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The inbetweeners: a review of the transition from child into adult care for young people with chronic health conditions

The National Confidential Enquiry into Patient Outcome and Death reviewed the barriers and facilitators in the process of the transition of children and young people with chronic health conditions into adult health services. The report focuses on five issues – developmentally appropriate healthcare, the involvement of children and young people and their parents or carers in transition planning, communication and coordination of care, the organisation of transition services and leadership – and makes recommendations for practice.

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Introduction

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) reviewed barriers and facilitators in the process of the transition of children and young people with chronic health conditions into adult health services (Michalski et al, 2023).

While children and young people with chronic conditions are surviving into adulthood at higher rates than before (McDonagh and Viner, 2006), it is widely recognised that the process of transfer into adult health services does not always work well (Royal College of Nursing, 2013). The process can be especially complex when a young person has multiple conditions and there is no adult team to transfer to, or when they are discharged from child health services at 16 years of age and the adult service does not start until the age of 18 years (Care Quality Commission, 2014). This NCEPOD report highlights an issue that is fundamental to this gap in care: transition is often seen as the responsibility of the team that the young person is leaving, instead of all healthcare professionals. Therefore, it is important that transition is a constituent of all specialties' job descriptions, to ensure that developmentally appropriate healthcare is made part of core business (Rapley et al, 2019). The report highlights five areas where the process of transition can be improved.

Study method

The aim of the report was 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. Children and young people aged between 13 and 25 years with one or more of 12 chronic conditions were identified retrospectively over 2 years, and up to five per hospital were selected for further review. Data were collected from primary, community, physical and mental healthcare organisations in England, Wales and Northern Ireland. Clinician questionnaires were sent to all teams responsible for providing ongoing healthcare. The overall quality of transition care was assessed by a multidisciplinary group of clinicians who reviewed the case notes and questionnaires. Data around the organisation of services were also collected from children and young people and parent carers with experience of transition and from health and social care professionals working with children and young people.

Report findings and recommendations

Where transition had started, 112/542 (20.7%) children and young people were preparing to transfer, 142/542 (26.2%) were peri-transfer and 288/542 (53.1%) had fully transferred from child into adult health services. Just over half (462/829; 55.7%) of the children and young people had multiple conditions, and 191/254 (75.2%) children and young people approaching transfer or transferring into adult services were considered by clinicians to have a disability which could add additional complexity to their care.

Table 1. Key recommendations for healthcare professionals
Ensure that 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
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 and/or carer access to this plan
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
Implement an overarching trust or health board transition policy for all young people with ongoing healthcare needs
Convene an overarching trust or health board transition team to provide a 'one-stop shop' model of holistic care for young people moving from child into adult healthcare services

There was a noticeable contrast between the views of clinicians and reviewers on the overall quality of the transition process. Clinicians completing the questionnaires thought the process of transition worked well for most (322/401; 80.3%) of the children and young people they cared for, whereas the reviewers graded the overall process of transition as good for only 66/293 (22.5%) children and young people and poor for 123/293 (42.0%).

The five key findings (Table 1) were:

1. The need for developmentally appropriate healthcare
2. The need for 'person-centred' transition planning that involves the young person
3. Communication and coordination of care between all involved in the transfer to adult services needs improvement
4. The need for better organisation of transition services
5. Leadership needs improvement.

This article presents data relating to these areas. The report, complete recommendation list and other support tools are available at https://www.ncepod.org.uk/2023transition.html

Developmentally appropriate healthcare

Training in developmentally appropriate healthcare was mandatory for staff in 37/169 (21.9%) organisations. Only 16/167 (9.6%) organisations included transition in the job descriptions of all healthcare staff involved in this process. Data from the health and social care professional survey indicated that where training was received it was poor (37/155; 23.9%). The poor quality and availability of training in developmentally appropriate healthcare was further highlighted by the reviewers, who found that transition was started at an appropriate age for only 91/280 (32.5%) children and young people by all relevant services and in 219/322 (68.0%) cases there were missed opportunities to address transition. For most children and young people, acknowledgement of transition and initiation of developmentally appropriate healthcare is happening too late because of a lack of training provided to healthcare professionals.

Recommendation

Ensure that 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.

Patient and parent and/or carer involvement in transition planning

The study revealed discrepancies in how involved children and young people and parents and/or carers were in healthcare planning. Children and young people should be engaged in their individual healthcare plans as well as shaping the design of the system in the organisation in which they are being treated. A total of 118/192 (61.5%) organisations had a policy stating that the children and young people should be offered the opportunity to be involved in their transition process, and in 86/118 (72.9%) organisations this took the form of jointly developing care plans. Data from the clinician questionnaire indicated that 141/187 (75.4%) children and young people were involved in their transition process, but in the reviewers' opinions, few (56/290; 19.3%) young people were involved in their transition process. Person-centred healthcare planning should be made a priority in the transition process to allow the young person to participate in decisions about their care when moving into adult health services.

Recommendation

Develop a personalised transition plan with each young person who will need to move from child into adult healthcare services. Give the young person and their parent and/or carer access to this plan.

Communication and coordination

The reviewers found evidence that 346/438 (79.0%) children and young people were under the care of multiple specialties, and for 254/346 (73.4%) children and young people this involved multiple teams across two or more trusts or health boards. Coordination between teams was lacking in 165/242 (68.2%) cases reviewed and in a further 155/270 (57.4%) cases there was no evidence that there had been communication about transition between teams; an indicator that many young people are falling into a gap between services.

Recommendation

Request input into the multidisciplinary team for young people with ongoing healthcare needs as required from relevant healthcare professionals, educational services and a representative of the social care team where applicable.

The organisation of services

A total of 111/192 (57.8%) organisations reported providing child, adolescent and adult services. An adolescent clinic to which young people could be referred was present in 60/186 (32.3%) organisations and only 34/192 (17.7%) used a flagging system in their electronic patient records to identify young people with chronic conditions, while only 99/192 (51.6%) organisations had an overarching transition policy. Better organisation of healthcare services would ensure that there is a direction for children and young people moving to adult health services and ensure that receiving services and GPs are involved.

Recommendation

Implement an overarching transition policy at trust or health board level for all young people with ongoing healthcare needs.

Leadership

The National Institute for Health and Care Excellence (2016) recommends that a senior executive should support the development and publication of transition strategies and policies, yet just 74/157 (47.1%) organisations reported an executive board member responsible for transition policies and 78/166 (47.0%) reported input from a senior manager to implement such policies. Furthermore, only 87/192 (45.3%) organisations had at least one clinical lead for transition to action any transition policies on the ground and, where joint child and adult clinics did exist, less than a third (40/132; 30.3%) had any form of formal commissioning or funding.

Recommendation

Convene an overarching trust or health board transition team to provide a 'one-stop shop' model of holistic care for young people moving from child into adult healthcare services. This should include a senior executive responsible for developing a transition policy and strategies.

Conclusions

The NCEPOD report highlights the barriers and facilitators to good transition in five areas: developmentally appropriate healthcare; the need for 'person-centred' transition planning that involves the young person; communication and coordination of care between all involved in the transfer to adult services; the organisation of transition services; and leadership. The

Key points

- All organisations should ensure that developmentally appropriate healthcare training is delivered for all specialties.
- All young people with chronic conditions, and their parents and/or carers where appropriate, should be offered the opportunity to be involved in their healthcare planning.
- All relevant specialties should be offered the opportunity to be involved in a multidisciplinary team for young people with ongoing healthcare needs.
- Organisations should implement an overarching transition policy for all specialties to allow for age-appropriate spaces and services to be available to all young people with chronic conditions.
- Local clinical leads and executive board members should work together to ensure that transition policies are in place.

report makes 11 recommendations for clinicians and management to implement in practice, all of which support previous recommendations in this area.

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