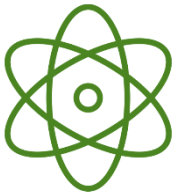
EXECUTIVE SUMMARY

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.

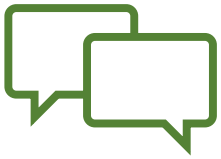
2. INVOLVE YOUNG PEOPLE AND PARENT/CARERS IN TRANSITION PLANNING AND TRANSFER TO ADULT SERVICES

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.