Appendix II

Standards and guidelines for child to adult transition

Standards and guidelines exist for child and adult services supporting transition that are both generic and condition-specific. Below is a non-exhaustive list of some of the different standards that are available at the time of publishing.

Consider exploring the following outlets to find standards and guidelines that are pertinent to your audit:

1. National guidelines e.g. NICE/NHSE.
2. Quality assurance guidelines e.g. CQC.
3. Guidelines from research projects e.g. the NIHR funded Newcastle Transition Research Group.
4. Standards published by professional bodies e.g. Royal Colleges
5. Condition-specific charities
6. National financial incentives e.g. best practice tariff, CQUIN

National Guidelines

The NICE quality standards: QS140

Statement 1: Young people who will move from children's to adults' services start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.

Statement 2: Young people who will move from children's to adults' services have an annual meeting to review transition planning.

Statement 3: Young people who are moving from children's to adults' services have a named worker to coordinate care and support before, during and after transfer.

Statement 4: Young people who will move from children's to adults' services meet a practitioner from each adults' service they will move to before they transfer.

Statement 5: Young people who have moved from children's to adults' services but do not attend their first meeting or appointment are contacted by adults' services and given further opportunities to engage.

The quality standard guidance contains examples of quality measures that can be used to assess services.

https://www.nice.org.uk/guidance/qs140/resources/transition-from-childrens-to-adults-services-pdf-75545472790213

Guidelines from Research Projects

Implication for Transition Services - Newcastle Transition Research Group:

https://research.ncl.ac.uk/transition/

1. Transitional care should be commissioned by commissioners of adult services as well as by commissioners of child services.

Where an adult service to which to transfer young people with a long-term condition is not commissioned, commissioners should set out explicitly that the transfer arrangements will usually be to primary care and require appropriate documentation and assistance to the young person to make their first appointment.

2. A framework to provide ‘Developmentally Appropriate Healthcare’ across NHS organisations should be commissioned, with the stipulation that this is owned at Chief Executive and Board level.

3. NHS organisations should adopt a Trust-wide approach to implementation of better transitional care. A Transition Steering Committee, chaired by a Trust-wide Transition Coordinator, can facilitate this.

4. Child clinicians should plan Transition procedures jointly with the relevant named adult clinicians and general practitioners.

5. Child and adult healthcare providers should explore with a young person how they approach Transition and personalise the clinical approach thereafter.

6. The features ‘Appropriate parent involvement’, ‘Promotion of young people’s confidence in managing their health condition (health self-efficacy)’ and ‘Meeting the adult team before transfer’ were associated with greater satisfaction with services, participation, subjective wellbeing and measures of disease control.

7. Maximal service uptake would be achieved by a service which encouraged parental involvement, ensured the same staff were seen at each clinic, emphasised the importance of good communication with young people, and encouraged young people to make decisions about their care.

Good value for money would be offered by a service which provided: ‘Parental involvement that suited both parent and young person’, and a ‘Protocol for promotion of young people’s confidence in managing their health condition’.

Quality Assurance Guidelines

CQC Inspection framework core service: Transition services

http://www.cqc.org.uk/sites/default/files/20160713_NHS_specialist_core_service_inspection_framework_transition_services.pdf

Professional Standards:

Does the trust use monitoring and fail safe mechanisms to ensure that the young person is regularly attending the adult services. Is the young person only discharged from children's services once it is certain their care has been successfully transferred?

Do young people have a named key worker designate in adult services to support the transition process?

Do transition plans for current and ongoing health needs include a written agreed history that includes past medicines, surgery and other interventions?

Is there a named and identified consultant or lead health professional identified who will be responsible for the health care of the young person before they are discharged from the children's health services?

Are 'health passports' (or a similar mechanism) in use to ensure that relevant professionals have access to essential information about the young person?

Patients experience coordinated care with clear and accurate information exchange between relevant health and social care professionals.

How does the trust ensure that information transfer to the adult service is efficient and effective? – for example, the use of problem orientated records, a Health Passport for the young person, and keeping GPs fully informed.

Do young people have a preparation and education programme to enable the young person to function in the adult setting – does this include rights on confidentiality and consent?
Is there an agreed process for joint strategic planning between children's and adult health services?

Standards Published by Professional Bodies

Royal College of Surgeons of England - Standards for Children's Surgery

As part of the governance and leadership arrangements, these standards stipulate that there should be a "policy in place and an identified lead for the transitional care of young people moving to adult services, including children and young people with special needs".

https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0ahUKEwiA_orZr_3ZAhVCLcAKHUDODugQFggpMAA&url=https%3A%2F%2Fwww.rcseng.ac.uk%2F-%2Fmedia%2Ffiles%2Frcs%2Flibrary-and-publications%2Fnon-journal-publications%2Frcs_standards_for_childrens_surgery_2013.pdf&usg=AOvVaw3scZe-ydfyOeQ4DtloWcDY

Royal College of Paediatrics and Child Health - Facing the Future: Standards for Children with Ongoing Health Needs

Developed in collaboration with Royal College of General Practitioners, Royal College of Psychiatrists, Royal College of Nursing and Royal College of Physicians. Eleven standards organised along the child's journey with the aim to ensure children's healthcare provision is co-ordinated and joined up. The standards are designed to ensure that child health services are proactive and planned and that children are involved in designing and evaluating care so that service are built around their needs. Standards 4-8 focus in improving the long-term care and management of children including transition planning. Standard 6 in particular recommends that "service planners ensure there us a designated person within the child health service who is responsible for ensuring g that developmentally appropriate transitional care is provided and co-ordinated by both child and adult services".

https://www.rcpch.ac.uk/system/files/protected/page/Facing%20the%20Future%20Standards%20for%20children%20with%20ongoing%20health%20needs%202018-03.pdf

Charities

The National Deaf Children's Society – Commissioning Audiology Services for Young Adults

Good quality audiology services for young adults:

- Are accredited under the UKAS/RCP IQIPS programme or are actively using the Self-Assessment and Improvement Tool (SAIT) with the expectation of receiving accreditation in the near future.
- Have participated in the development of a documented transition pathway and policy that has been developed and agreed with all key stakeholders.
- Routinely consult young adults in relation to current services and relevant new developments, and ensure they are appropriately represented in service user satisfaction surveys.
- Maintain positive relationships with the paediatric audiology service as well as other local services, such as education, social care and voluntary service providers, to ensure that young adult's holistic needs are met.
- Are able to offer an introductory appointment for transitioning individuals before the young person has been discharged from the paediatric service.
- Have ensured that all staff who come into contact with deaf young adults have received appropriate training on understanding, engaging and communicating with them.
- Provide a range of information that meets the needs of the local population and is easily accessible to deaf young adults.
- Are able to offer a young person-led and flexible approach to timing of transfer to allow for the large variation in development and readiness to move on to adult services.
- Have access to current NHS contract hearing aids to ensure continuity of provision.
- Have training in paediatric hearing aid fitting prescriptions and protocols, including FM equipment and other assistive devices, to ensure young adults are not changed to new prescriptions without an identified clinical need and they are able to continue to successfully use assistive equipment in higher education that they are familiar with.
- Have protocols in place that outline shared care or alternative arrangements for young adults in higher education living away from home.
- Have clear policies on the provision and/or sale of other assistive devices, such as Bluetooth streamers, that may be purchased elsewhere but require pairing with the hearing aids by the audiologist.
- Have accessible battery provision and clear information on availability that take account of periods living away from home for students in higher education.

- Have an accessible contact and appointment booking system that does not rely on telephone only.

- Have access to community language or BSL interpreters as needed.

http://www.ndcs.org.uk/professional_support/transition.html

National Financial Incentives

Paediatric Diabetes Best Practice Tariff Criteria

a) On diagnosis, a young person with the diagnosis of diabetes is to be discussed with a senior member of paediatric diabetes team within 24 hours of presentation. A senior member is defined as a doctor or paediatric specialist nurse with ‘appropriate training’ in paediatric diabetes;

b) All new patients must be seen by a member of the specialist paediatric diabetes team on the next working day;

c) Each provider unit can provide evidence that each patient has received a structured education programme, tailored to the child or young person’s and their family’s needs, both at the time of initial diagnosis and ongoing updates throughout the child or young person’s attendance at the paediatric diabetes clinic;

d) Each patient is offered a minimum of four clinic appointments per year with a multi- disciplinary team (MDT), i.e. a paediatric diabetes specialist nurse, dietitian and doctor. The doctor must be a consultant or associate specialist/speciality doctor with training in paediatric diabetes or a specialist registrar training in paediatric diabetes, under the supervision of an appropriately trained consultant (see above). The dietitian must be a paediatric dietitian with training in diabetes (or equivalent appropriate experience);

e) Each patient is offered additional contact by the diabetes specialist team for check-ups, telephone contacts, school visits, troubleshooting, advice, support etc. Eight contacts per year are recommended as a minimum;

f) Each patient is offered at least one additional appointment per year with a paediatric dietitian with training in diabetes (or equivalent appropriate experience);

g) Each patient is offered a minimum of four haemoglobin HbA1C measurements per year. All results must be available and recorded at each MDT clinic appointment;

h) All eligible patients must be offered annual screening as recommended by current NICE guidance.34 Retinopathy screening must be performed by regional screening services in line with the national retinopathy screening programme, which is not covered by the paediatric diabetes BPT and is funded separately. Where retinopathy is identified, timely and appropriate referral to ophthalmology must be provided by the regional screening programme;

i) Each patient must have an annual assessment by their MDT as to whether input to their care by a clinical psychologist is needed, and access to psychological support, which should be integral to the team, as appropriate;

j) Each provider must participate in the annual Paediatric National Diabetes Audit;

k) Each provider must actively participate in the local Paediatric Diabetes Network. A contribution to the funding of the network administrator will be required. A minimum of 60% attendance at regional network meetings needs to be demonstrated. They should also participate in peer review;

l) Each provider unit must provide patients and their families with 24 hour access to advice and support. This should also include 24 hour expert advice to fellow health professionals on the management of patients with diabetes admitted acutely, with a clear escalation policy as to when further advice on managing diabetes emergencies should be sought. A provider of expert advice must be fully trained and experienced in managing paediatric diabetes emergencies;

m) Each provider unit must have a clear policy for transition to adult services

n) Each unit will have an operational policy, which must include a structured 'high HbA1C' policy, a clearly defined DNA/was not brought policy taking into account local safeguarding children board (LSB) policies and evidence of patient feedback on the service.

http://www.cypdiabetesnetwork.nhs.uk/files/7015/1238/6565/Updated_Guide_for_Paediatric_Diabetes_Best_Practice_Tariff_Criteria_V2_2.pdf