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 to 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

	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.*	• 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. • 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. • 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	NICE 2016, NG43: Transition from children's to young adults' services for young people using health or social care services NICE 2016, QS140: Transition from children's to adults' services CQC 2014, From the pond into the sea. Children's transition to adult health services

	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*	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. • 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.	Welsh Government 2022: Transition and handover from children's to adult health services
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*	• In total, 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, with 28/124 (22.6%) only copying young people into letters after transfer to 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). • 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. • 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). • 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).	NICE 2016, NG43: Transition from children's to young adults' services for young people using health or social care services Department of Health 2011. Quality criteria for young people friendly health services Welsh Government 2022: Transition and handover from children's to adult health services

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*	• 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.	NICE 2016, NG43: Transition from children's to young adults' services for young people using health or social care services NICE 2016, QS140: Transition from children's to adults' services RCPCH 2018, Facing the Future: Standards for children with ongoing health needs Welsh Government 2022: Transition and handover from children's to adult health services
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*	• Clinicians completing the clinician questionnaire considered that 462/829 (55.7%) young people had multiple conditions and that 105/254 (41.3%) young people preparing for or transferring to adult services had a life-limiting condition. • 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). • 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). • 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. • A total of 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). • 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 to 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.	NICE 2016, NG43: Transition from children's to young adults' services for young people using health or social care services Welsh Government 2022: Transition and handover from children's to adult health services

		• Education, health, and care plans (EHCPs) are legal documents for children who require additional support to enable them to access education. 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. There was evidence in 121/335 (36.1%) sets of notes that the young person had an EHCP. 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. • 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.	
5.	Involve primary care throughout the transition process from child to 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*	• 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. • Data from the clinician questionnaire indicated all young people (254/254; 100.0%) were registered with a GP and these details were recorded in the hospital records for all of them. Clinicians who responded said that young people were encouraged to access primary care for their other health needs in 163/182 (89.6%) instances. • There were 123/147 (83.7%) young people for whom there was no receiving adult specialty were therefore discharged back to their GP for ongoing care. • 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 to 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. • Only 10/33 young people and 4/69 parents/carers said that the young person's GP was involved in the transition process.	NICE 2016, NG43: Transition from children's to young adults' services for young people using health or social care services CQC 2014, From the pond into the sea. Children's transition to adult health services Together for Short Lives 2023, Stepping Up. Transition pathway to enable a good transition to adulthood for young people with life-limiting and life-threatening conditions RCPCH 2018, Facing the Future: Standards for children with ongoing health needs Welsh Government 2022: Transition and handover from children's to adult health services

	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*	• 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. • 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. • 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%). • 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). • 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. • 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). • 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 to adult services. • 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. • 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). • NICE also recommends that organisations have a senior manager responsible for implementing those strategies, but only 78/166 (47.0%)	NICE 2016, NG43: Transition from children's to young adults' services for young people using health or social care services NICE 2016, QS140: Transition from children's to adults' services CQC 2014, From the pond into the sea. Children's transition to adult health services Together for Short Lives 2023, Stepping Up. Transition pathway to enable a good transition to adulthood for young people with life-limiting and life-threatening conditions Department of Health 2011. Quality criteria for young people friendly health services RCPCH 2018, Facing the Future: Standards for children with ongoing health needs Welsh Government 2022: Transition and handover from children's to adult health services

		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. • 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. • 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. • 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. • 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.	
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*	• 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. • 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. • 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). • 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). • 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). • 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	NICE 2016, NG43: Transition from children's to young adults' services for young people using health or social care services CQC 2014, From the pond into the sea. Children's transition to adult health services Together for Short Lives 2023, Stepping Up. Transition pathway to enable a good transition to adulthood for young people with life-limiting and life-threatening conditions Department of Health 2011. Quality criteria for young people friendly health services RCPCH 2018, Facing the Future: Standards for children with ongoing health needs Welsh Government 2022: Transition and handover from children's to adult health services

		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). • 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. GPs responded very positively with 146/152 (96.1%) giving young people the opportunity to be seen alone. • Where the organisation had an overarching transition policy, that policy covered all young people with long-term conditions in just 76/98 organisations. • 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. • However, 98/175 (56.0%) organisations had separate transition policies for different specialties.	
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*	• 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.	RCPCH 2018, Facing the Future: Standards for children with ongoing health needs Welsh Government 2022: Transition and handover from children's to adult health services
9.	Ensure staff in all organisations complete training in developmentally appropriate healthcare and the transition from child to 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*	• 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.[20] 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). • 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).	NICE 2016, NG43: Transition from children's to young adults' services for young people using health or social care services CQC 2014, From the pond into the sea. Children's transition to adult health services

		• 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). • 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, 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).	Department of Health 2011. Quality criteria for young people friendly health services
	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*	• Figure 2.1. - 2,469 clinician questionnaires were sent for completion, and of these 887 were subsequently cancelled. The most common reason for cancelling a questionnaire was because no ongoing care could be identified by the team. • 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. • 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.	NICE 2016, NG43: Transition from children's to young adults' services for young people using health or social care services Welsh Government 2022: Transition and handover from children's to adult health services
11.	Ensure that transition from child to 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*	• 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. • 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. In fact, only 57/138 (41.3%) funding arrangements/contracts specified transition at all. 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).	NICE 2016, NG43: Transition from children's to young adults' services for young people using health or social care services CQC 2014, From the pond into the sea. Children's transition to adult health services