult services
- Other services (please specify)

4. Do you provide care to young people: (Please tick all that apply)

- Preparing for adulthood
- Peri-transfer from child to adult health services
- Fully transferred from child to adult health services
- Other (please specify)

5. Do you provide care to young people with any of the following conditions? (Please tick all that apply)

- Epilepsy
- Sickle cell anaemia
- Juvenile idiopathic arthritis
- Cerebral palsy
- Spina bifida
- Duchenne muscular dystrophy
- Post transplant patient (kidney, heart and liver)
- Autism
- Rett syndrome
- Brain tumour (medulloblastoma)
- Type 2 diabetes and obesity
- Chronic kidney disease
- Other
- Unknown

If other, please specify

What goes well/does not go well

6a. In your opinion, how well do you think the process of transition from child to adult health services works in your organisation?

	1 (Not at all well)	2	3	4	5 (Extremely well)	Unknown
The process of transition goes:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Based on this answer, please think about the transition services provided to young people in your organisation and indicate:

6b. Up to three things that go well

6c. Up to three things that could be improved

Block 4

We would now like to ask a few more specific questions about the transition process

The transition service

7. Does your organisation have a transition service?

Yes No

Unknown

Not applicable

8. Are you involved in transition services within your organisation?

Yes No Unknown

9a. Are you a transition lead or part of a team leading on transition within your organisation?

Yes No Unknown

9b. If part of a transition team, is this

- An overarching transition team that supports transition across every specialty

- A specialty based transition team
- Other (please specify)

10a. Pre-transfer to adult services, in general, do all young people have a key worker?

- Yes No Unknown
-

10b. Post transfer to adult services, in general, do all young people have a key worker?

- Yes No Unknown
-

Commissioning

11a. How would you rate the overall commissioning arrangements for transition services in your area?

- | | | | | | | |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| | 1 (Poor) | 2 | 3 | 4 | 5
(Excellent) | Unknown |
| Commissioning arrangements for transition are: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

11b. When there are problems, what do these broadly relate to? (Please tick all that apply)

- No problems
- Differences between children's and adults commissioning
- Delay in approvals by commissioning bodies
- More than one commissioning body (e.g. local and specialist/national commissioners)
- No formal commissioning arrangements
- Health and social care overlap and/or disagreement in commissioning
- Other (please specify)

11c. Where applicable, please give details of significant improvements/success with the commissioning of transition services in your area:

The transition pathway

12a. Are there any care pathways where there is no equivalent adult service for young people to transition to?

- Yes
- No
- Unknown

12b. What happens where there is no equivalent adult service for young people to transition to?

13. Do you/your organisation check the transfer process has worked for young people post transition to adult services?

- Yes
- No

- Unknown

- NA - only involved with young people post transition

Involvement of young people and parent carers in the transition process

14a. How would you rate the involvement of young people and parent carers in the transition process within your organisation?

	1 (Poor)	2	3	4	5 (Excellent)	Unknown	Not applicable
Young people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parent carers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

14b. Please give any further information regarding the involvement of young people and parent carers in the transition process within your organisation: (we would like to share examples of where this works well or barriers to this process)

MDT working and the coordination of care

15. If young people are under the care of multiple clinical teams (including primary and social care), in general is care coordinated across the different teams?

Yes No Unknown

16. How would you rate the coordination of care across multiple clinical teams?

	1 (Poor)	2	3	4	5(Excellent)	Unknown	Not applicable
Coordination of care is:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17a. How are primary care involved with the transition of young people from child to adult services?

17b. Please give any further information about MDT working and the coordination of care:(we would like to share examples of where this works well or barriers to the process)

Communication

18. In general, how would you rate the quality of communication with regards to the transition process with:

	1 (Poor)	2	3	4	5 (Excellent)	Unknown	Not applicable
Young people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parent carers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Colleagues in the parallel service in paediatric or adult care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other services in this organisation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other organisations providing care to young people in this locality?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please give further details:

19a. Does your organisation use any technology platforms to help young people through the process of transition?

- Yes No Unknown
-

19b. If YES, please give further details:

Training

20a. Have you received training in: (Please tick all that apply)

- Developmentally appropriate healthcare/adolescent healthcare/caring for young people
- Consent for young people
- Confidentiality for young people
- The use of the Mental Capacity Act in relation to young people
- Transition from child to adult health services
- None of these

20b. How would you rate the quality of this training?

	1 (Poor)	2	3	4	5 (Excellent)	Unknown	Not applicable
Developmentally appropriate healthcare/adolescent healthcare/caring for young people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Consent for young people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Confidentiality for young people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The use of the Mental Capacity Act in relation to young people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	1 (Poor)	2	3	4	5 (Excellent)	Unknown	Not applicable
Transition from child to adult health services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

20c. Please give further details:

Quality of the transition process

21. In your opinion, what one thing would improve the process of transition from child to adult health services?

Clinician interviews

As part of this study we may also be undertaking interviews to ask the provision of care for young people transitioning from child to adult services. If you would be willing to be contacted as part of the interview process please give your details below:

Name

Email address

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