NHS England

Quick Guide:

Commissioning for transition to adult services for young people with Special Educational Needs and Disability (SEND)

NHS England Information Reader Box

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Quick Guide
Commissioning for transition to adult services for young people with Special Educational Needs and Disability (SEND)

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Equality and Health Inequalities statement

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- considered the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- considered the need to reduce inequalities between patients in access to, and outcomes from, healthcare services, and to ensure that services are provided in an integrated way where this might reduce health inequalities.

See NHS England's **Equality and health inequalities legal duties guidance** for more information.

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1 Introduction

This Quick Guide is intended to help local areas develop their transition processes for young people with Special Educational Needs and Disability (SEND) from childhood to adulthood.

It works in conjunction with the existing national guidance shown in the box below. The format is based on the ten key transition principles published by the National Institute for Health and Care Excellence (NICE) in 2016. Local areas can use this as a resource to inform their own practice.

This Guide should be read in concurrence with the NHS England Quick Guide for Health Services for Children and Young People with Special Educational Needs and Disabilities and the **Children and young people: Quick guide about personal health budgets and Integrated Personal Commissioning.**

- **Transition from children's to adults' services for young people using health or social care services - NICE guideline (NG43).**
- **Quality standard [QS140] Published date: December 2016**
- **Part 3 of the Children and Families Act 2014**
- **Part 1 of the Care Act 2014**
- **Part 8 of the SEND code of practice: 0 to 25 years**
- **People with Learning Disabilities health checks**
- **Building independence through planning for transition A quick guide for practitioners supporting young people - NICE**

2 Participation and co-production

Young people and their families must be at the centre of every stage of the transition pathway. They must be involved in the development of every element of the local transition strategy. Their involvement is required by key legislation such as the **Children and Families' Act 2014** and the **Health and Social Care Act 2012**. There are two legal duties that require CCGs and commissioners in NHS England to:

- enable patients and carers to participate in planning, managing and making decisions about their care and treatment through the services they commission
- ensure the effective participation of the public in the commissioning process itself, so that services reflect the needs of local people.

Young people and their families should be involved in the design, delivery and evaluation of the transition pathway. Local areas should encourage opportunities such as peer support, and the inclusion of disabled young people on school councils and youth forums.

Young people are invaluable to commissioners. Not only can they provide real time feedback on their experiences of services, but they can also identify gaps in

commissioning. Working in co-production on transition policies and strategies will be of benefit when piloting new transition materials and creating new tools.

You may find the following resources useful:

Resource	Link
Transforming Participation in Health and Care Developed by NHS England to support commissioners to improve individual and public participation, and to better understand and respond to the needs of the communities they serve.	**Transforming participation in health and care: Guidance for commissioners** **Involving people in health and care guidance**
NNPCF Position Statement – Post 16 Roles of Parent Carers	**National Network of Parent Carer Forums**
Children and young people's participation and advocacy resources	**Royal College of Paediatrics & Child Health**
Newcastle University & Northumbria Healthcare NHS Foundation Trust Three studies on the Transition research programme, which relies on the involvement of young people.	**Three studies on the Transition programme**
Making Ourselves Heard One of the Council for Disabled Children's specialist networks, established to focus exclusively on the participation of children and young people.	**Making Ourselves Heard**

Changing Our Lives, and Changing Young Lives Works in partnership with disabled people, and those with mental health difficulties, to find solutions to social injustice and health inequality. Takes a community development approach, as we know that local people and communities are best placed to find solutions to local problems.	**Changing Our Lives**
Preparing for Adulthood programme (PfA) Delivered by the National Development Team for inclusion (**NDTi**).The programme is funded by the Department for Education as part of the Delivering Better Outcomes Together consortium.	**Young people and family participation** **Delivering Better Outcomes Together**

Examples from local authorities These are examples of LAs that have a process in place to support the strategic participation of children and young people.	**Salford City Council** **Somerset County Council** **Young People's Participation in Health Services ebook.pdf**
Building Transition into the Local Offer Website Kingston and Richmond - Young People's Hub.	**SEND Local Offer Website**
Fixers A group of young people using their past to fix the future.	**Caitlyn's Fixers**

3 Person-centred transition planning

Every young person is unique and so is their transition into adulthood. Their individual characteristics, aspirations, and families, and the different services they use, all need to be taken into account throughout the transition process.

A **person-centred approach** should be adopted to ensure that transition planning is effective. This sees the person using care and support as an individual and an equal partner, who can make choices about their own care and support. It is **strengths-based** and focuses on what is positive and possible for the young person, responding to their preferences rather than a pre determined set of transition options.

You may find the following resources useful:

Resource	Link
Preparing for Adulthood This person-centred planning toolkit focuses on young people aged 14-25, who are preparing for adulthood and will be transferring from a statement of Special Educational Needs (SEN), or are receiving support at college following a Learning Difficulty Assessment (LDA).	**Preparing for Adulthood Review Toolkit**
Ready Steady GO - Southampton Children's Hospital Transition resources for long-term conditions.	**Transition to adult care: Ready Steady GO**
Personalising Education Recognises that every pupil is an individual. A collaboration by Real Life Options, Helen Sanderson Associates, the International Learning Community for Person-Centred Practices, and partner schools and colleges.	**Personalising education**
Council for Disabled Children This practical decision-making toolkit is aimed at supporting those working directly with children or young people with SEND.	**Council for Disabled Children Decision making toolkit**

4 Clear leadership and accountability

The multidisciplinary nature of transition requires leadership and ownership across the transition pathway, to ensure there are no gaps in the support provided for young people.

To provide this leadership, each health and social care organisation, in both children's and adult services, should nominate:

- a strategic lead to be accountable for transition strategies and policies
- an operational lead to be accountable for implementing and reviewing the transition strategy.

Leadership should cover both physical and mental health services. For example, Camden & Islington NHS Foundation Trust operate a **Minding the Gap Transitions Team**. This is a service for agencies working with young people who need advice on moving from children's to adult settings.

5 Strategic vision across children's and adults' services

Each local area should develop a joint mission or vision statement that clearly sets out the goals for young people and their families, and how services will work together to achieve a smooth transition.

The vision should be developed with young people, their families and professionals, and include information on how services will work together to help young people prepare for adulthood, with particular focus on:

- education and employment
- independent living
- having friends and relationships, and being part of the community
- being as healthy as possible – it is important to look at young people's health needs in a holistic way, including emotional and sexual health.

You may find the following resources useful:

SEND Code of Practice 2015	**SEND Code of Practice: 0 to 25 years**
Council for Disabled Children Transition e-learning resources.	**The role of health practitioners in implementing the Children and Families Act**
Co-Producing the Leeds Vision - PfA and Leeds City Council Production of a vision of their 'Child Friendly Leeds' strategy	**Preparing for Adulthood: co-producing the Leeds vision** **Leeds City Council: Our Vision and Strategies**

6 Understanding transition needs

It is important that we work with young people to develop a transition pathway to strengthen and support them, whatever their needs may be.

Local areas should carry out an assessment of the needs of young people supported by children's services, to ensure they are responding to the needs of their local population. **The Care Act 2014** provides a clear framework for using this information to plan for transition.

This assessment should draw on information about local need, from sources such as:

- Joint Strategic Needs Assessment data
- local services, including Child and Adolescent Mental Health Services (CAMHS), therapy services, children's social care teams, and Children's Continuing Care
- Education, Health and Care (EHC) plans.

You may find the following resources useful:

University of York 2000-2010 Research Prevalence of life-limiting conditions in young people aged 18-40	**Together for Short Lives: Final Report**

Council for Disabled Children These resources have been produced to help practitioners write good quality EHC plans.	**Education, Health and Care plans: Examples of good practice**
NHS England Commissioning Guidance for Rehabilitation Model of rehabilitation on page 13 illustrates that transition is critical for patients and their families.	**Improving Rehabilitation Services**
Leicester Local Authority Joint Strategic Needs Assessment 2014 Puts particular focus on young people with an autistic spectrum disorder.	**Developing our understanding of transition from children's to adult services**

7 Transition process and protocols

To ensure that there is clarity on how young people are supported through their transition, each area should develop a shared transition process between children's and adults' services. This will include protocols and arrangements for the sharing of information, such as safeguarding data. This process could include, for example:

- plans for adult services to meet young people prior to transition
- joint clinics
- parental involvement

This process must be in line with the statutory requirements set out in the **Children and Families Act 2014** and the **Care Act 2012**. Both Acts set out a timetable for transition for young people with Education, Health and Care plans, and children receiving support from children's social care services. They also introduce the requirement to undertake Child's Needs Assessments, to help meet young people's needs when they move from children's to adults' services.

You may find the following resources useful:

Council for Disabled Children Transition Guides Useful resources for helping to plan transition, with examples of what good processes should look like.	**Council for Disabled Children: Transition guides**
Research in Practice 'Lifespan' approach to transition Includes key research messages relating to personalisation, and makes use of existing evidence to explore the challenges and opportunities of a lifespan approach to personalisation.	**Lifespan Personalisation: Strategic Briefing**
Preparing for Adulthood - Factsheet Examines the links between the Children and Families Act 2014 and the Care Act 2012.	**Factsheet: The Children and Families Act and The Care Act**
Preparing for Adulthood Contains learning examples from the demonstration sites.	**Preparing for Adulthood Resources** **Preparing for Adulthood: Developing Practice**
Ready Steady GO - Southampton Children's Hospital Transition resources for long-term conditions.	**Transition to adult care: Ready Steady GO**
The 10 Steps Transition Pathway and 10 Steps Transition Toolkit Developed by Lynda Brook and Jacqui Rogers with the support of the Transition Team at Alder Hey Children's NHS Foundation Trust.	**10 Steps: Transition to Adult Services**

Sheffield Parent Carer Forum Transition Timeline Written by parents for parents, with advice on stages of transition, information and best practice.	**Sheffield Parent Carer Forum: 14-25 Transitions Guide**

8 Developing joint commissioning arrangements

Delivering appropriate support to improve outcomes, including specific services for young people in transition, requires effective commissioning, including of new services.

This requires clearly-defined joint commissioning arrangements that encompass children's and adults' services, including arrangements for pooled budgets between those services across health, education and social care. Areas should consider where formal integration of services and use of Section 75 pooled budget mechanisms are appropriate.

You may find the following resources useful:

Preparing for Adulthood Joint Commissioning Guidance	**Joint Commissioning in Action Guide** **Preparing for Adulthood: New Joint Commissioning Resource Guide**
Together for Short Lives Information on Jointly Commissioning Palliative Care	**Together for Short Lives: Jointly Commissioning Palliative Care**
In Control A national charity working for an inclusive society where everyone has the support they need to live a good life. The website contains a range of useful resources, reports and toolkits. Report aimed at developing knowledge and practice that assists in the introduction of personal health budgets for children and young people with long term conditions.	**In Control** **In Control: The Challenges for Commissioners**

Kids Charity A family guide to personalisation, personal health budgets and Education, Health and Care plans. Provides support and advice for parents and carers of disabled children and young people, as well as commissioners.	**KIDS – Making it Personal 2**
Together for Short Lives Transition Taskforce Leading the development of a coordinated approach to providing care and support to young people with life-limiting conditions.	**Together for Short Lives: Transition Taskforce**

9 Training and development of staff

To ensure that staff have a shared understanding of inclusion there must be a focus on person-centred planning.

In order to achieve a successful transition, staff must work with families, whilst supporting the young person to take increasing ownership of their own health care. This, however, does require the child and adult workforce to plan and work together in a different way.

You may find the following resources useful:

Preparing for Adulthood Workforce Development Guide This guide has been endorsed by Skills for Care and Skills for Health. It is aimed at employers and staff within education services - schools, further education colleges and local authorities; social care in children's and adult services; and health services - community, specialist, hospital and primary care.	**Preparing for Adulthood: Workforce Development Guide**

Health Education England: E-learning Adolescent Health Programme The Adolescent Health Programme (AHP) is an e-learning programme for healthcare professionals working with young people. Suitable for GPs, school nurses, community paediatricians and the child health team, AHP aims to ensure that all health professionals have essential youth communication skills and understand young people's rights to consent and confidentiality.	**e-learning for Health Care: Adolescent Health Programme**
Challenging Behaviour Foundation: Positive Behaviour Support Workshops and study pack for schools and colleges, designed to reduce challenging behaviour by showing staff how to create and implement Positive Behaviour Support Plans.	**Challenging Behaviour Foundation: Positive Behaviour Support Study Pack**
Local Government Association, Association of Directors of Adult and Social Care, and NHS England Guidance on creating appropriate support.	**Directors of Adult Social Services: Building the right support**

10 Role of Named Worker

According to NICE Guideline (NG43) the Named Worker is defined as a role rather than a specific job title. It might, for instance, be someone who already has the title keyworker, transition worker or personal adviser.

A Named Worker could be drawn from a range of roles, including a GP, nurse, youth worker, allied health professional, health/social care/education practitioner, or another professional who has a meaningful relationship with the young person.

The nature of this role will vary depending on individual circumstances, but the Named Worker will be the link between the young person and the practitioners involved in their support, including their GP. They will help the young person plan for their future as well as navigating services and coordinating appointments where there is a complex mix of care and support.

A Named Worker should collaborate with primary care in transition planning and ensuring appropriate support is offered, particularly with the following aspects of transition:

- The Named Worker should support the young person for a minimum of 6 months before and after their move between children's and adult's services.
- For disabled young people in education, the Named Worker should liaise with educationalists, to ensure that comprehensive student-focused transition planning is provided. This should involve peer advocacy and friends.

You may find the following resources useful:

Resource	Link
Council for Disabled Children: Developing key working This report looks at key approaches to working with children and young people with special educational needs or disabilities, and their families.	**Council for Disabled Children: Developing Key Working**
Council for Disabled Children Transition Network A network for practitioners, young people and their families, interested in learning more about transition.	**Council for Disabled Children: Transition Information Network**
Together for Short Lives Examines how to embed key working approaches in the care of children with complex needs.	**Together for Short Lives: Embedding key working for children with complex needs**

11 Needs of specific groups

To ensure that young people who face particular challenges and experience poor outcomes are properly supported, it is important that local areas pay particular attention to this group. It can include:

- young people with neurodevelopmental disorders, including learning disability and/or autism
- those with behaviours that challenge, who may be at risk of being admitted to residential healthcare settings such as Assessment and Treatment Units
- young people with life-limiting or life-threatening conditions and
- looked after children moving out of care.

You may find the following resources useful:

For young people with neurodevelopmental disorders The Kent Transformation Plan is an example of best practice.	**Kent Local Transformation Plan**
For young people with behaviours that challenge A useful information pack from the Challenging Behaviour Foundation.	**Challenging Behaviour Foundation: Planning for the Future**
For young people with life-limiting or life-threatening conditions Transition guidance from Together for Short Lives.	**Stepping Up: A guide to enabling a good transition**
For young people with life-limiting or life-threatening conditions The Together for Short Lives Transition Care Pathway audit tool is contained within the Standards Framework for Children's Palliative Care.	**Together for Short Lives: Standards Framework for Children's Palliative Care**
For looked after young people Department for Education statutory guidance for local authorities to support looked-after children's aspirations for their further and higher education.	**Promoting the education of looked-after children**
For young offenders A joint national protocol for transitions in England between the Youth Justice Board (YJB), National Probation Service (NPS), and National Offender Management Service (NOMS), to support the planned and safe movement of young people from youth offending teams (YOT) to probation services.	**Joint national protocol for transitions in England**

For young people in receipt of mental health services NHS England guidance for transitions out of children and young people's mental health services.	**Commissioning for Quality and Innovation (QUIN) Guidance 2017-2019**
For young people in the community The Queen's Nursing Institute Transition of Care Programme aims to improve care for young people in the transition process from children's to adults' community healthcare.	**Queen's Nursing Institute: Transition of Care Programme** **QNI Transition of Care Newsletter - December 2017**
For young people with a learning disability The learning disabilities health check scheme is one of a number of GP enhanced services. Designed to encourage practices to identify all patients aged 14 and over with learning disabilities, to maintain a learning disabilities 'health check' register, and to offer these patients an annual health check.	**Learning Disabilities Health Check Scheme**
NHS England A range of resources on improving the health of people with learning disabilities. Guidance for Transforming Care Partnerships in commissioning support and services for children and young people with learning disability, autism or both.	**Learning Disabilities: Improving Health** **Developing support and services for children and young people with a learning disability, autism or both**