

# Commissioner's Guide to the NCEPOD Report - '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**

## INTRODUCTION

The transition of a young person to 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.*'

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. 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), all of which highlighted issues with the transition planning and transfer to adult healthcare.

The process of transition is complex as the needs of each young person are not identical. 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, or where children and young people's services end at age 16 and the adult service does not start until age 18. 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. This may result in them only seeking contact when in crisis, 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 to 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 to 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.

## KEY FEATURES OF A GOOD TRANSITION SERVICE

### 1. Developmentally appropriate healthcare should be seen as 'core business'

Developmentally appropriate healthcare acknowledges young people as a distinct group and works to empower young people to slowly take responsibility for their healthcare needs. It should take account of the young person's cognitive abilities and provide holistic care in conjunction with all specialties involved, both in child and adult services. Developmentally appropriate care should comprise a part of all healthcare profession's job descriptions.

### 2. Patients and parent carers should be involved in healthcare planning

NICE recommends that individual plans regarding transition are co-produced with the young person, and where appropriate the parent carer. This includes ensuring patients, and where appropriate parent carers, are copied into all correspondence. They should also be invited to all MDT meetings and be considered part of the team who are planning and facilitating the transition process.

### 3. There should be good communication and coordination between everyone involved in the transition process

Excellent communication between the young person, their family or carers, primary care clinicians and colleagues in, social care where relevant, and education services allows for a co-ordinated approach to transition across the pathway. This is particularly important to keep the process 'person-centred'. The reviewers 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 specialities.

### 4. Services should be organised to accommodate young people who are transitioning to adult services

Having a range of services that are developmentally appropriate for young people transitioning to adult services is essential. This is particularly the case when it comes to adolescences. 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.

### 5. Strong leadership is needed from all senior members of the healthcare organisation. This includes commissioning bodies and senior executive board members when it comes to implementing and supporting the transition process by providing sufficient funds for infrastructure and sufficient time in job plans for staff involved in the transition process.

As the transition process can incorporate many specialties, sites, and individuals a lead clinician should take accountability for the young person's transitional care. Only 87/192 (45.3%) organisations had at least one clinical lead for transition. Beyond this, a senior executive board member should support the lead clinician through 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] and 78/166 (47.0%) organisations reported that there was input at this level.[4,5] At the same time, a member of the transition team/clinical lead should also support the executive board member (unknown for 26). This was only reported as happening in 60/166 (36.1%) organisations.

## KEY FINDINGS OF THE STUDY

### Patient population

Information on young people aged between 13 years and their 25<sup>th</sup> birthday transitioning from child to adult health services were collected over an 18-month period from 1<sup>st</sup> October 2019 – 31<sup>st</sup> March 2021. Twelve conditions were chosen to identify a broad sample of young people with a complex chronic condition for inclusion in the study.

- Epilepsy
- Sickle cell anaemia
- Juvenile idiopathic arthritis
- Cerebral palsy
- Spina bifida
- Duchenne muscular dystrophy
- Post-transplant patients – kidney, heart and liver
- Autism spectrum disorder and Rett Syndrome
- Brain tumours (medulloblastoma)
- Type 2 diabetes and obesity<sup>1</sup>
- Chronic kidney disease

### Organisation of services

- Organisational questionnaires were 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.
- Only 19/192 (9.9%) organisations provided a ‘one-stop model’ for all specialties, where health and wellbeing are addressed during one hospital visit (potentially reducing the need for families/young people to travel for multiple appointments). 72/192 (37.5%) had it in place for some specialties.
- 38/145 (26.2%) of clinicians indicated that one of the barriers to transition not starting was the structure of the transition service. 26/145 (17.9%) of clinicians thought that transition could not be facilitated due to an absence of a transition service at the organisation.
- 111/192 (57.8%) organisations reported that they provided child, adolescent, and adult services. However, 27/192 (14.1%) organisations had an age-appropriate environment to deliver transitional care for all specialties, and 79/192 (41.1%) for some specialties.

### Leadership, commissioning, and audit

- 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.
- 74/157 (47.1%) organisations had a senior executive responsible for supporting the development and publication of transition strategies and policies.
- NICE 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. Only 60/166 (36.1%) organisations had a member of the transition service supporting the executive board (unknown for 26).
- 98/175 (56.0%) organisations had separate transition policies for different specialties.
- While 166/192 (86.5%) transition clinics staffed by both children and young people’s and adult services, only 40/132 (30.3%) had any formal commissioning or funding for them. In fact, only 57/138 (41.3%) funding arrangements/contracts specified transition at all.
- Audits of transition strategies and policies 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).
- 131/156; 84.0%) did not undertake a gap analysis to identify young people who were under children and young people’s services.
- 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.

### Training in developmentally appropriate healthcare

- 37/169 (21.9%) organisations had mandatory developmentally appropriate training for staff in place. Of these organisations, 81/169 (47.9%) had training which was non-mandatory and 51/169 (30.2%) provided no training (unknown for 23).
- 72/134 (53.7%) of GPs received training for developmentally appropriate/adolescent healthcare. However, only 24/139 (17.3%) practices provided mandatory training that covered taking over the care of young people with long-term conditions (unknown for 18).
- In the health and social care survey, 246/371 (66.3%) of respondents indicated they received training on the use of the Mental Capacity Act 2005 in relation to young people. A similar number reported that they received specific training on confidentiality and consent.
- Yet, 166/371 (44.7%) of the same respondents said they received training in developmentally appropriate healthcare and only 139/371 (37.5%) received training in transitioning young people to adult services. 70/371 (18.9%) received no training in any of the aforementioned areas.

### Transition planning

- 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.
- While it is recognised that transition planning appointments require more time, 23/165 (13.9%) organisations offered longer appointments for young people during transition (unknown for 27).
- 99/192 (51.6%) organisations had an overarching transition policy, 84/99 stated that all young people going through transition planning have a transition plan in place from early adolescence.
- However, the 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).
- Giving young people and their carers information and tools to help them learn about the transition service would enable them to better understand what was available to them. Yet, 202/365 (55.3%) clinicians completing the health and social care professional survey stated that their organisation had a transition service, and only 42/184 (22.8%) had a transition page on their website.
- The organisational questionnaires showed that 17/112 (15.2%) of GPs were involved with the transition for the young person registered with their practice.
- 123/147 (83.7%) organisations reported there was no receiving adult specialty, and therefore young people would be discharged back to their GP for ongoing care,
- In 20/192 (10.4%) organisations the staff caring for children and young people stopped being involved with the young person at transfer to adult services, while a further 38/192 (19.8%) remained involved until after the first visit to adult services.
- The survey of young people and their carers found that 20/41 young people and 49/67 parents reported that no discussion of holistic needs were had with any healthcare professional during their transition period.
- 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.

### Young person involvement, correspondence, and self-management

- 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.
- 20/136 (14.7%) organisations had a transition service in place where 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.
- 57/124 (46.0%) organisations had a policy stating that young people should be copied into correspondence both pre- and post-transfer to adult services. However, organisations reported that 28/124 (22.6%) only copied young people into letters after transfer to adult services (unknown

for 68).

- The 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).
- The clinician questionnaire data showed that on approaching transfer 141/187 (75.4%) young people were involved in their transition process (unknown for 67).
- 99/232 (42.7%) of reviewers rated involvement of young people in their transition process as poor when the transition process was being started.
- The reviewers 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 specialities (unknown for 148).
- In the survey of young people, (5/50) said they were invited to transition meetings.
- Most transition policies stated the age transition should start (95/98) but only 79/98 stated that young people should be given support to learn how to self-manage their condition(s)
- In 172/363 (47.4%) cases reviewed (unknown for 75), the reviewers found that most young people were not being given the opportunity to develop skills for self-management of their health needs.
- 30/128 (23.4%) GP practices had resources to develop young people's self-management of their health needs (unknown for 24).

### Communication and co-ordination between specialities

- 346/438 (79.0%) young people were under the care of multiple specialities 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.
- 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%) (unknown for 76).
- Indeed, the reviewers considered there were barriers to communication with the young person evident in 132/312 (42.3%) cases reviewed (unknown for 126).
- 100/151 (66.2%) organisations had a pathway to liaise with primary care for young people transitioning to 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.
- 67 young people only considered primary care as part of their care team.
- The organisational data showed that 3/39 of the regular members of the transition team responsible for transition were GPs, youth workers or occupational therapists.
- 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.
- 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.
- 12/170 (7.1%) of reviewers found limited evidence of communication between the hospital teams and healthcare teams in other settings and primary care.

### Job planning and missed opportunities

- The organisational data showed 16/167 (9.6%) transitional care was included in the job descriptions of all healthcare staff involved in transition. 92/167 (55.1%) had transitional care included for some specialties and 59/167 (35.3%) who were involved in transition had no mention of transitional care in their job descriptions.
- It is recommended that transition begins at the age of 13.<sup>[4,5,18]</sup> However, the reviewers found that it was more commonly mentioned in the case notes around the ages of 17 or 18.
- The reviewers found evidence transition was started at the appropriate age for 91/280 (32.5%)

young people by all services and 72/280 (25.7%) by some services.

- 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).

## SUPPORTING DOCUMENTS

- RCN Lost in Transition (2013) <https://www.swswhd.co.uk/image/Clinical%20information/Transition/Lost%20in%20Transition%202013.pdf>
- CQC From the pond to the sea (2014) [https://www.cqc.org.uk/sites/default/files/CQC\\_Transition%20Report.pdf](https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf)
- Acute Care Toolkit (RCP) (2015) <https://www.rcplondon.ac.uk/projects/acute-care-toolkits>
- Campbell F et al: Transition of care for adolescents from paediatric services to adult health services (Review) (2016) <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD009794.pub2/epdf/full>
- NICE Transition from children's to adults' services for young people using health or social care services (2016) <https://www.nice.org.uk/guidance/ng43> reviewed in May 2020
- NICE Transition from children's to adults' services. Quality Standard [QS140] (2016) <https://www.nice.org.uk/guidance/qs140>
- British Youth Council, the Association for Young People's Health, & Youth Focus North West You're welcome pilot (2017) [https://www.youngpeopleshealth.org.uk/yourewelcome/wp-content/uploads/2017/02/YoureWelcome\\_RefreshedsStandards.pdf](https://www.youngpeopleshealth.org.uk/yourewelcome/wp-content/uploads/2017/02/YoureWelcome_RefreshedsStandards.pdf)
- Colver A et al: (2020) Facilitating transition of young people with long-term health conditions from child to adult health services. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6964170/pdf/clinmed-20-1-74.pdf>
- YPHSIG HEEDSSS app: <https://www.yphsig.org.uk/>  
<https://apps.apple.com/us/app/heedsss/id1418543003>  
<https://www.health.nsw.gov.au/kidsfamilies/youth/Pages/heedsss-videos.aspx#plan>
- Ready, Steady, Go, transition programme: <https://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx>
- Growing up, gaining independence: <https://www.gosh.nhs.uk/your-hospital-visit/growing-gaining-independence/>
- 10 Steps. Transition to Adult Services: <https://10stepstransition.org.uk/>
- The transition research programme: <https://research.ncl.ac.uk/transition/>
- E-Learning for Healthcare: <https://www.e-lfh.org.uk/>
- Queens Nursing Institute. Transition of Care Programme. Managing the transition from children's to adult's community services. <https://www.qni.org.uk/nursing-in-the-community/from-child-to-adult/>
- RCPCH: <https://www.rcpch.ac.uk/resources/transition-adult-services>
- 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