Making healthcare work for young people

A toolkit to support delivery of 'Developmentally Appropriate Healthcare' in the NHS
About this toolkit

The toolkit is designed to support all working in the NHS, from clinicians to chief executives, to promote the health of young people and to play their part in making healthcare work for this age group. It gives practical suggestions about how healthcare can be tailored to young people’s needs as they develop and change through adolescence into young adulthood – such care is termed ‘Developmentally Appropriate Healthcare’.

Providing health services that support effective and successful transition of young people with long-term conditions from childhood to adulthood is an NHS priority. A programme of research funded by the NIHR has focused on the question of how health services can do this effectively (See Transition Research Programme). A key finding of this research is the need to provide Developmentally Appropriate Healthcare for all young people from 10-24 years.

Developmentally Appropriate Healthcare (DAH) recognises the changing biopsychosocial developmental needs of young people and the need to empower young people by embedding health education and health promotion in consultations. In operational terms DAH focuses on the approach of healthcare providers to and engagement with each young person and their carers alongside the structure of the organisations in which care takes place.

- Understanding biopsychosocial development and holistic care
- Acknowledgement of young people as a distinct group
- Adjustment of care as the young person develops
- Empowerment of the young person by embedding health education and health promotion in consultations
- Working across teams and organisations

Supporting change at the organisational level, within teams and in clinical practice

The delivery of Developmentally Appropriate Healthcare is not just the responsibility of an individual clinician but requires a team approach and work across the organisation. The toolkit addresses these different levels of delivery. In our research, we found that pockets of good practice in one clinical specialty does not necessarily spread to other parts of an organisation. We want to share best practice at every level to enable implementation consistently throughout healthcare. Making small changes in clinical practice as well as larger scale changes at an organisational level will all contribute to better health outcomes for young people.

Change for all young people accessing health services

This guidance refers to all young people from 10-24 years. The toolkit was developed in secondary and tertiary care settings but includes tools which will be useful in other settings including primary care.

How many young people use secondary care?

In 2010/11 in England, 3,700 young people aged 10-19 years were admitted to hospital in a typical NHS trust serving a population of 270,000. This had increased by 15% since 1999. There were more admissions in the age range 10-19 than in the age range 1-9 years.

In 2008/09 in England, 24,500 young people aged 11-19 years attended outpatients in a typical NHS trust serving a population of 270,000, and a further 16,800 young people aged 20-24 years.

About 100 young people with long term conditions reach age 16 each year in a typical NHS trust serving a population of 270,000. As transition takes place over at least 7 years, the number of young people in transition at any time in a typical trust is about 700.


Colver A. How can health services contribute most effectively to facilitating successful transition of young people with complex health needs from childhood to adulthood? In: Report to NIHR: Programme Development Grant. Newcastle: Newcastle University, 2010.
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Acknowledgements
This toolkit was developed by Janet McDonagh, Tim Rapley, Jeremy Parr; Allan Colver and Helena Gleeson working together with the Association for Young People’s Health. We would like to thank everyone who provided us with feedback on the toolkit and all those who contributed to the Transition Research Programme. This includes members of the Young Person’s Advisory Group UP, Research Assistants, Principle Investigators, Collaborators and Advisers. Finally we would like to thank the young people, their families and the clinicians, managers and commissioners who took part in the research.

Disclaimer
This toolkit presents a wide range of resources, some of which come from academic publications, and some were identified during the course of the Transition Research Programme. Inclusion in this toolkit does not mean all the resources have official endorsement from AYPH or the Transition Research Programme.

This toolkit was funded by the National Institute for Health Research (NIHR) under the Programme Grants for Applied Research programme: RP-PG-0610-10112. The views expressed are those of the authors and not necessarily those of the UK National Health Service, the NIHR or the Department of Health.

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Focusing on improving healthcare for young people is important. The Lancet commission on adolescent health and wellbeing (2016) states that there are ‘tremendous unrealised opportunities’ in focusing on the healthcare of young people and that this represents an investment in the health of future adults.

‘Developmentally Appropriate Healthcare’ is about making healthcare work for young people by recognising their changing developmental needs, and the role of healthcare in addressing these throughout adolescence and young adulthood. This is also an overarching principle in NICE guidance on transition from children’s to adult services.

Young people and transition: Young peoples’ development is a time of great transition. Alongside, the changes in their bodies and minds, transitions occur in many other areas of their life such as education, home, finances and relationships as they start to navigate the world with greater independence. For young people engaged with health services, the transfer from child to adult services is a critical transition in their lives and like all transitions, it presents both a risk and an opportunity for a young person in their development. Developmentally appropriate healthcare recognises this and aims to support the young person in their development throughout this time.

‘A stage, not an age’: Each young person makes this journey to adulthood in a way unique to them, and young people’s development does not have a fixed time frame attached. Much of this development will take place after reaching the legal age of adulthood at 18. Recent research in neuroscience tells us that the brain is indeed still developing until the mid-twenties.

Making healthcare work for young people: Healthcare needs to respond to young people’s changing developmental needs, from the way healthcare professionals engage and communicate with young people in the consulting room through to how services are planned, delivered and commissioned.
1. Defining Developmentally Appropriate Healthcare

This toolkit is based on findings from an NIHR funded Transition Research Programme that aimed to provide the NHS with evidence about what might help young people with long-term health conditions as they transfer from child to adult services. Click here for further information.

One part of the research considered the barriers and facilitators of ‘developmentally appropriate healthcare’ in three hospitals in North England and the Midlands.

A key finding was the need for clarity and consistency about what it means to provide developmentally appropriate healthcare. The research identified the following dimensions of care as particularly important and these are themes throughout the toolkit.

Developmentally Appropriate Healthcare (DAH) recognises the changing biopsychosocial developmental needs of young people and the need to empower young people by embedding health education and health promotion in consultations. In operational terms DAH focuses on the approach of healthcare providers to and engagement with each young person and their carers alongside the structure of the organisations in which care takes place.

Acknowledgement of young people as a distinct group

“We need to recognise they’re not mini adults or big kids, they are their own group with their own needs.”

Adolescent and young adult health professional

Understanding biopsychosocial development and holistic care

“…awareness of issues for young people in society and young people as a kind of developmental stage around things like mental health, sexual health, confidentiality, consent… seeing that young person in that wider context…”

Health professional, adult hospital

Adjustment of care as the young person develops

“It never stops changing. That’s the challenge… you see one person one time, and three months later… some other developmental issue has taken primacy.”

Manager, general hospital

Empowerment of the young person by embedding health education and health promotion in consultations

“It feels a bit like a gentle educational role… to sort of try and highlight those areas that do need exploring.”

Paediatric health professional

Working across teams and organisations

“I think, as I say, it is important from a trust-wide perspective that people are thinking in joined up manner.”

Paediatric health professional

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**Resources**


2. Working across your organisation

a. Strategic recognition of young people as a distinct group

Recognition that young people are a distinct group with their own needs (neither ‘big kids’ nor ‘mini-adults’), should be at the heart of strategic planning and inform all levels of service development, delivery and commissioning:

- Chief Executives should demonstrate their commitment to this by requiring that improvement is sought across all the Trust’s directorates
  - The improvements sought should be realistic and concrete, as set out in this toolkit – rather than aspirational
  - Senior managers should require accountability from each directorate in relation to improvement plans

- Clarity about leadership
  - Appoint an executive champion for young people’s health who leads on improvement. This should include addressing the barriers to improvements for young people across both child and adult services and having input into Trust policies
  - Consider a separate transition champion depending on the size of your organisation. See NICE guidance on transition

- Make sure organisational monitoring collects data on young people as a distinct group

- Ensure you have appropriate organisational policies that support a youth friendly culture
  - This should include a transition policy developed with the involvement of stakeholders, including young people and child and adult health professionals
  - There should be consistency of policies in both adult and child services in relation to transition

- Consider how your current organisational policies may affect young people and adapt them. For example:
  - Trust wide policies on “Did not attend an outpatient appointment” may need to be more flexible when applied to young people to recognise the specific challenges they face and the importance of keeping young people engaged in healthcare
  - Policy approaches to young people being admitted as inpatients may need adapting to accommodate young people
b. Participation, engagement and co-production

- Consider young people’s participation at all levels of the organisation
  - How do you share young people’s feedback across the organisation?
  - How many young people give you service user feedback? What does it tell you?
  - How can you involve young people in research you or others are undertaking?
  - How are young people involved in the development of new services?

- Work with experts in participation locally and nationally to support a sustainable approach to engagement for the young people you work with, and your organisation

- Use resources outlined here to plan how you work with young people

“Adults see the end point, without thinking about all the ways to get there. Young people see all the possible ways forward, without necessarily keeping the end point in mind. You need both!”

A CHAT member

Examples from practice

Northumbria Healthcare NHS Foundation Trust
The Child Health Action Team (CHAT)

CHAT are a group of young people who support service development across children and young people’s healthcare services. They undertake a range of tasks: e.g. being part of staff interview panels; rating services as ‘mystery shoppers’; designing ward art; developing information leaflets.

United Progression (UP) is the young people’s working group on the Transition Research Programme being led by the trust. Members have experience of accessing a range of healthcare services and their role is to represent the voices of young people in the research. The UP group aims to work in partnership with the adult researchers to oversee the governance and delivery of the Transition programme.

Facilitation staff, with dedicated time to support children’s and young people’s participation, are employed to work with the young people and help them deliver their input.

Resources

- Children and young people’s participation and advocacy resources RCPCH
- Reaching marginalised young people AYPH
- NHS youth forum’s tips to involve young people in healthcare planning NHS England
- Walk the talk – top tips about providing a youth friendly health service NHS Health Scotland
c. Organisational culture and the environment

Consider how you can adapt the environment in which young people are seen. Adapt it in a way that ensure young people feel it is a safe and appropriate place for them. This can include adapting the ethos and culture of a unit as well as the physical space. Many of these changes can be simple and cheap and easy to implement.

- Ensuring the appointment letter is addressed to them directly as well as to their carers when needed
- Having adult sized chairs rather than child sized chairs
- Making the Wi-Fi code visible
- Having information available (including posters) that are useful and interesting to young people
- Make sure you involve young people in any significant changes and feed back to them what has happened as a result of their work

Consider having age-banded clinics for young people in both child health and in adult services (i.e. for under 25’s using adult services)

“For them to have a defined space that is their space where they have nurses and clinicians that understand that they are stepping into an environment that is different from an adult space.”

Hospital manager

Resources

Acute care toolkit: Acute care for adolescents and young adults RCP
A public health approach to promoting young people’s resilience AYPH

Making health care work for young people – A toolkit to support Developmentally Appropriate Healthcare
d. Use incentives and drivers to support change

- **You're welcome** – Quality criteria for young people friendly health services

Achieving You’re Welcome for your organisation is a way to celebrate and recognise youth friendly health services. As a Department of Health standard it should be highlighted in CQC inspections and other assessments of your organisation to ensure that this area of good practice in your work is recognised. Click [here](#) for further information.

- **CQUINs** – The Commissioning for Quality and Innovation framework can be used to focus on improving health care for young people. Using this tool can support increased transparency and the sharing of overall improvement in healthcare for young people. However sustained change is more challenging since a CQUIN only lasts for one year. [Download NHS England 2015/16 guidance](#).

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e. Transition care

Preparing young people for the move from child health to adult services is critical to ensure good health outcomes for young people. It is much more than simply the event of transfer of responsibility for a young person’s care from child to adult services and should always be considered in the context of a young person’s development.

- **NICE guidelines** set out how an organisation can support transition for young people through its infrastructure.

- **The Transition Research Programme** gives more information about how health services can contribute most effectively to facilitating successful transition of young people with complex health needs.

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“Everyone in the hospital needs to be helping the young person to look forward.”

Paediatric health professional

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3. Having a team approach

Who is this section for and what is it about?

This section is for those clinical teams working with young people and so includes clinicians, managers and administrative support staff. It aims to ensure that the whole of your team is working effectively with young people. The section is subdivided into:

a. Training and workforce development
b. Information sharing and review processes
c. Facilitating transition from child health to adult services

a. Training and workforce development

- You’re Welcome quality criteria for young people friendly health services recommends all staff who are likely to meet young people receive training on:
  - Communicating easily with young people
  - Promoting attitudes and values that are young people friendly
  - Meeting standards established in the current NHS Knowledge and Skills Framework
  - Confidentiality
  - Consent
  - Seeing young people on their own

- Ensure that the whole team has had training to work in a developmentally appropriate way and keep records

- Consider training staff in strength-based approaches such as motivational interviewing and solution focused approaches

- Consider e-learning as part of training

- Teams can develop their own bespoke workforce development solutions through multidisciplinary training relevant to their own setting.

Resources

- Adolescent Health Programme
- E-Learning for Healthcare
- European training in effective adolescent care and health for teachers EuTEACH
- Motivational interviewing techniques for working with young people
- Department of Health, Australia

Making health care work for young people – A toolkit to support Developmentally Appropriate Healthcare
Examples from practice

Adolescent Health Training Days: Northumbria Healthcare NHS Foundation Trust

All staff, including receptionists, healthcare assistants, nurses, doctors, were encouraged to attend this training. The course was attended by 120 staff from hospital and community; paediatric and adult health as well as support services.

Small group day workshops were delivered over one year and learners received follow-up support to carry out a workplace based project:

Modules
- Adolescent development and epidemiology
- Young people’s experience of healthcare & You’re Welcome
- Signposting: Advocacy and health promotion
- Communication skills and top tips
- Consent and confidentiality
- Meet the experts: Young People’s panel
- Mini projects: Completing a small-scale, work-based quality initiative proposal

Facilitating factors included:
- Managerial and executive support
- Back-fill funding to service areas, to enable staff to attend training days

Feedback from learners highlighted the need to recognise young people specific roles and tasks in staff job plans.

Making health care work for young people – A toolkit to support Developmentally Appropriate Healthcare
b. Information sharing and review processes

- Prior to transfer ensure adult services are included in transition planning
- Ensure primary care is fully informed by sharing your approach throughout
- Hold regular multi-disciplinary meetings ideally, with adult and child teams present
- Share information about young people across the team
- Copy adult service into all correspondence

Examples from practice

Adolescent Rheumatology Service, Birmingham Children’s Hospital

Weekly adolescent only clinic
Weekly adolescent multidisciplinary team meetings

Clinical coordinator role

At the weekly adolescent clinic, a clinical coordinator meets and greets all young people in the waiting room and:

- ask whether they wanted to be seen independently for some or all of the consultation
- ask which Dr/therapist/nurse they would like to see
- review readiness checklists (e.g. READY STEADY GO)
- help young person prioritise issues they wish to raise with clinicians

The clinic environment

A variety of posters, up to date magazines and informational resources are used to try and make the multi-user waiting area more youth-friendly.
c. Facilitating transition from child health to adult services

- Establish a process so that a multi-disciplinary summary of patient history can be prepared in time for transfer
- Identify a transition co-ordinator at managerial level within the team
- All young people should have a named worker responsible for coordinating their transition

Team meetings should address:

- Adolescent and transitional care issues of patients attending the service
- Transition planning and listing what could be covered in the clinic and by which team member
- The priorities of individual young people so that they can be addressed first on the day
- Use the information collected in the HEEADSSS assessment in team meetings to structure discussion about young people

Examples from practice

Proforma for joint planning of Transition between young person, family and team, Adolescent Rheumatology Service, Birmingham Children’s Hospital

This proforma was developed by an occupational therapist (Janine Hackett) to ensure effective communication across the team

The objectives of the proforma are to:

- Document transition planning progress over time
- Ensure continuity between rheumatology team members
- Ensure effectiveness, consistency and pacing of information
- Ensure assessment of health literacy, and information giving
- Support strategies such as brief intervention and motivational interviewing
- Avoid unnecessary repetition and ‘potential nagging’
- Assist team members to remember non-medical ‘hooks’ that assist in the engagement of young people

This was adopted by the READY STEADY GO programme in Southampton
4. Engaging with young people in clinical practice

Who is this section for and what is it about?

Young people tell us that the relationships they form with clinical staff are important for their care. It is what happens in these encounters that often predicts their future engagement in healthcare, and in turn their own health outcomes (Ambresin, 2013).

This section is for healthcare professionals working with young people. It focuses on good practice in one to one consultations with young people. It is sub-divided as follows:

a. How healthcare can support a young person’s development

b. Confidentiality, privacy and the role of the family

c. Communicating with young people

d. Engaging young people in their own healthcare

e. Preparing young people for transition to adult services

Assess the wider aspects of a young person’s life using approaches such as HEEADSSS.

Examples from practice

The STEPP Approach to Adolescent Development

During consultation, use conversations as part of the psychosocial screening to assess developmental maturity as follows:

Sexual maturation and growth

- Is the intellectual, pubertal and growth stage appropriate for their chronological age?

Thinking

- Is the young person using concrete or abstract constructs?
- Do they have sufficient self-esteem and/or sense of purpose?

Education/employment

- Is the young person in work or education that, in their culture, is appropriate for their age?

Peers/parents

- How connected is the young person to their peers and parents?
- Who is responsible for the young person’s healthcare decisions?

See STEPP model opposite This will determine how best to communicate with young people about their health and its management. (See Communicating with young people)
HEEADSSS

HEEADSSS is a tool which can be used as part of a conversation with a young person in a consultation or in a team setting. It provides a framework for a psychosocial assessment and a holistic approach to healthcare.

The acronym HEEADSSS stands for:

- **Home** environment – where does the young person live and who with? Do they have good support systems at home?
- **Education** and employment – at what stage of education/employment are the young people at? Are there any changes they are expecting soon?
- **Eating** – does their weight concern them? Have they been on a diet in the last year?
- **Activities** – what do they like doing in their leisure time? Do they have a supportive peer group?
- **Drugs** – does the young person smoke, drink or use drugs?
- **Sexuality** – relationships, sex and sexuality.
- **Suicide** / depression – what sort of things do they do if they are feeling sad/angry/hurt?
- **Safety** – personal safety, injury, online safety

- When using the HEEADSSS tool with a young person in juvenile arthritis, a discussion of weight and shape issues led her to disclose that she wasn’t taking her medication because she was worried about weight gain.
- A discussion about activities a young person enjoyed helped to make the treatment goal of enhanced physical activity relevant to his love of football.
- Consideration of pubertal stage is an important aspect of developmental assessment of all young people (see STEPP), particularly in view of the evidence of the importance of pubertal timing and the psychosocial development of young people. Simple question-based tools facilitate such assessments for the non-specialist and can be less awkward for young people. Self-assessment tools, although not always reliable, can also be used to facilitate discussion about puberty and sexual health.

“**What works for one 14-year-old may not work for another because of developmental maturity and their resulting needs.**”

From the Pond to the Sea

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**Resources**

Klein D, Goldenring J, Adelman W. HEEADSSS 3.0: The psychosocial interview for adolescents updated for a new century fueled by media
*Contemporary Pediatrics* 2014

Doukrou M, Segal TY. Fifteen-minute consultation: communicating with young people - how to use HEEADSSS, a psychosocial interview for adolescents.
*Archives of Disease in Childhood: 2017: [Epub ahead of print]*

Puberty assessment growth charts
*RCPCH*

The 5As: a tool to support conversations about prevention and risk assessment
*RACGP*
b. Confidentiality, privacy and the role of the family

Uncertainty about confidentiality is one of the biggest fears and barriers for young people in accessing healthcare. Health professionals can address this by:

1. Displaying their confidentiality policy in the waiting room
2. Making it clear at the start of the consultation that information is confidential unless there is a risk of serious harm to the young person

How can you balance the privacy of the young person with the needs of families?

Every young person has the right to be seen on their own whatever their age and sometimes they need privacy to discuss aspects of their healthcare away from their parents/carers. On the other hand, young people, as at any age, have the right to a chaperone but one must not assume this should be the parent/carer.

However, parents and carers are also integral to the care of young people and need support and information. Getting this balance right is not always easy and what’s needed will change over time. Being flexible and listening to the needs of young people should be at the heart of practice. Some ideas to consider are:

- Make sure there is always time to see the young person on their own
- Ensure this information is in the appointment letter so all are prepared
- If parent/carers are present always introduce yourself to the young person first. Consider asking the young person to introduce you to other people in the room
- Send copies of letters to young people aged 11 or older and make sure language is clear
- Check out with young people how they would like their parents or carers involved
- Involve parents and carers in treatment decisions in a way that has been agreed by the young person

“I always start by asking the young person if they understand what I mean by confidentiality.”

Paediatric health professional

Resources

NHS Youth Forum – youth rights in healthcare posters NHS England

NHS Youth Forum – youth rights in healthcare leaflet NHS England

Confidentiality and young people toolkit RCGP Adolescent Health Group

Children and young people ethics toolkit BMA

Adolescence: boundaries and connections – An RCN guide for working with young people RCN

Chaperoning: The role of the nurse and the rights of patients Guidance for nurses RCN

Parenting resources RCPsych

Making health care work for young people – A toolkit to support Developmentally Appropriate Healthcare
c. Communicating with young people

How you communicate with young people in consultations matters. Young people report that the thing they value most in health services is the attitude of health professionals and how they communicate with them (Ambresin, 2013).

Several approaches to communication can support your work with young people:

- Build resilience in a young person by highlighting and focusing on their own coping skills. Solution focused techniques can help to do this in a constructive way.
- Use motivational interviewing skills to focus on what matters to the young person and work with realistic goals.
- When you start to see young people independently, discuss what will be shared with parents/carers at the end of the consultation and ask the young person to inform their parents while you are there. This helps to ensure that the young person understands what you have planned and demonstrates their competency to themselves and their parents.

“Ask the young person, out of 10, what priority is taking your medication in your life; and how confident are you in taking your medication? If they score 5/10 on confidence then ask what it would take to move from 5 to 7…”

Paediatric health professional

Resources


Children and Young People Centred Communication Me first

Motivational interviewing techniques for working with young people

Department of Health, Australia

Guidance on using technology to enhance access and communication

University of Warwick and King’s College London
d. Engaging young people in their own healthcare

An important aim of developmentally appropriate healthcare is to encourage young people to be engaged in their own healthcare e.g. developing shared management of their health, and accessibility and youth friendliness of services.

Shared management. Health professionals need to adjust care as the young person develops. For example, shifting in emphasis towards them taking more responsibility as the young person gets older.

'Did not attend' (DNA). When young people do not attend appointments, this can present a serious risk to young people's health outcomes especially given that DNA rates are higher amongst vulnerable young people. Adult services in NHS trusts often have a policy that people are not offered further appointments after a single DNA. For young people however this blanket approach can mean that they may become further disengaged from healthcare at a critical time. The way that clinicians respond to DNA's is therefore an important aspect of making healthcare work for young people.

The following practices are recommended:

- Record and follow up on DNA's with young people and families
- Record contact details for both young person and the family – these may be different!
- Explore and document the reasons for young people not attending appointments
- Check whether Trust policies include an exception clause which allows you to use your clinical judgement about whether to send a further appointment

See Working across your organisation

Contacting the service

It is useful to consider different ways that a young person can contact the service. Many young people are more comfortable using digital technologies than letters or phone calls for instance and getting this right can improve access to services (Griffiths et al, 2015).

“As a way of getting round the automated system, I spoke to the senior manager in IT to discuss how we could have a more flexible response to DNA’s for young people.”

Paediatric health professional

Resources

Health information for young people, from young people YouthHealthtalk

Walk the Talk – promoting youth friendly health services
NHS Health Scotland

MyHealth Passport: for young people and assessment use
Good 2 Go Transition Program

Ready steady go: A programme to help young people gain the knowledge and skills to manage their condition.
University Hospital Southampton

Ask 3 questions – helping patients become involved in healthcare decisions
Advancing quality alliance, NHS
e. Preparing young people for transition to adult services

Key principles to bear in mind as a clinician are:

- Transition planning should start early and at the latest by year 9 (aged 13-14)
- Involve the young person’s family and carers in transition planning
- Ensure that the transition planning process is properly documented. This can be done via a clinic proforma
- Discuss with the young person how their confidence and independence are progressing – around for example confidence in talking with clinicians, making appointments, managing medication, the role of primary care including the registration process etc. Young people will be at different stages, depending on their condition and maturity
- Ensure familiarity with adult services and foster confidence that the move to adult services or primary care is desirable and part of growing up. This can be done through:
  - Providing an opportunity to visit the adult clinic before transfer and to meet adult staff
  - Providing an information leaflet about the service they will transfer to
  - Informing other healthcare providers (and in particular primary care) about the patient’s history and providing the young person with a copy of this information

“You assist the young person to prepare and plan for the move, so you do that consciously …to help them realise and to help them take responsibility to some extent for the move from children’s to adult services.”
Hospital manager

“The only way transition will work is if you have helped the family think positively about it.”
Paediatric health professional

Resources

The Transition Programme: a 5-year programme of research examining how health services can contribute most effectively to the successful transition of young people with complex health needs from childhood to adulthood.

Transition from children’s to adults’ services for young people using health or social care NICE guidance

NICE quality standards for transition
NICE

From the pond into the sea: Children’s transition to adult health services
Care Quality Commission

Support for young people with SEND in preparing for adulthood
Preparing for adulthood

Transition Information Network: Sharing information and good practice for disabled young people, families & professionals
Council for Disabled Children
We hope that you have found this toolkit helpful. As the Transition research programme disseminates information about Developmentally Appropriate Healthcare and Transition we would be happy to send you updates. We would also be interested to hear what you think about the toolkit and how you are using it in your trust.

If you would like to send us information or get updates please email Transition@ncl.ac.uk