Transition from Children's to Adults' Health Services

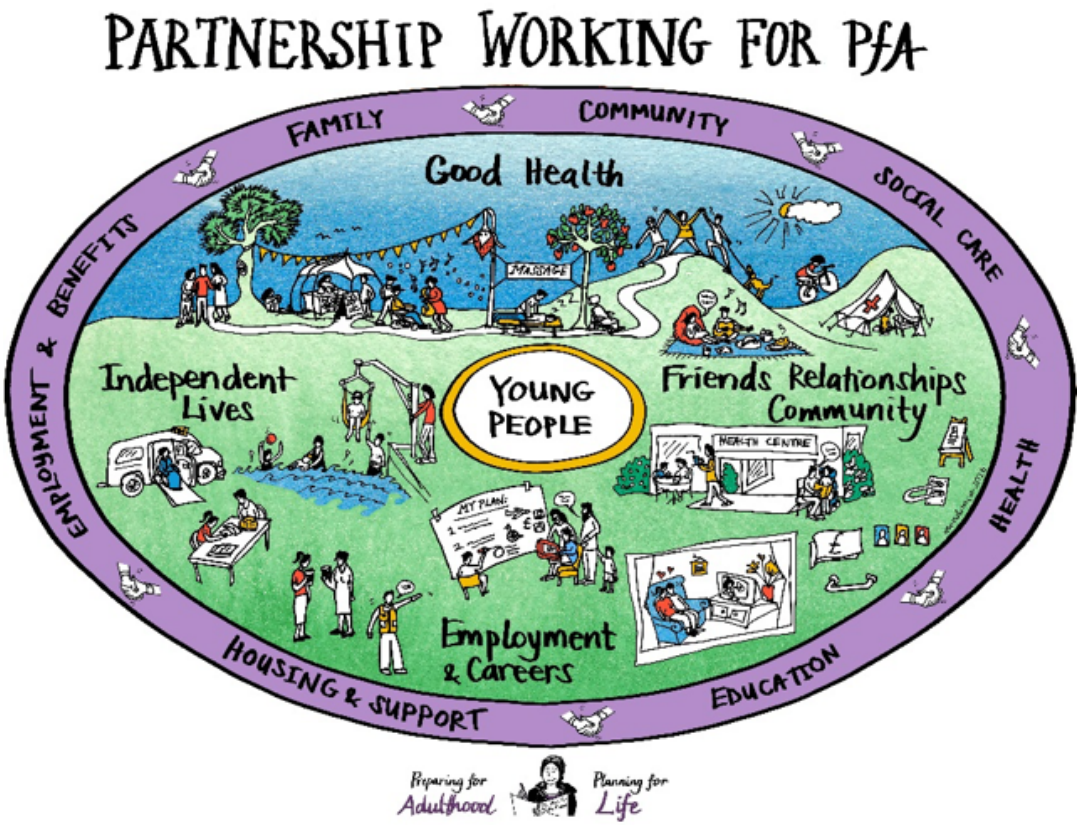
Supporting Young People who have Special Educational Needs and/or Disabilities from aged 13 years into Adulthood

Futures
Advice, skills & employment

RAINBOW
Parents Carers Forum

NHS
Nottingham City
Clinical Commissioning Group

Nottingham
City Council


PARTNERSHIP WORKING FOR PfA
FAMILY
COMMUNITY
SOCIAL CARE
HEALTH
EDUCATION
HOUSING & SUPPORT
EMPLOYMENT & BENEFITS
Good Health
Independent Lives
YOUNG PEOPLE
Friends Relationships Community
Employment & Careers
Preparing for Adulthood
Planning for Life

Contents

Introduction

This information is intended for use by young people, resident in Nottingham city, who have Special Educational Needs and/or disabilities (SEND), and their families and for practitioners from all services; education, health and care as a brief guide to the pathways and processes of transition from local children's to adults' health services. NICE, the National Institute for Health and Care Excellence published best practice guidance in February 2016:

https://www.nice.org.uk/guidance/ng43

A working sub group of the multi-agency Preparing for Adulthood (PfA) Steering Group has compiled this document, drawing on the NICE guidance as appropriate. It is anticipated that the information it contains, particularly in Section 2, will be updated regularly, as many services are currently reviewing and developing their individual transition protocols.

The PfA Steering Group recognises that this is an interim document. Our longer-term proposal is to co- produce a full protocol with young people, parents, carers and professionals. The full document will align with the City's development of work towards a Whole Life Approach for people who have SEND. We are committed to co-producing a Local Charter with young people, parents and carers and professionals. In the meantime, this document should be read alongside the Nottingham City Multi-Agency Preparing for Adulthood Protocol.

Section 1 Principles

Transition Planning

Transition planning is part of the preparation for adulthood process, which should begin from year nine (age 13 or 14) at the latest, and ideally much earlier than that. Planning for the transition from children's to adults' health services should:

- Use a person-centred approach, ensuring that the young person is a partner, along with their families, carers and supporting professionals
- Be strengths-based, focusing on what is positive and possible for the young person
- Empower the young person to make decisions and build their confidence to direct their own care and support over time
- Focus on outcomes that are based on a young person's aspirations and support them to lead as independent a life as possible

Service managers in both adults' and children's services, across health, social care and education, should proactively identify and plan for young people in their locality with transition support needs. Every service involved in supporting a young person should take responsibility for sharing safeguarding information with other organisations, in line with local information sharing and confidentiality policies. Education, health and social care services should work together to:

- Ensure a smooth and gradual transition for each individual, not based on a single rigid age threshold
- Involve all practitioners providing support to the young person in the initial planning
- Review the plan at least annually, if not more frequently, and share the outcome with all those involved

For children and young people with complex health needs, it can be the case that a paediatrician or another health practitioner co-ordinates all interaction with health services, and that treatment is delivered at home, at hospital, or at school. Many adult specialist services do not have the same eligibility criteria as children's specialist services, and the General Practitioner (GP) will be vital in navigating and referring within the range of adult health services. It is therefore essential that the child or young person is known to their GP and that the GP is actively involved in planning for transition.

Support Before and During Transition

Transition planning is complex and involves a number of different services and professionals as well as the young person, their family, and other important people in their life. The 'named worker' is ideally the person who the young person wishes to have as the individual who will lead and coordinate their transition into appropriate services. Individual service areas, for example; education, social care and health, would also have an identified 'named worker' for the young person. However, for the purpose of this document the named worker will be identified as the person nominated to lead and coordinate the young person's transition into adult health services.

Consequently, the named worker should be someone who the young person has a good relationship with and who is able to navigate the young person's transition into the complex array of health services. An example of the named worker could be any of the following; transition worker, personal advisor, a nurse, social care representative.

The named transition worker should:

- Help the young person navigate services, bearing in mind that many may be using a complex mix of care and support
- Help the young person to be involved in their transition planning, ensuring that the young person's communication needs are taken into account
- Ask the young person regularly how they would like their parents or carers to be involved throughout their transition, recognising that a young person may hold different views to those of their parents, and that they may need opportunities to raise concerns or queries separately from their parents and carers
- Follow the principles of the Mental Capacity Act and other relevant legislation as necessary
- Be the link between the young person and the various practitioners involved in their support, including the named GP, and, if applicable, practitioners from relevant adult services

- Arrange appointments with the GP where needed as part of transition, and think about ways to help the young person to get to appointments, if needed
- Support the young person to make visits to the adult services they may potentially use
- Support the young person's family, if appropriate
- Ensure that young people who are also carers can access support
- Act as an advocate or representative for the young person, if needed
- Provide advice and information, and direct the young person to other sources of support and advice, for example peer advocacy support groups provided by voluntary and community sector services

The named worker should consider working with the young person and their support team to create a personal folder to share with adult services. It could contain:

- A one-page profile, including their strengths, achievements, hopes and goals
- Information about their education and social needs
- Their preferences about parent or carer involvement
- Information about their health conditions
- Emergency care plans
- Any history of unplanned admissions to hospital
- A one-sheet summary of essential information for use in unplanned admissions to hospital

Transition planning is part of the preparation for adulthood process

The named worker should ensure that the young person is offered support with the following aspects of transition, if relevant for them (which may include directing them to other services):

- Education and employment
- Community inclusion
- Health and wellbeing, including emotional health
- Independent living and housing options

The named worker should liaise with education practitioners to ensure comprehensive student-focused transition planning is provided. This should involve peer advocacy, and friends and mentors as active participants.

The named worker should:

- Support the young person for the time defined in any relevant legislation, or a minimum of 6 months before and after transfer (the exact length of time should be negotiated with the young person)
- Hand over their responsibilities as a named worker to someone in adults' services (if they are based in children's services)

Support after Transition

If a young person has moved to adults' services and does not attend meetings, appointments or engage with services, adult health and social care practitioners, working within safeguarding protocols, should try to contact the young person and their family, and involve other relevant professionals, including the GP.

If, after assessment, the young person does not engage with health and social care services, the relevant provider should refer back to the adult services named worker[s] with clear guidance on re-referral (if applicable).

If a young person does not engage with adults' services and has been referred back to the named worker[s], the named worker[s] should review the person-centred care and support plan with the young person to identify either how to help them use the service, or an alternative way to meet their support needs.

Help with NHS Health Care Costs

When a young person reaches 19 and is no longer in full time education, some NHS health care costs may be incurred (prescriptions, dental care, vision and hearing testing). Help can be obtained through the NHS Low Income Scheme and further advice and information can be found by contacting 0300 3301343

https://www.nhs.uk

ensuring that the young person is well supported and their health needs are fully understood

Section 2 Services

Introduction

The following information is a list of the most widely used health services in relation to children and young people who have a special educational need and/or disability. It is intended to provide an overview of the current transition practice within these services and highlight if there is an equivalent adult service for young people to transition into. At times, within the health service arena, transition involves transferring a young person's care to several adult services so individual health need is met appropriately.

The overall aim is to ensure that the young person is well supported and their health needs are fully understood so that the health provision(s) they are transitioning into are prepared and able to meet specific health need.

Updates and contact details for the organisations that deliver the services listed in this section can be found be found via the following web pages:

https://www.nottinghamcitycare.nhs.uk/
https://www.nuh.nhs.uk/
https://www.nottinghamshirehealthcare.nhs.uk/

Specialist Community Public Health Nursing Service – School Nursing and Health Visiting

The Specialist Community Public Health Nursing Service, 0-19yrs have a 'Transfer In and Out procedure for Children, Young People and Families Services'. The policy provides clear guidance for practitioners when they are involved in the transfer of care of children, young people and families. This includes transfer of care to services within Nottingham city and services outside of Nottingham. For young people with additional needs, the service will identify the appropriate adult health service and ensure that an effective transfer of information is given with the young person's consent. All young people with additional needs are transferred to adult services on a case by case basis to ensure a bespoke transition occurs.

https://www.nottinghamcitycare.nhs.uk/find-a-service/services-list/public-health-nursing-health-improvement-co-ordinators/

Community Paediatrician

Transition arrangements will depend on what the underlying diagnosis/condition is that requires ongoing follow-up. For those with complex needs in special schools, paediatricians work closely with other multi-agency staff. For young people with significant intellectual disabilities who have ongoing health needs, paediatricians refer them into the Intellectual Disability Services at Highbury Hospital. For young people with intellectual disabilities without ongoing health needs, paediatricians advise General Practitioners of the need for an annual health check. For young people with Autistic Spectrum Disorders (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) paediatricians are able to refer via the single point of access at Highbury Hospital for appropriate services.

Young people with ADHD are referred on to the Adult Mental Health Service via the Single Point of Access (SPA) at Highbury Hospital. Those with specific conditions e.g. epilepsy are transitioned into the appropriate adult service (e.g. adult neurology) – the actual timing of the transition is negotiated between the family and professionals involved.

https://www.nuh.nhs.uk/nottingham-childrens-hospital

Community Children's and Young People's Service

The Community Children's and Young People's Service is a community healthcare service which is commissioned by Nottingham City and Nottinghamshire County Clinical Commissioning Groups for children/young people who have complex health problems and/or disability. The service provides nursing support for children and young people from 0-19 years and up to 25 years if individual health provision can be better met by this service. However, it is expected that young people will transition to adult health services at the appropriate time. Those receiving support at the time of transition will be supported by that professional currently working with them, young people eligible for this service can be referred to for transition health advice.

The service also provides therapy services for children/young people, for example; Occupational therapy, Physiotherapy and Speech and Language therapy in a variety of settings.

Paediatric Physiotherapy and Occupational Therapy

The Paediatric Physiotherapy and Occupational Therapy Service will assess the young person's individual needs to determine the type of support to enable them to lead an independent life in their home and community. A transition report outlining abilities, needs and recommendations is then shared with appropriate agencies and referrals made where appropriate.

Paediatric Speech and Language Therapy

Speech and Language Therapists (SLT) help with speech and language difficulties and advise on eating and drinking difficulties.

A transition report is provided to the adult Speech and Language Therapy Service at the point of leaving children's SLT. The report provides information, advice and recommendations in the form of a care plan to support the young person's individual needs. This will be used as part of the transition process for young people with eating and drinking difficulties or assisted communication users.

Specialist Paediatric Dietetic Service - Children's Development Centre, City Hospital

Transition planning occurs for those children who have feeding devices e.g. gastrostomy or nasogastric tubes. Once a feeding device is placed, the Home Enteral Feeding Team will then take over the dietetic care and continue into adulthood if appropriate. Young people who do not have a feeding device, but require dietetic input will be transitioned into the adult dietetic service.

There is also a Dietetic Learning Disabilities Team based at Highbury Hospital and young people with an identified learning disability and dietetic need can be transitioned into this service.

https://www.nottinghamcitycare.nhs.uk/find-a-service/services-list/community-nutrition-dietetics-service/

Paediatric Continence Specialist Service

Children and young people with SEND who require nursing assessment, investigation, treatment and management with bladder and bowel problems can be referred to this service from 4 years. Young people are transferred to the Adult Urology Service at 18 years if required. Assessment for appropriate continence products occurs at 18 years and is carried out by the District Nursing Service.

https://www.nottinghamcitycare.nhs.uk/find-a-service/services-list/continence-advisory-service/

Primary Care Liaison Team (Intellectual Disability)

This service is to offer advice, education and liaison to G.P practices, patients, carers and primary care services. The main focus of the team is to educate and advise regarding annual health checks and health action plans, detecting un-met health needs, making reasonable adjustments to practice and preventing unnecessary hospital admissions for people aged 14 years onward, who are registered with a Nottingham City G.P. There is an element of 1-1 work with patients; however, the team's primary role is to act as a facilitator and educator.

https://www.nottinghamshirehealthcare.nhs.uk/ldpclt

Community Learning Disability Nursing Team (CLDT)

This service is for 18-65 year olds with a diagnosis of an intellectual or learning disability. The service works closely with other health professionals and gives advice about physical and mental health problems.

https://www.nottinghamshirehealthcare.nhs.uk/cldt

Acute Learning Disability Liaison Team

The team will accept referrals to work with any adults (18+) with a learning disability (and/or who are transitioning from paediatric to adult service) who are accessing or have a planned treatment within any part of the NUH and the Treatment Centre. This would include outpatient appointments/ pre op assessments, day procedures and hospital admissions (both planned and emergency).

https://www.nottinghamshirehealthcare.nhs.uk/learning-disability-liaison-team

...focusing on what is positive and possible for the young person

Community Dental Service

This service is available for children and adults with a sensory impairment, physical or learning disability, mental health illness or a complex medical history, so a dental practitioner can see them for regular dental care. Clinics are held at five clinics in the City and South of the County. Referrals can be made by any health professionals.

http://www.nottinghamshirehealthcare.nhs.uk/salarieddentalservice

Children's Hearing Assessment Centre

This service provides audiological assessment and care for children from birth until they leave school. Generally, children transfer to the care of the adult team when they are 16 years old, however, if they have additional needs they will remain with this service until they are 19 years old. If they have learning difficulties, they will then be transferred to the Missing out Service.

https://www.nuh.nhs.uk/childrens-hearing-assessment-centre

The Missing Out Service - Hearing Services

The Missing Out Service (MOS) is a specialist service that has a dedicated team who specialise in the hearing care of adults with any form of learning disability; the Children's Hearing Assessment Centre will refer young people to this service.

https://www.nuh.nhs.uk/childrens-hearing-assessment-centre

The Learning Disabilities Audiology Service was created to provide on-going support to young adults with a diagnosed learning disability and hearing related problems and/or who wear a hearing aid who require additional support in their assessment. Additionally, the service continues to monitor young persons with Down syndrome due to high risk of early onset age-related hearing loss (early onset presbycusis), which can be overlooked. These patients are reviewed annually in order to monitor hearing levels.

Typically, Transition, "transfer of audiology care" to the Adult Learning Disabilities Audiology Service should take place at 16 years of age. However, this will depend on the developmental age of the young person and their ability to perform audiological assessment.

> **...navigating the young person's transition into the complex array of health services...**

Youth Justice Service Nursing Service

The YJS Nursing Service (YJSNS) is commissioned primarily to reduce health inequalities and improve health outcomes for young people who are under the supervision of the Nottingham City Youth Justice Service. Young people entering this service will have a health assessment. This information with the consent of the young person can be used when transferring their care to primary care services. The young person's health assessment may identify a special educational need and/or disability and the young person will be referred to the appropriate health provision up to the age of 19 years.

https://www.nottinghamshirehealthcare.nhs.uk/youth-offending-team-nursing-service

Targeted Children's and Adolescent Mental Health Service

This service is for young people with emerging to moderate mental health difficulties that are creating problems in their lives in areas such as relationships and education.

Transition from Nottingham City Targeted CAMHS to Adult Mental Health services is direct from the Single Point of Access (SPA). There is guidance in place for processing referrals received into the SPA where a young person is already 17 years and 6 months old. There are robust processes in place, which will determine which service the young person will transition in to.

Targeted CAMHS have a number of 'equivalent adult services' depending on mental health presentation, presence of risk and the young person's willingness/ability to engage. For example, Let's Talk Wellbeing who accept referrals from 17 years and 9 months.

http://www.bemhnottingham.co.uk/public/about/

Children's Continuing Care

A Continuing Care package will be required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone. The provider will ensure children or young people and their families are at the centre of the children's continuing care process and are responsible for the case management of those eligible for continuing care funding, including those with a Personal Health Budget. The service will ensure that a robust process for children's continuing care is implemented and will ensure that processes are clearly communicated to all appropriate professionals across agencies.

The transition arrangements are set out in the Children's and Young Person's Continuing Care Framework, Adult NHS Continuing Healthcare Framework and the service specification from the CCG. At the age of 14, Children's Continuing Care Service notifies Adult Continuing Healthcare of children who may have the potential at that time, to require continuing care funding. An adult service review at 17 years is undertaken with the child's social worker, so an eligibility decision can be made prior to 17.5 years. If eligible and stable, a follow up assessment is completed prior to their 18th birthday to confirm ongoing eligibility of any funding in accordance with the adult framework. At 18, the case is closed to Children's Continuing care and if eligible opened to adult funding.

The Children's Continuing Care Framework is not directly aligned to the adult service. The criteria for eligibility between the two services is different. If there is on-going eligibility, the young person will have their care transferred to Adult Continuing Care.

http://www.nottinghamcitycare.nhs.uk

Assistive Technology

From 1st May 2018, eligibility for a subsidised alarm and for Telecare equipment will be based on whether citizens are in receipt of a social care service.

The revised eligibility criteria will mean the following:

- Social care staff are able to make a referral for the young person/family they are supporting. This includes the need to put equipment in place to prevent/reduce social care costs;
- Non-social care staff/teams will need to find out if the young person they are supporting is in receipt of a social care service (not just eligible) before advising whether any recommended equipment will be funded or will need to be self-funded;
- Families where social care is not in place will need to self-fund any equipment and alarm changes

Referrals to the Assistive Technology Service will still be made through the online referral system and enquiries can be made to the service either by phoning 01157 469010 or emailing atservice@nottinghamoncall.org.uk

Self-referrals can be made to the service, however, an eligibility assessment will then be needed to see whether the equipment can be funded or needs to be self-funded.

For a breakdown of the self-funding service packages and equipment costs:

http://nottinghamoncall.org.uk/packages-service/

Section 3 Glossary

ADHD	Attention Deficit Hyperactive Disorder
Assistive Technology	Any product or service designed to enable independence for disabled and older people. This includes Telecare-equipment and service, which enables a citizen to live independently and safely in their own home
Audiology	Hearing and related disorders
ASD	Autism Spectrum Disorder
BEMH	Behaviour Emotional and Mental Health
CAMHS	Children's and Adolescence Mental Health Services. The NHS services for school age children with mental health needs
CCG	Clinical Commissioning Groups. Clinically led NHS bodies responsible for planning and commissioning health care in local areas
CLD	Community Learning Disability Team: A Service for adults (18-65) with a diagnosis of intellectual disability. The team include psychiatrists, psychologists, nurses, physiotherapists and occupational therapists
Gastrostomy	An opening from the abdomen into the stomach for nutritional support via a feeding device
I D	Intellectual Disability. Generalised developmental delay with an IQ below 70
I Q	Intelligence Quotient. Measurement of intellectual ability
KOOTH	An online counselling and emotional well-being support service for children and young people
Learning Difficulty/Disability	Health services and education services use the terms Learning Difficulty and Learning Disability differently, as directed by their government departments. The Department for Education refers to all needs in this category as Learning Difficulties. Young people with a primary special educational need of Moderate Learning Difficulties (MLD), Severe Learning Difficulties (SLD) or Profound and Multiple Learning Difficulties (PMLD) should all be classified as having a Learning Disability by Health professionals.
Learning Difficulty	(Department of Health definition) - Specific Learning Difficulties (SpLDs) affect the way information is learned and processed. They are neurological (rather than psychological), usually hereditary and occur independently of intelligence. They include; Dyslexia, Dyspraxia or Development Co ordination Disorder, Dyscalculia, Attention Deficit Disorder
Learning Disability	(Department of Health definition) - Learning disability includes the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence); with a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development.
Let's Talk Wellbeing	Assessment and treatment for mild to moderate common mental health problems
Mental Health Services	Services supporting people with mental health needs

Named worker	Named worker is a role rather than a job title – this should be one of the people from among the group of workers providing care and support to the young person, who has been designated to take a coordinating role, for example, a nurse, a youth worker, an allied health professional or another health and social care practitioner. It could also be someone who already has the title keyworker, transition worker or personal adviser
Naso Gastric Tube	A plastic tube inserted into the nose past the throat and down into the stomach
National Health	Public Health Services in England, Scotland, Wales and Northern Ireland. Free at the point of delivery for people ordinarily resident in the United Kingdom
Occupational Therapy Service	Occupational Therapists are health and social care professionals who help people of all ages – babies, children, adults and older people – to carry out activities (or occupations) they need, want, or are expected to do, but are prevented from doing so as a result of physical or mental illness, disability, or as a result of changes in their lives as they get older. Occupational Therapists can suggest alternative ways of doing activities, providing advice on learning new approaches, helping people to get the most from life.
Person-centred	This means seeing the person using care and support as an individual and an equal partner who can make choices about their own care and support. These recommendations seek to ensure that all of a young person's needs are supported, including those related to their wider context (for example, education and employment, community inclusion, health and wellbeing including emotional health, and independent living and housing options)
Primary Care Services	Care delivered in the Community such as GP and Community nursing
Secondary Care	Care associated with services delivered in hospital settings
Single Point of Access	One contact point for making a referral for a service
Speech and Language	A field of expertise practiced by Speech and Language therapists. (Usually around communication, eating, drinking and swallowing)
Strengths-Based	Strengths-based practice involves the person who uses services and the practitioners who support them working together to achieve the person's intended outcomes, in a way that draws on the person's strengths. The quality of the relationship between those providing support and those being supported is particularly important, as are the skills and experience that the person using support brings to the process (Strengths-based approaches Social Care Institute for Excellence)
Therapy	
Transfer	The actual point at which the responsibility for providing care and support to a person moves from a children's to an adults' provider
Transition	The process of moving from children's to adults' services; it refers to the full process including initial planning, the actual transfer between services, and support throughout.
Urology	The area of medicine related to the Urinary System
Valuing People	A New Strategy for Learning Disability in the 21st Century (DOH, 2001)

Transition from Children's to Adults' Health Services

Supporting Young People who have Special Educational Needs and/or Disabilities from aged 13 years into Adulthood

Futures
Advice, skills & employment

RAINBOW
Parents Carers Forum

NHS
Nottingham City
Clinical Commissioning Group

Nottingham
City Council