Transition to Adulthood

Topic Information	
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Executive Summary

Definition and description of Transition (in this document)

Transition is a process and period of change; a transformation, conversion, adaptation, adjustment, alteration, changeover and metamorphosis.
The time between childhood and emerging adulthood and the process of planning and transferring from children's education, health and care services and support, and managing new relationships to ensure a smooth a transition to adult education, employment independent living, health and social care services and support including end of life provision.

Current transition support in Nottinghamshire was formally determined in Nottinghamshire's Multi-Agency Transition Protocol: Supporting Young People with SEN and Disabilities from Age 14 Year 9 into Adulthood (2010) and defines a targeted population. It is currently under review in order to widen the scope and improve equity of service provision. A position statement document is being produced which will establish current service provision, activity, gaps in service, and examples of good practice. This will encourage an integrated service approach to keep pace with the increasing need and the legislation requirements in the Children and Families Act 2014, Special Education Needs and Disability (SEND) [1]and The Care Act 2014. This work is currently being undertaken by NCC Transitions –Preparing for adulthood working group supported by the Children's Programme and Projects Team and will not be completed in time to include in this document.

This JSNA chapter presents seven recommendations for improved service experience in transition from children's to adult services with planning & support that is sensitive to the developmental needs & maturation psychology of emerging adulthood to ensure success.

[1] Special educational needs and disability code of practice: 0 to 25 years
Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities.(2013) Department of Education and Department of Health
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf

Data and information for this (whole) population in transition is not available nationally or locally so it is difficult to establish a clear picture of need in Nottinghamshire. This is reflected in the recommendations below.

See summary statement 'Nottinghamshire County Council Children's Integrated Commissioning Hub (ICH) on behalf of Nottinghamshire Clinical Commissioning Groups (CCG's) Project on a page: Transition to adult services in Education Health and Social Care at appendix 1.

Recommendation 1: Review of existing Transition Planning strategy and practice
Existing Transition Planning strategy and practice now needs to be reviewed and updated in line with the statutory requirements in the Children and Families Act and SEND reforms.

Recommendation 2: Develop quality robust joint and integrated commissioning arrangements
It is essential that health services observe the requirement for joint commissioning in delivering the NHS England mandate for disabled children and young people. Transitioning from Children to Adult Services may require an examination of funding and budget levels with a well-managed 'push' for changes from Children Services and a reciprocal 'pull' from Adult Services. The transition planning should include activity which meets individual needs and reach into Adult Services and out of Children services.

In commissioning integrated services it is important to consider the transition between paediatric and adult health services for young people with less complex needs (i.e. no co-morbidity, but with long term health conditions, for example asthma or diabetes).

Recommendation 3: Ensure the collection of robust transition activity data and information
There is no systematic approach to collating robust information around transitions and service level activity. Information is patchy and it is difficult to correlate the information or conduct any meaningful analysis in order to inform service development. Additionally, transitioning from Children to Adult Services needs better data sharing, which is essential for forward planning, quality assurance and efficient commissioning.

Recommendation 4: Patient and families experience
Patient and families experience is at the centre of strategic decision making and planning as well as at operational and personal level. Young People and their parent/carers will be involved in the commissioning process shaping services through customer service feedback, consultation and coproduction of service provision and participation at the highest level.

Recommendation 5: Systematic approach to ensuring transition plans are in place
Effective transition starts at 14 years old for up to 5 years if needed and means identifying and tracking (from data systems), young people through key transition points in their life. Appropriate and timely support can be provided for young people only where data systems identify young people who are in need of help. This includes how agreements about the ways agencies will work together to support disabled young people and their families are set out in integrated transition protocols.

Recommendation 6: Committed resources to manage this work
Strategic level agreement and planning is essential to success at operational level. There should be designated leadership, time and capacity to maintain a focus on transition to inform service change and improvement. An effective multiagency steering group or Board should be developed to implement protocols and pathways.

Recommendation 7: The role of health and wellbeing boards in measuring the outcomes from transition planning

Health and Wellbeing boards should measure outcomes for children and young people in transition from children's to adult services, especially those with disabilities, palliative care needs and long term health conditions and consult with those young people. Their priorities should be reflected in the Health and Wellbeing strategy.

Full JSNA Report

Introduction

Leaving school, going to college or work and living independently is a marker of transition to adulthood. This is a challenging time for many young people and their families and for young people with a disability, complex healthcare and social care needs and for their parents and carers, this can be an especially challenging time. The support they may have enjoyed through local parents' groups or local children's services will be moving away and adult service provision on an entirely different model will take its place.

Families with children with additional education, health, including health and wellbeing and social care needs can be found across all social groups. In families with children and young people who have long term conditions, SEND or life threatening and end of life care needs, the role of carer tends to fall to the mother. A proportion of mothers are single parents and either work part time or are not in employment. The management and care of some children very often means one or more parents are needed to look after them. This means low income and strong links to health inequalities. Additionally, children who experience poverty have increased rates of disability and ill health and 29% of disabled children live in poverty.[2] Young people with disabilities will require additional levels of support to enable them to have the same quality of life and chances as those young people without additional needs; therefore, good transition planning is essential.

As with all children preparing for adulthood, emotional, social and economic independence planning is essential. Young people with additional needs have more complex arrangements to manage, to reduce risk and increase outcomes in adulthood. At the point of transition to adulthood, legal and organisational arrangements change. New information needs to be accessed and new plans have to be made and this means taking into consideration the legal position and whether there is mental capacity or if power of attorney is required. The young person may require forms of communication other than speech in order to ensure their full participation in expressing their future aspirations and life choices.

A 'whole child' focus will ensure person-centred planning: timely assessment, a coordinated action plan and location of suitable placements (housing, education and training/employment) is vital to mitigate against this. The availability of appropriate provision is key to maximise education training and employment opportunities, to enjoy social relationships and to live independently.

Currently, as seen in The Care Quality Commission report 'From the pond to the sea: Children's transition to adult health services' (2014),[3] and in both national and local consultation, there is now an increasing awareness of poor transition experience for young people and their families.

> *'…..a health and social care system that is not working, that is letting down desperately ill youngsters at a critical time of their lives. We have put the interests*

[2] Nottinghamshire Joint Needs Assessment for children and young people with disability and SEND (2012)

[3] From the pond to the sea: Children's transition to adult health services. The Care Quality Commission (2014)https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report_Summary_lores.pdf

> *of a system that is no longer fit for purpose above the interests of the people it is supposed to serve*[4]
> Professor Steve Field, Chief Inspector of Primary Medical services and Integrated Care (2014)

NHS England has now prioritised transition planning for young people with a long term condition (LTC), Disability and Mental Health, and there are many young people who would benefit from a transition plan in health, social care and education and this will be addressed by the current EHC process and the current Transformation Project.[5]

Locally, current transition support in Nottinghamshire was formally determined in Nottinghamshire's Multi-Agency Transition Protocol: Supporting Young People with SEN and Disabilities from Age 14 Year 9 into Adulthood (2010) and defines a targeted population. It is currently under review by Nottinghamshire County Council's Transitions – Preparing for adulthood working group, supported by the Children's Programme and Projects Team in order to widen the scope and improve equity of service provision. This is described in detail in section 3.

Summary risks of no or poor transition planning

There is increasing evidence that well organised transition protocols and programmes have measurable benefits for young people and their parents. Equally, poorly planned transition is not just extremely distressing for young people and their families, who already have a lot to deal with; it can also lead young people not to adhere to their treatment, resulting in greater illness, adverse social and educational outcomes, additional health service costs and even earlier death.[6]The summary below details the risks of no or poor transition planning;

There are 5 primary concerns with young people with palliative care needs in transition[7];

1. Small numbers may lead to young people being overlooked and no plans are in place
2. Planning is often poor
3. Reduction in services as an adult
4. The challenge of increasing needs (in adult services) can become a crisis
5. Without true consultation, support is not sensitive to young people's wishes wants and desires. These can be very different to mature adults due to the stage of life they are in and assumptions should not be made.

Additionally, there is a cost of not providing good quality transition planning support and accessible services for young people with complex and additional needs.[8] [9] This can be an opportunity cost of not completing education and training which impacts on economic activity and independence or on the resources costs to the public purse as well as a reduced quality of life, health and well-being and relationships or even long term mental health problems.

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[4] From the Pond to the Sea: Children's Transition to adult health services (2014) The Care Quality Commission https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf

[5] Nottinghamshire County Council Transformation Project: Integration of The Children's Disability Service (CDS), Special Education Needs and Disability (SEND) and Health Disability Services: Transition Work stream (2015)

[6] Transition: Getting it Right for Young People – Improving the transition of young people with long-term conditions from children's to adult health services, Department of Health and Department for Education and Skills (2006) http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4132149.pdf

[7] Don't let me down: Ensuring a good transition for young people with palliative care needs Together for short lives and Marie Curie Cancer Care 2012 https://www2.mariecurie.org.uk/documents/press-and-media/news-comment/dont-let-me-down.pdf

[8] Fair Society, Healthy Lives The Marmot Review Strategic Review of Health Inequalities(2010) http://www.instituteofhealthequity.org/Content/FileManager/pdf/fairsocietyhealthylives.pdf

[9] Whose Crisis 2003, SEU 2004, Layard 2005 Mental Health transitions for young people: challenges and solutions Dr Yvonne Anderson (2013) http://www.slideshare.net/NHSIQ/mental-health-transitions-for-young-people-dr-yvonne-anderson
Pushed into the Shadows: Young People's experience of adult mental health facilities. Office of the Childrens Commissioner (2007)https://www.childrenscommissioner.gov.uk/sites/default/files/publications/Pushed_into_the_shadows.pdf

The consequences of a young person with no transition plan or a poor plan that doesn't meet need or changing needs are:

- The "cliff-edge" [10] and the lack of understanding of (reduced) service provision for adults.
- Deterioration of physical health
- Poor emotional health and wellbeing
- Crisis presentation and escalation of problems in education health and social circumstances
- School/college/work breaks down
- Relationships and family breakdown
- Homelessness
- Health (and social) inequalities
- Adverse economic impact on the individual rendering them dependent on informal carers or the State, which has social and economic policy implications in the economic cost of adult care
- Risk of increased morbidity/mortality

Emerging adulthood and the key characteristics[11]

The term 'emerging adulthood' is preferred over 'young adult' as it is a process rather than a fixed state. The period of emerging adulthood lasts from 18 to 25 years; it is a gradual process and the markers of adulthood are reached later. The routes to adulthood are diverse in timing and sequence with a period of prolonged maturation.
The milestone tasks include:

- Leaving home
- Completing education
- Attaining economic independence
- Independent living
- Establishing a key long term relationship.

There is also a degree or psychosocial development and maturation leading to self-sufficiency.

Delivering safe & robust transition for young people
Why do young adults need a different approach?

- Three great transitions: school to work, home to independent living, parented to becoming independent/a parent
- The brain is still changing - up to 25 years to full development
- The prevalence of mental Health in adolescents is deteriorating - and incidence rises from 1:10 in children to 1:6 in adults
- Learning Disability & SEN - uncertain transition services

Patterns of service use and access develop early in life, so how young people experience services when they first use them will affect engagement as adults

[10] From the pond into the sea: children's transition into adult services Care Quality Commission (2014) https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report_Summary_lores.pdf

[11] The STEPP Project: Supporting health transitions for young people with life-limiting conditions: researching positive practice. Professor Bryony Beresford York University (2012) http://www.york.ac.uk/inst/spru/news/appgBP.pdf)

What do we know?

1) Facts and figures

1.1 National

Life limiting, life threatening and end of life care

Finding the appropriate terminology to describe the young people we are talking about is complicated and there is no right answer. Young people are usually said to have a "life-limiting condition" where there is no reasonable hope of a cure or a "life-threatening condition" where the possibility of a cure exists. While such descriptions can be useful, they are essentially medical, whereas young people's needs extend beyond healthcare to social care, leisure, education and employment. So the term "young people with palliative care needs" is used and while this also has medical connotations, it focuses on needs rather than conditions and it comes closer to recognising needs which are social as well as health related.

There are more than 40,000 CYP aged 0-19 in England who have long term health conditions which, for most, will eventually end their lives and for which they may require palliative care. This represents a 30 percent increase between 2000/01 and 2009/10. The highest rate of increase was among those aged 16-19. Nottinghamshire is a County of average needs consistently reflecting the national picture and therefore this national trend is reasonably representative of the population of young people in Nottinghamshire[12].

The prediction is for significant growth in needs of this population group in the future as children born with significant health needs are surviving and thriving and living longer and well into adulthood in ways we could not have anticipated even 10 years ago. Significant advances and improvement in treatment and care, such as surgical interventions, medical treatment and pharmacology, multidisciplinary therapeutic interventions, technical support and the provision of assistive technology all mean that the comfort, quality and length of life is increased.[13]

Concerns in understanding and navigating health care services

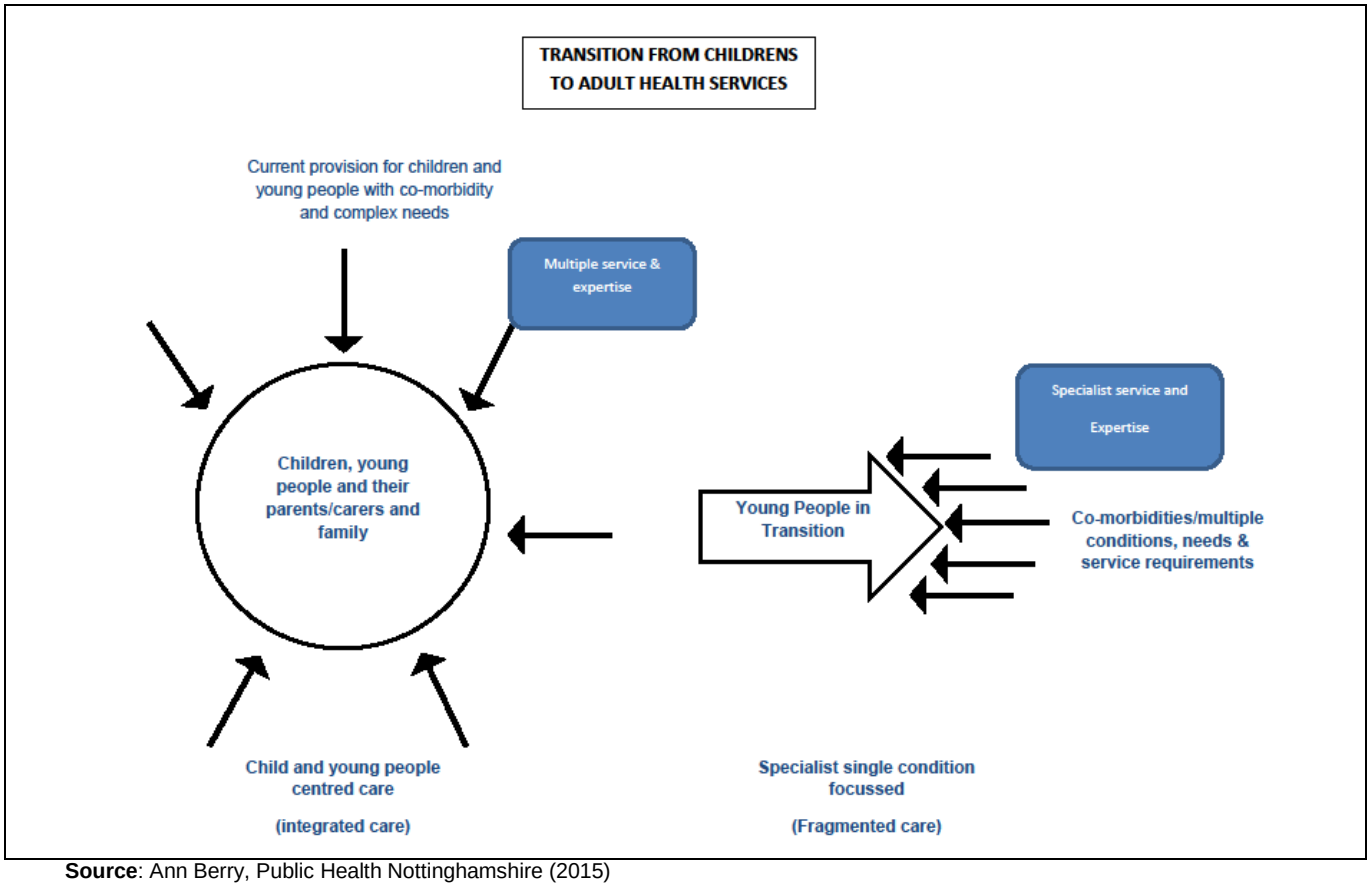
The local NHS provision is complex. It has a commissioning and provider function and organisations. It provides many services to the population including public health and protection (Public Health Nottinghamshire and Public Health England), primary, secondary and tertiary care services and in the third sector.

The services are structured and managed differently for children and adults; paediatrics services are more centralised and are holistic in their approach. Adult services specialise in functions of the body and are therefore less holistic. For young people with co-morbidity (many diagnoses) complex care needs this can be very challenging especially in transition. The young person healthcare coordination and management becomes more complicated and cumbersome just at a time when they are challenged by so many other changes in their lives on the way to adulthood and independent living. Support and follow up is crucial at this time to ensure safety good health and healthy habits to adopt throughout adult life.

See diagram below.

[12] Don't Let me down: Ensuring a good transition for young people with palliative care needs Together for short lives and Marie Curie Cancer Care (2012) https://www2.mariecurie.org.uk/documents/press-and-media/news-comment/dont-let-me-down.pdf

[13] Don't Let me down: Ensuring a good transition for young people with palliative care needs Together for short lives and Marie Curie Cancer Care (2012) https://www2.mariecurie.org.uk/documents/press-and-media/news-comment/dont-let-me-down.pdf



Source: Ann Berry, Public Health Nottinghamshire (2015)

1.2 Local priority groups

In 2010, a Nottinghamshire's Multi-Agency Transition Protocol: Supporting Young People with SEN and Disabilities from Age 14 (Year 9) into Adulthood was developed and implemented (see section 3 for a detailed description of the protocol). A summary of the activity data and analysis has been provided by Nottinghamshire County Council and can be found in table below, with further detail in section 5.

Figure 1: Summary of service level data

Source: various (see text)

Group	Period	Total number
Are currently on the roll of the Nottinghamshire Learning Centre (of admissions from 2010)	2013 (snapshot)	67
Have a statement of SEN	Jan 2013 (snapshot)	1,496
… and in Year 9		*165*
Number on roll (Year 9 and above) in Nottinghamshire special schools	Jan 2013 (snapshot)	470
Are in receipt of the local authority's High Level Needs (HLN) funding allocation	2010/11 to 2013/14 (4 years)	117
… and have Cognition and Learning Needs		*15*
Are a looked after child (LAC) with a transition plan	1998 to 2013 (15 years)	46
Attend an independent non-local authority education/care setting	2010/11 to 2013/14 (4 years)	70

Note: groups not all mutually exclusive (i.e. Grand total may include double-counting)

The number of statements of special education need (SEN) in Nottinghamshire is comparatively low arising from the local offer satisfying needs without recourse to a statement of SEN (since September 2014 referred to as an Education Health and Care Plan (EHCP). As previously stated, the target groups for transition in Nottinghamshire was defined in the Transitions Protocol and represent children with the greatest and most complex needs or who are vulnerable. These groups of young people were chosen in 2010 as they represent those with the most complex health, social care and education needs and this reflects the national picture.

The availability of consistent quality data and information is poor, with no data or information from NHS providers and clinical commissioning groups (CCGs), making comparisons with other areas impossible. This reflects the national picture and Recommendation 9 from the Joint Nottingham City and Nottinghamshire County Integrated Community Children and Young People Healthcare Programme Report (2013) is to;

'Develop meaningful quality and outcomes measures as key performance indicators, which can be reported without creating burdensome and unnecessary bureaucracy for providers or commissioners. This should include standard, comparable measures relevant to all services to facilitate ease of reporting and consistency and to enable benchmarking as well as key outcome measures appropriate to individual services.'[14]

The local priority of transition of looked after children (LAC) who have poor outcomes; 60 - 80% of LAC have some level of emotional and/or mental health problem and
Health literacy and self-management in adulthood was determined from consultation with the Nottinghamshire Safeguarding Strategy Group and from the recommendations from the Office of Standards in education (OFSTED) Report 2015.

There is currently no data available to estimate the level of need of young people for a person-centred transition plan within the local population. In addition, there is limited service activity data as there has been no requirement to date to record and report it. The information presented in this section is somewhat limited but does give an indication of transition activity in the County. It is therefore likely that there is unmet need for those who are not included in the numbers in the data presented below. There are many reasons for this. There is no national population data for children in transition who need a transition plan and support from public services. It is not routinely or systematically collected or collated and therefore it is difficult to determine net need e.g. 1 in 10 or 1 in 500. This reflects the national position too and so it is not possible to determine need or unmet need.

'Data compiled….goes some way towards quantifying the range and incidence of severity (complexity) of needs. There are however significant problems of reliability with all data currently collected…recommendations will support the work that will address the issues of data collection and recording so essential to planning. *Doran Report 2012*

There is a range of young people and conditions that will need or want transition planning and support that have not been identified and so is unknown. There are diverse groups of children with diverse conditions and circumstances which are highly individual and can be complex, which may need or want a transition plan and support as follows;

Health

- Medical conditions, co-morbidities and complex medical continuing care
- Long term conditions
- End of life care

[14] 'This Report is different….'Joint Nottingham City and Nottinghamshire County Integrated Community Children and Young People Healthcare (ICCYPHP) Programme Report (2013) Recommendation 9
http://www.mansfieldandashfieldccg.nhs.uk/index.php/latest-news/136-iccyph-report

- Mental Health and wellbeing
- Learning Difficulties (LD)

Social

- Complex social circumstances and looked after children (LAC) where the state is the statutory parent and have interrupted health and education

Education

- Are on the roll of a special school
- Have a statement of special educational needs (SEN) or Education Health and Care plan
- Are in receipt of the local authority's High Level Needs (HLN) funding allocation

Children born with significant health needs are surviving and thriving and living longer and well into adulthood in ways we could not have anticipated even 10 years ago. Significant advances and improvement in treatment and care, i.e., surgical interventions, medical treatments and pharmacology, multidisciplinary therapeutic interventions, technical support and the provision of assistive technology all mean that the comfort, the quality and length of life is increased.

2) Targets and performance

There are currently no agreed targets.

3) National and Local Drivers

There is increasing evidence that well organised transition protocols and programmes have measurable benefits for young people and their parents. Equally, poorly planned transition is not just extremely distressing for young people and their families. It can also lead young people not to adhere to their treatment, resulting in greater illness, adverse social and educational outcomes, additional health service costs and even earlier death.[15]

In addition, poor long term condition management and transition to adult services are sited in the Francis Report[16] (care and compassion), Berwick Report[17] (safety), Keogh Report[18] (failing hospitals and the Winterbourne View i.e. Long Term conditions, Disability and Mental Health and Wellbeing and this reflects the national priorities.

The children and Young People's Health Outcome Forum see transition to adult services as a priority and a cross cutting theme.[19]

3.1 Legislation

The main legislation supporting Transition is as follows;

- The Children and Families Act 2014
- The Care Act 2014

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[15] Transition: Getting it Right for Young People – Improving the transition of young people with long-term conditions from children's to adult health services, Department of Health and Department for Education and Skills (2006) http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4132149.pdf

[16] The Francis Report: Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry (Executive Summary) The Mid Staffordshire NHS Foundation Trust Public Inquiry Chaired by Robert Francis QC (2013) http://webarchive.nationalarchives.gov.uk/20150407084003/http://www.midstaffspublicinquiry.com/sites/default/files/report/Executive%20summary.pdf

[17] The Berwick Report: A promise to learn – a commitment to act Improving the Safety of Patients in England National Advisory Group on the Safety of Patients in England (2013) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/226703/Berwick_Report.pdf

[18] The Keogh Report: Review into the quality of care and treatment provided by 14 hospital trusts in England: overview report Professor Sir Bruce Keogh KBE (2014) http://www.nhs.uk/nhsengland/bruce-keogh-review/documents/outcomes/keogh-review-final-report.pdf

[19] LGA briefing on the report of the children and young people's health outcomes forum (2015) See more at: http://www.local.gov.uk/childrens-health/-/journal_content/56/10180/3684797/ARTICLE#sthash.XelUAuoY.dpuf http://www.local.gov.uk/childrens-health/-/journal_content/56/10180/3684797/ARTICLE

- The Equality Act 2010

SEN reforms under the Children and Families Act 2014

Transition was a high priority following SEN reforms under the Children and Families Act 2014. These reforms were introduced in September 2014, and prior to this date, the County Council is a Special Educational Needs and Disability (SEND) Pathfinder for their development. This includes transitions planning. The government is undertaking a range of reforms that have the potential to improve young people's transition experiences.[20] These include:

- Significant changes to social care legislation
- The Care and Support White Paper
- The extension of personal budgets to healthcare
- Proposals to the changes in the SEND system
- The Health and Social Care Act's and the Children and Families Act 2014 has an emphasis on joint commissioning of services

The Children and Families Act 2014

- The new Act and code of practice for SEND provides statutory guidance for organisations who work with and support children and young people with SEND. This new legislation placed a duty on statutory organisations to work together to align Health, Education and Social Care arrangements from September 2014.This legislation now incorporates 0-25 year olds. It suggested that local authorities should ensure early transition planning is in place for all children and young people with an EHC plan. Planning must be person centred and should be from Year 9 onwards. Review meetings which are statutory under this new guidance must consider what provision is required to assist in preparing the young person for adulthood and independent living and where possible employment. The EHC plans should be forward looking for important transition points in a child and young person's life. Information in the EHC plan will include the arrangements for monitoring progress, including transition review arrangements.
- The new local offer for disabled young people states what will be provided by adult services and all information about young people with disabilities including those with long term conditions should travel with them across organisational boundaries. This is in the form of a care plan covering clinical, social and educational needs which supports the process of transition.

The Care Act 2014[21]

- Part 1 of The Care Act pulls together threads from over a dozen different Acts into a single, modern framework for care and support. It reforms how the law works, prioritising individual wellbeing for Adults with care and support needs over the age of 18, with a particular focus on person-centred practice and outcomes, putting people in control of their care and support.
- The Act says that if a child, young carer or an Adult caring for a child (a "child's carer") is likely to have needs when they, or the child they care for, turns 18, the local authority must assess them if it considers there is "significant benefit" to the individual in doing so. This is regardless of whether the child or individual currently receives any services.

[20] National Development Team for Inclusion (NDTi) and the Council for Disabled Children 'Better Life Outcomes: Delivering support and aspiration for disabled young people (2014) http://www.preparingforadulthood.org.uk/media/300444/pfa_delivering_sept_2013.pdf

[21] The Care Act (2014) http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

- It also gives local authorities a legal responsibility to cooperate and to ensure that all the correct people work together to get the transition right. It makes clear that the local authority can combine any "transition" assessments with any other assessment being carried out for some other person (provided all parties agree).

- The provisions in the Act relating to transition to adult care and support are not only for those who are already receiving children's services, but for anyone who is likely to have a need for adult care and support after turning 18. Equally for those without EHC plans, early conversations with local authorities on preparation for adulthood are beneficial – when these conversations begin to take place will depend on individual circumstances.

3.2 The Doran Review 2012: The Right Help at the right time in the right place
In a recent review of the transitions process, the Doran Review [22](2012) states;

"Effective management of transitions from one stage of education to another and on to life after school is a key component to effectively meeting the needs of all children and young people. It is crucial when considering any changes for those children and young people with ***complex additional support needs****. The review regularly heard concerns about all transitions including; into school, from primary to secondary, from one kind of school to another and particularly from school to adult services. Adequate time for planning and preparation, full involvement of the child and family and coordination of professionals were identified as contributing to successful transitions. When any of these are not properly addressed problems arise. By far the greatest concern for parents was about the move to adult services and the fear of the young person falling into a "black hole" where there was no direct accountability for continuing services."*

There are nine key concerns in current transitions practice both nationally and locally. The seven principles of good practice detailed below enable their resolution and meet the recommendations in section 11. They ensure we get it right for every child by upholding the rights enshrined within the United Nations Convention on the Rights of the Child (UNCRC) as children and young people experience transition.

The following table summarises this;

9 Key Concerns	7 Principles of good practice
Person centred approaches are often lacking or in consistency	All plans and assessments should be made in a person-centred way
Lack of the voice of the young person in transition planning	Support should be co-ordinated across all services
Planning starts too late	Planning should start early and continue up to age 25
There is a lack of support for future transitions	Young people should get the support they need
Lack of information for young people and their carers	Young people, parents and carers must have access to the information they need
Confusing legislative and policy framework	Families and carers need support
Support is not coordinated between services	Legislation and policy should be co-ordinated and simplified
Too many people are not regarded as eligible for support	
Confusing language	

[22] Information and learning from the aiming high for disabled children, transition support programme. Council for disabled children (2011)The Right Help at the right time in the right place: Strategic Review of Learning Provision for Children and Young People with Complex Additional Support Needshttp://www.scotland.gov.uk/Publications/2012/11/7084/downloads#res408307

3.3 Strategic Direction in Health Services

NHS England National Transitions Forum (NTF)
The vision of the NHS England National Transitions Forum (NTF) is for all children and young people moving into adulthood have a consistent and excellent experience of healthcare. They aim to share learning from existing good practice, successes, challenges and barriers to implementing clinically and patient designed Transition models working collaboratively to deliver both national agenda and local priorities by working together.

Regional/Local Role: Strategic Clinical Networks (SCNs)
The work of the East Midlands Strategic Clinical Network (EMSCN) in consultation with stakeholders in health is reflected in the document 'Moving on to adult services-transition process for young people: Guidance for clinical colleagues in adult and primary care services'. This guidance has been adopted locally in the Nottinghamshire Children's Integrated commissioning Hub (ICH) and included in all community children's services specifications for which it has commissioning responsibilities. It can be found in appendix 2.

Monitoring and evaluation of Transition Service Practice
The EMSCN also promotes national best practice and advocates the use of the Transition Dashboard -performance tracker.[23]

The STEPP Project Research Report[24]
Supporting health Transitions for young people with life-limiting conditions: researching Evidence of Positive Practice. This research aimed to understand the experiences, priorities and concerns of young adults and their families and identify positive practice which supports the transitions of young people with life-limiting conditions from children's to adult health care.

What does this mean to practitioners and services?
Emerging adults are a minority population within adult services. There is a need to support and manage parental involvement and determining when it is needed and wanted or not needed and unwanted and by whom, the young person, their parent/carer or their clinician.

There are relatively undeveloped and underdeveloped skills for both staff and for emerging adults which impacts on management, decision making, autonomy and self-management.

Emerging adults have multiple areas of attainment – this is a challenging stage in life. The impact of their health and wellbeing (underlying health conditions) will impact on their emerging adulthood and maturation, their readiness and ability to engage in the process, their expectations and life experiences and their different trajectory to other 'emerging adults' can create additional barriers.

Advance care planning and continuum of planning to guard against gaps during the process of transfer from children's to adult healthcare services. This is not the normal pattern of lifespan and different practice is required. A continuum of planning is required:

- Planning for health fluctuations
- Self-care prompts

[23] Improving Patient Experience for Children and Young People: A Report prepared by The Patient Experience Network for NHS England (2015) http://patientexperiencenetwork.org/wp-content/uploads/2013/11/PEN-Improving-PE-for-Children-Young-People-Report-FINAL-Electronic-file.pdf

[24] The STEPP Project: Supporting health transitions for young people with life-limiting conditions: researching positive practice. Professor Bryony Beresford York University (2012) http://www.york.ac.uk/inst/spru/news/appgBP.pdf)

- Planning for medical crises
- Emergency care plans
- Planning for deterioration
- Advance care planning
- Planning for end of life
- Clarity about the role of parents and families in planning

Examples of good practice for integrated transition services
There are many examples of good practice and processes for an integrated approach. For example Southampton Children's Hospital have developed the 'Ready steady Go' programme[25].

'NHS England's Commitment to Carers, The NHS Constitution belongs to us all' (2014)
The document 'NHS England's Commitment to Carers, The NHS Constitution belongs to us all' (2014) is a recent and welcome guidance for the development of the Transitions planning. Carers, charities and partner organisations have worked with NHS England to draw up eight priorities – and 37 commitments – that will help the NHS to deliver the care and support carers have said they need especially during the key transition period. See link below.[26]

3.4 Strategic Direction in Local Government
Local strategies

The Nottinghamshire Multi-Agency Transition Protocol: Supporting Young People with SEN and Disabilities from Age 14 (Year 9) into Adulthood 2010 was implemented in 2010/11.

The six target groups for transition in Nottinghamshire as defined by The Nottinghamshire Multi-agency Transitions Protocol (2010) include children and young people who:

1. Are on the roll of the Nottinghamshire Learning Centre
2. Have a statement of special educational needs (SEN)
3. Are on the roll of a special school
4. Are in receipt of the local authority's High Level Needs (HLN) funding allocation
5. Are a looked after child
6. Attend an independent non-local authority education/care setting is at risk

The groups above were identified as having children and young people with the highest level of physical disabilities, learning difficulties, learning disabilities, mental ill-health and long term conditions which are life limiting and life threatening including palliative care which require transition planning for the complex health education and social care arrangements needed. At that time the work around Transition was led by the SEND work steam and although it went some way to integrating education health and education it was predominately education/SEND focussed.

The groups identified as entitled to a person-centred transition plan were chosen in 2009 during the development of the Nottinghamshire's Multi-Agency Transition Protocol: Supporting Young People with SEN and Disabilities from Aged 14 (year 9) Into Adulthood was based around a vision;

'In Nottinghamshire, we are ambitious for our children and young people. We have a clear vision which states that we will work together to provide integrated services for all children and young people in Nottinghamshire to improve their life chances and help them maximise their potential. Our planning around transitions has captured this vision and seeks to ensure

[25] http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx
[26] NHS England's Commitment to Carers, The NHS Constitution belongs to us all' (2014) http://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf

that children and young people and their families are supported in an integrated way through the transition into adult life'.

Nottinghamshire's Multi-Agency Transition Protocol: Supporting Young People with SEN and Disabilities from Aged 14 (year 9) Into Adulthood (2010)

The planning around transitions has taken into account the low level of Special Educational Needs statements in Nottinghamshire and the protocol sets out a commitment to ensure the most vulnerable children and young people in Nottinghamshire benefit from an effective transition plan. The groups are not mutually exclusive and reflect a national picture.

The needs of young people with long term, life limiting and end of life conditions are unlikely to change and may, due to the nature of the disease or disability, worsen over time. Good transition management will ensure safety, comfort and quality of life. There are likely to be other young people with less complex needs who may benefit from a transition plan but are not getting one. It is difficult to establish a firm description and quantify these groups as current data and information collected doesn't allow this. The work of the Transitions work stream group is undertaking a desk review of services and producing a 'Position Statement' to submit to the Improving Outcomes for Children with Disabilities Steering Group. .

The standard person centred transition plan ensures the management of these complicated arrangements from children's to adult services. The process should begin when children are in Year 9 at school -13 years of age and over. An initial plan is developed in Year 9 and reviewed annually in Years 10, 11 and 12. The ages that young people transition to health and social care services vary according to their circumstances and needs – for example, a young person may not leave education until the age of 19 and therefore is still entitled to children's services and yet at 18 years of age they are able to be transferred to an adult care team.

The plan includes post 16 education options including transport, apprenticeships, employment, supported employment and day centre care. It will also include adult health and social care services provision and will involve assessments for care, personal budget, direct payments and short breaks. Under the Section 5 of the Disabled Persons Act (services, consultation and representation) 1986, the local authority must seek information from adult care social services during the transition planning process as to whether a young person is likely to require adult social services assistance. Health bodies should also ensure that their adult NHS Continuing Health Care unit is appropriately represented at all transition planning meetings relating to disabled young people, whose needs suggest that there may be potential eligibility for adult NHS continuing health care funding. Living away from the family home, housing and independent living options will also be included in this plan.[27]

The protocol is currently under review in order to widen the scope and improve equity of service provision. A position statement document is being produced which will establish current service provision, activity, gaps in service, and examples of good practice. This will enable an integrated service approach to keep pace and increasing need and the with legislation requirements in the Children and Families Act 2014, Special Education Needs and Disability (SEND)[28]and The Care Act (2014). This work is currently being undertaken by NCC Transitions – Preparing for adulthood working group, supported by the Children's

[27] Nottinghamshire's Multi-Agency Transition Protocol: Supporting Young People with SEN and Disabilities from Age 14 (Year 9) into Adulthood (2010)

[28] Special educational needs and disability code of practice: 0 to 25 years
Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities.(2013) Department of Education and Department of Health
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf

Programme and Projects Team and will not be completed in time to include in this document.

In September 2014, Statements of SEN were replaced by Education Health and Care (EHC) Plans. These will cover young people up to age 25 and extend the rights and protections to young people in further education and training.

As previously stated, Nottinghamshire was one of a number of pathfinder authorities in England who are introducing their EHC plan pathway and new arrangements a year early to provide feedback to the government. This helped inform the new legislation to be introduced in 2014. The pathway was developed with children, young people and families. The new Local Offer outlines what can be provided and what is available for children and young people who are transitioning to adult services.

4) Local Views

National and local consultations show that transition from children's to adult's services for young people with ongoing complex needs and disabilities is frequently raised as a concern by young people, parents and professionals. These include anxieties about:

- A change in the young person's personal carers
- Reduced packages of care
- Reduced access to services e.g. therapies
- Loss of established communication links with key professionals

4.1 Local consultation on experiences of transition

Much of what we know about young people and families' experiences of transition locally is anecdotal. Generally, parents of children with more complex needs feel they get a better service than those whose children have less complex needs, where anticipated services do not materialise or at least not in the form they were expecting. However, in 2014 a small scale consultation facilitated through The Nottinghamshire Parent Hub (NPH) and Third sector provider A Place to Call Our Own (APTCOO) with a Survey Monkey questionnaire and small group discussions with parents and young people. The comments made are insightful;

Comment on transitions planning in education settings

'The support from school for my daughter's transition (from school) to college has been very poor, with delay after delay and inaccurate information and a general lack of interest in my daughter's future. Time was running out so in the end we organised our own transition plan, calling on the support of relatives and a local voluntary sector organisation. It has been a frustrating and upsetting experience for all the family.' *Parent, Nottinghamshire 2014*

Comments on transitions planning in healthcare settings

'Training needs to be identified for both staff and carers; training to parents and carers to provide this as appropriate and if wanted, as not all parents want this additional role. Some parents reluctantly accept responsibility for managing the timing and taking of blood, administrating analgesics for pain, dealing with an infected central line, maintaining GI feeding tube and use of hoists, as adult services are not currently set up to provide these services. The needs for these services have grown with the children and, although children's services have responded, adult services haven't.' Parent, Nottinghamshire 2014

Transition is often a handover and not a transition at all, this means the role of parents as experts of their child's history and experience is paramount. There needs to be joint appointments with both Paediatricians and Adult Specialist Consultants to discuss conditions and specific health problems and issues, and Adult Specialist Consultants to have an 'open door' to the paediatrician who has intimate knowledge of the patient and their family setting for continuity. Transition is an opportunity for reciprocal learning from all disciplines.'

'Effective transition needs clinical champions and parent and young people champions to support others with their transition.' Parent, Nottinghamshire 2014

Comment on transition planning in palliative care services

'I didn't want my son to transfer to adult palliative care services as I thought it would be too unsettling at the time. It would mean all new buildings and service changes etc., and staff who didn't know my son. As a family we were settled with the plans we had. We had to produce a whole new plan that worked for us as a family in the adult palliative provision. We felt adult services did not see the urgency to get them in place as soon as possible for our peace of mind. Rapid transition planning was needed due to our son's imminent death'
Parent, Nottinghamshire 2014

"I don't want my personal carers [for my privacy and dignity] to change when I move to adult services" *Young person, Nottinghamshire (2012)*

4.2 Patient and parent/carer experience

Consultation with young people and their parents and carers was undertaken in 2012/13 to review and establish their experience of children's community healthcare services[29] including their experience of transition. In addition to the comments in this document a 'Statement of Expectation' was co-produced which is included in service specifications for providers to measure satisfaction. This can be found in appendix 3.

What have parents told us?

- They can be shut out, but left to cope without information
- Concerns that adult service won't listen when the young person is becoming ill
- Their rights as carers not explained nor considered
- What YP want is to be listened to and understood and to be taken seriously
- A well planned service where the transition and discharge arrangements happen smoothly it shouldn't be left to us or our families to manage it
- Flexible services focused on developmental age rather than chronological age and on our individual needs
- Choice, information and advice to help us make informed choices about our care and to help us move on
- Honesty about what can and can't be kept confidential
- Continuity of care – it take time to build relationships

4.3 Nottinghamshire Patient and Public Involvement: Transitions Priorities

During 2015, a parent representative (on transitions) has been working with the Health Transitions Lead and is now part of the NCC Transformation Project Transitions working group. The following priorities have been identified;

- **Mapping of services** – to highlight incompatibility in children's to adult services, the gaps in service, and give opportunity and the rationale to redesign integrated services
- **Complex needs and complicated arrangements** for services. For example, children's and adult social care services are entirely separate; patients with co-morbidities may have to coordinate care across different specialist teams and locations.
- **Complex caring needs of children** who are surviving and thriving with advances in medicine and technology; often this role is taken by the parents.
- **Legal position -** Legal status of child to adult happens overnight which can exclude parents to act in the best interests of their adult child if legal status of power of at tourney is not established.
- **Preparation for adulthood –** psychology of emerging adulthood needs to be included in care planning and service delivery.

[29] 'This Report is different….' Joint Integrated Community Children and young people's Healthcare Programme (2013)

5) Current Activity and Service provision

The person-centred transitions plan prepares a young person for adulthood and independent living. It has two functions;

- To support a young person to think about becoming and adult and what their life will be like. It is an opportunity to explore and discuss their needs, wants, aspirations and choices might be in relation to their education, employment, health and social care including end of life care.
- To enable plans and preparations for transition arrangements from children's to adult services.

It commences at age 13 years and in year 9 at school and is completed in stages throughout transition to adulthood from 16 years to 25 years dependant on the young person and their needs services used and legal status.

Parents and carers, the key worker and practitioners like Teachers Special educational needs coordinators (SENCO,) Paediatricians, Specialist Physicians Nurses, Therapists Social Workers and assistants work together to enable a seamless transition to adulthood and adult service provision contributing to the one assessment and plan as needed

5.1 Local Priorities in Social Care

There is a designated transitions team within Nottinghamshire County Council Adult Services. They work with some young people with disabilities from the age of 14 years who are eligible for support.If a young person feels they will need care and support when they turn 18, the Transition Team in Adult social care can assess their needs and, where appropriate, offer support to help them through their transition from children's services or set up a new package of support to support outcomes related to their wellbeing in adulthood. These outcomes will relate to their independence, employment and social needs.

Usually, the school or the children's social care services will recognize a young person's need for an assessment and make a referral to the Transitions Team. Alternatively, a young person can self-refer. The team will advise on appropriate timing for an assessment which will decide if the young person is eligible for care and support. It maybe some of their outcomes can be met without the need for a paid service. It will also detail the transition to adult services plan and will include outcomes, views and wishes that matter.

At Nottinghamshire County Council, the Education Department are committed to supporting successful preparation for adulthood and are guided by the Special Educational Needs and Disability Code of Practice[30]. For some children this is through the Education Health and Care Planning process that outcomes for adulthood are focussed on. High aspirations are crucial to success – discussions about longer term goals should start early and ideally well before Year 9 (age 13-14) at school. They should focus on the child or young person's strengths and capabilities and the outcomes they want to achieve[31].

The service activity data below gives some insight into the transition support currently provided, however as previously stated, data from services is inconsistent and insufficiently detailed to be used to assess met needs or outcomes.

[30] https://www.gov.uk/government/publications/send-code-of-practice-0-to-25

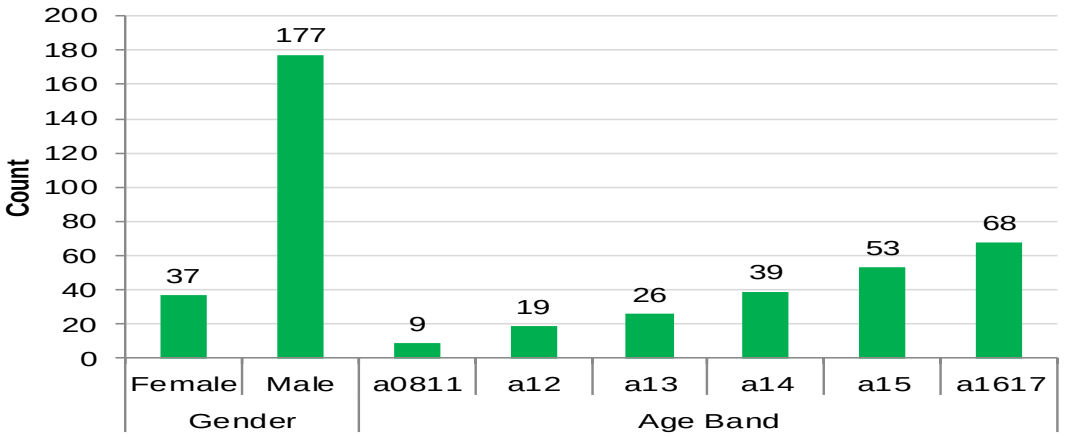
[31] Special educational needs and disability code of practice: 0-25 years, January 2015. Department for Education and Department for Health. https://www.gov.uk/government/publications/send-code-of-practice-0-to-25

Figure 1: Number of young people with transition plans by academic year and school placement type
Source: Nottinghamshire County Council 2014

Academic year	Independent /Non-Maintained Special schools	Special Independent Resource Panel Placements	Grand Total
2010/11	10	4	**14**
2011/12	3	11	**14**
2012/13	10	5	**15**
2013/14	20	7	**27**
Grand Total	**43**	**27**	**70**

* Note: Counts less than 5 have been suppressed (primary suppression). Additionally counts have also been suppressed where it would be possible to calculate the primary suppressed values (secondary suppression).

Figure 2: 2010-2013 Young people age and gender breakdown
Source: Nottinghamshire County Council 2014



* Note: Counts less than 5 have been suppressed (primary suppression). Additionally counts have also been suppressed where it would be possible to calculate the primary suppressed values (secondary suppression).

5.1.2. Have an Education Health and Care Plan

An Education Health and care plans (EHCP) is given to children and young people who need additional arrangements to access and support their learning. This can be identified soon after birth when there are complex health needs or following early developmental checks with parents and health professionals or by teachers in schools. EHCP was formerly known as a Statement of Special Educational Need (SEN)

Figure 3 shows a snapshot of activity from January 2013 and indicates there were 165 Year 9 pupils (out of a total of 1,496) with an EHCP by need and gender. They are predominantly males with the highest rates in the 14-16 years age group. It highlights gender prevalence with a 6:1 ratio of males to female diagnosed with a learning difficulty. This is more marked with Autistic Spectrum Disorder (ASD) of 32.3%. Figure 3 also shows a broad range of need which impacts on a child or young person's ability to learn in the school setting and gives rise to the need for a person centred transitions plan.

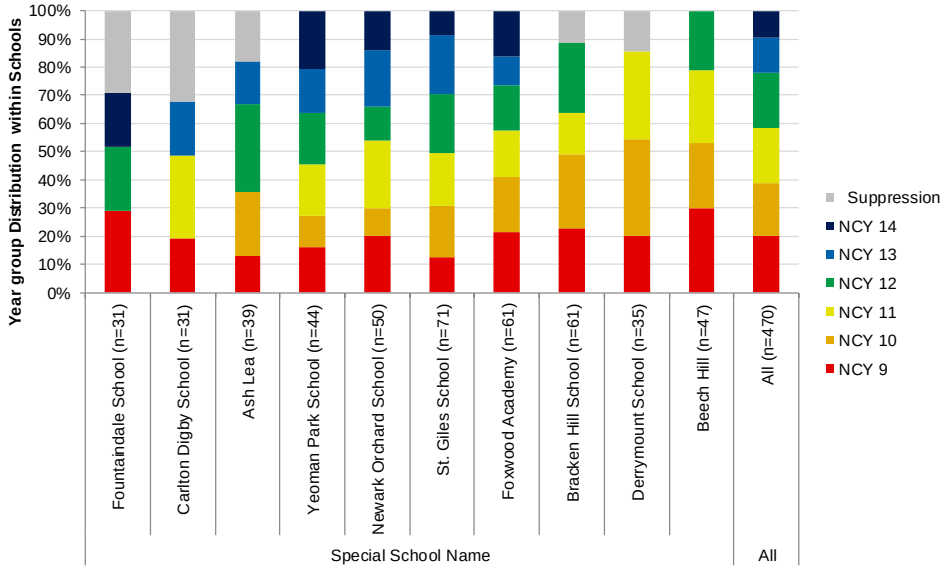
Figure 3: Young People with an Education, Health and Care Plan
Source: Nottinghamshire County Council 2014

Primary Need			Gender		
Area	**Code**	**Category**	**Male**	**Female**	**Total**
Cognition and Learning Needs (Learning Disability)	**MLD**	Moderate Learning Difficulty	110	46	**156**
	PMLD	Profound & Multiple Learning Difficulty	6	5	**11**
	SLD	Severe Learning Difficulty	45	23	**68**
	SPLD	Specific Learning Difficulty	*	*	**14**
Behaviour, Emotional and Social Development Needs	**BESD**	Behaviour, Emotional & Social Difficulties	232	46	**278**
Communication and Interaction Needs	**ASD**	Autistic Spectrum Disorder	413	70	**483**
	SLCN	Speech, Language and Communication Needs	91	40	**131**
Sensory, Physical and/or Medical Needs	**HI**	Hearing Impairment	23	12	**35**
	MSI	Multi-Sensory Impairment	*	*	**6**
	PD	Physical Disability	179	116	**295**
	VI	Visual Impairment	10	9	**19**
		Total	**1,122**	**374**	**1,496**
		Total Year 9			**165**

* Note: Counts less than 5 have been suppressed (primary suppression). Additionally counts have also been suppressed where it would be possible to calculate the primary suppressed values (secondary suppression).

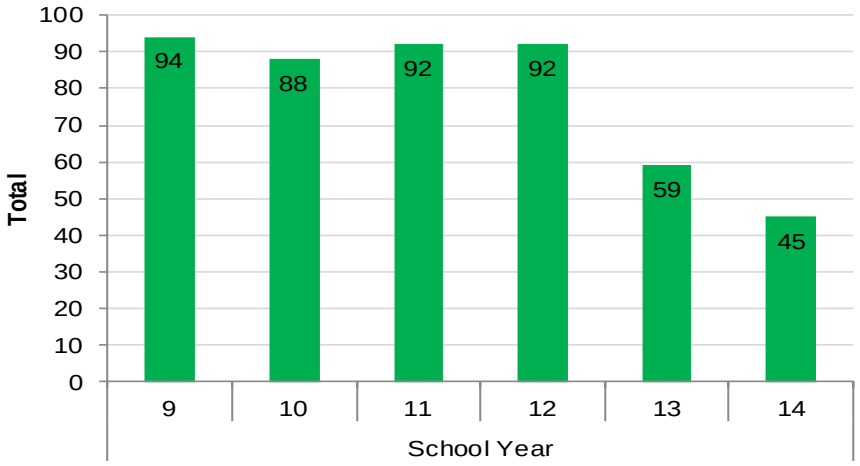
5.1.3 Are on roll of a special school year 9 and above
Figure 4 highlights that approximately 50% of the pupils in Year 9 stay on in school until Year 13 and shows variation between schools.
It shows a high level of achievement despite complex needs and developmental delay in achieving education milestones, despite the lack of suitable opportunities for employment and 'edu-care' in other non-school based training and further education establishments.

Figure 4: Number on roll (Year 9 and above) in Nottinghamshire special schools Jan 2013 year group distribution with schools
Source: Nottinghamshire County Council 2014



Note: Counts less than 5 have been suppressed (primary suppression). Additionally counts have also been suppressed where it would be possible to calculate the primary suppressed values (secondary suppression).
NCY = National Curriculum Year

Figure 5: Number on Roll (Year 9 and above) in Nottinghamshire Special Schools in January 2013 by Year group
Source: Nottinghamshire County Council 2014



5.1.4 Are in receipt of the local authority's High Level Needs (HLN) funding allocation

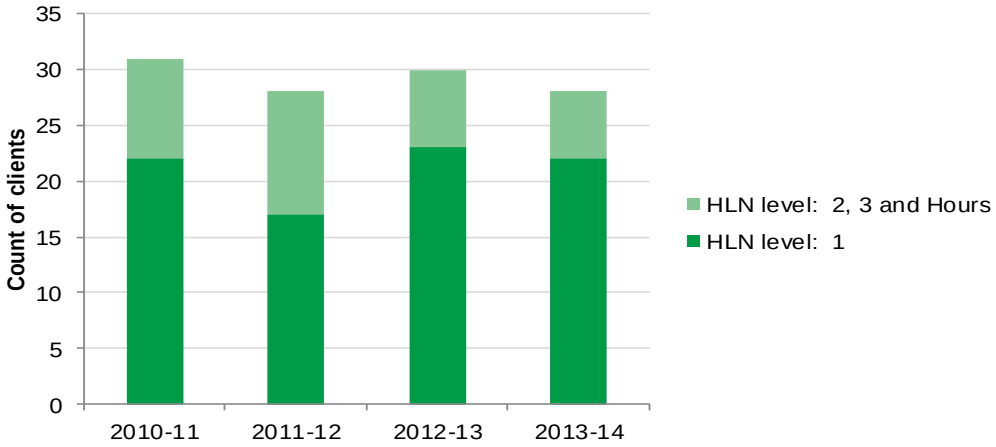
HLN funding is allocated to learners with additional needs and who require additional support not normally provided in the classroom to enable them to access school and learning. An EHC plan is not needed to access HLN funding.

Figure 6 below shows total HLN spend by year and term from 2010 to 2014 and ranges from £2,700 to £19,900 with the average funding per learner of £11,441. The average value of the 15 young people with cognition and learning need is £11,000 per young person. Between 2010/11 and 2013/14 the number of young people funded per year with HLN funding has remained consistent, ranging between 31 and 28 (Figure 7). There may well have been variation in funding levels between young people, as not all SEN categories were funded each year.

Figure 6 2010/11-2013/14 Total High Level Needs (HLN) Funding by year with term breakdown (numbers are in £)
Source: Nottinghamshire County Council 2014

	Total funding			
Period	**Summer**	**Autumn**	**Spring**	**Total**
2010-11	131,853	126,383	99,396	**357,790**
2011-12	124,225	113,375	92,064	**329,664**
2012-13	102,753	96,269	94,144	**293,166**
2013-14	129,723	103,842	86,806	**320,370**
All	*122,139*	*109,967*	*93,103*	***325,248***

Figure 7: 2010/11-2013/14 Number of young people funded per year with HLN level breakdown
Source: Nottinghamshire County Council 2014



Note: Counts less than 5 have been suppressed (primary suppression). Additionally counts have also been suppressed where it would be possible to calculate the primary suppressed values (secondary suppression).

The rate of funding increases substantially if a learner has a Statement of SEN and this reflects the complexity and level of need (Figures 8 and 9). In Nottinghamshire there is a graduated approach to service support and activity (through the local offer) and funding to meet informally assessed need prior to an EHCP (formally a statement of SEN) which will include a multi-agency person-centred transition plan. This is a local strategic approach and not based on research findings.

Figure 8: 2010/11- 2013/14 Average HLN funding per young person per year (with minimum and maximum range – numbers are in £000's)
Source: Nottinghamshire County Council 2014

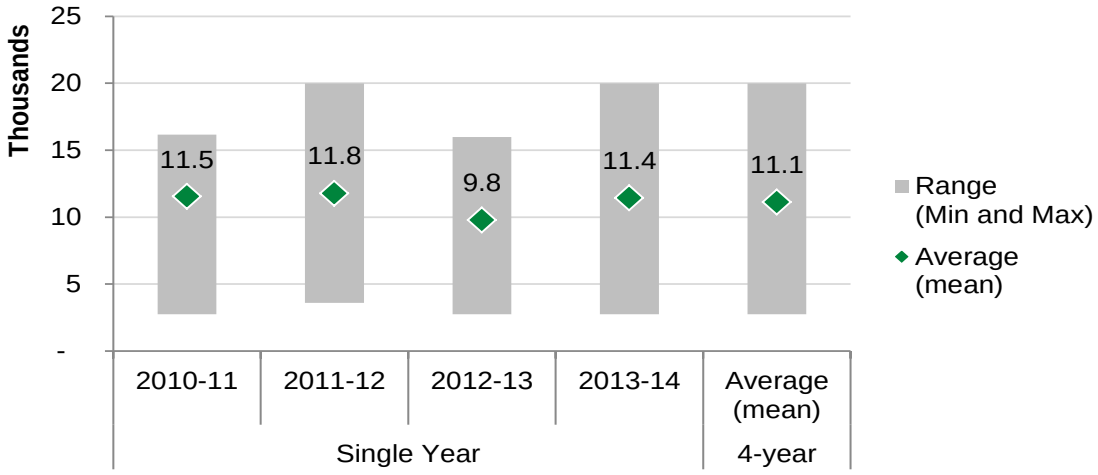


Figure 9: Total and average funding per young person with SEN with primary need and Statement status breakdown

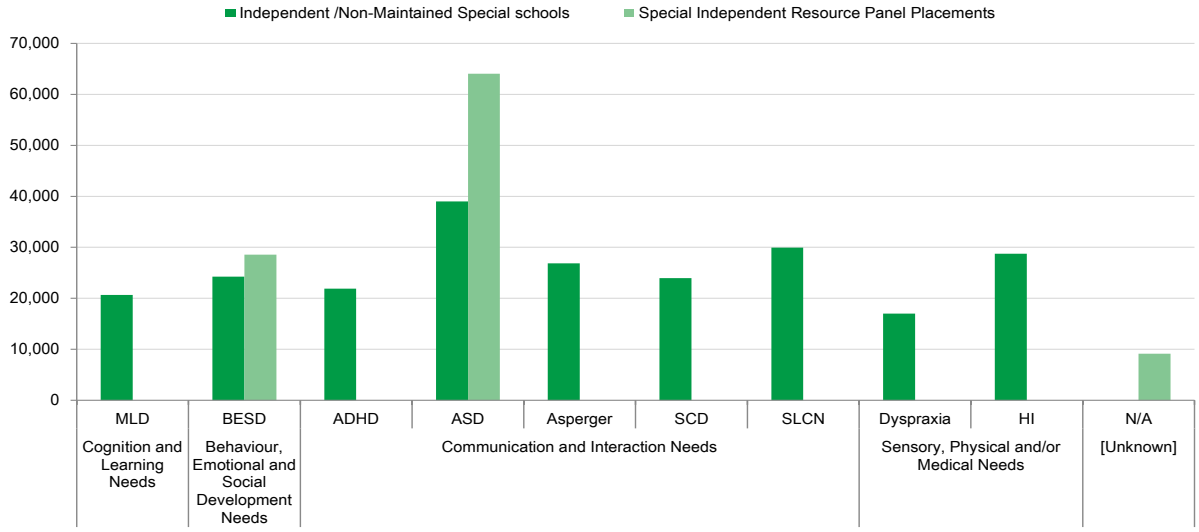
Source: Nottinghamshire County Council 2014

Period 2010/11 to 2013/14				Number		Average annual funding per person		
SEN Area Code	SEN Area Name	Capita ONE: Primary Need	SEN Category Name	Stmt.	No stmt.	Stmt. (£)	Not stmt. (£)	Average % increase in funding if a young person has statement
A	**Cognition and Learning Needs**			**7**	**8**	**12,984**	**9,957**	**30.4**
B	**Behaviour, Emotional and Social Development Needs**			**20**	**18**	**11,757**	**8,642**	**36.1**
C	**Communication and Interaction Needs**			**13**	**19**	**10,980**	**10,200**	**7.6**
D	**Sensory, Physical and/or Medical Needs**			**14**	**13**	**12,875**	**13,111**	**-1.8**
	[Other / unknown]			*****	*****	*****	*****	*****
A	Cognition and Learning Needs	MLD	Moderate Learning Difficulty	*	*	*	*	*
		SLD	Severe Learning Difficulty	*	*	*	*	*
		C&L	Cognition and Learning (non-specific)	6	5	13,317	10,987	21.2
B	Behaviour, Emotional and Social Development Needs	BESD	Behaviour, Emotional & Social Difficulties	20	18	11,757	8,642	36.1
C	Communication and Interaction Needs	ASD	Autistic Spectrum Disorder	*	*	*	*	*
		SLCD	Speech, Language and Communication Difficulties	*	*	*	*	*
		C&I	Communication and Interaction (non-specific)	11	13	10,797	10,910	-1.0
D	Sensory, Physical and/or Medical Needs	PD	Physical Disability	*	*	*	*	*
		VI	Visual Impairment	*	*	*	*	*
		SPM	Sensory, Physical and/or Medical Needs (non-specific)	10	13	12,884	13,111	-1.7
[Other / unknown]		-	[Category unknown]	*	*	*	*	*
		OTH	[Category Other]	*	*	*	*	*
Grand Total				**56**	**61**	**11,933**	**10,373**	**15.0**

** Note: Counts less than 5 have been suppressed (primary suppression). Additionally counts have also been suppressed where it would be possible to calculate the primary suppressed values (secondary suppression).*

Figure 10: Average placement costs per student over 2010/11 to 2013/14 with SEN category breakdown

Source: Nottinghamshire County Council 2014



* Note: Counts less than 5 have been suppressed (primary suppression).

5.1.5 Are a looked after child (LAC)
The numbers of LAC with transition plans of which over half were over 14 years old and mostly boys, during the period 1998- to 2013, there were 27 young people, 5 girls and 22 boys, aged 14 year old in year 9 to 16 years and over in year 12 who had transition plans. There were 29 LAC (63%) who had a disability.

5.1.6 Attend an independent non-local authority education/care setting and is at risk
There are a total of 70 children and young people attended an independent non-local authority special schools education/care setting during the period 2010 to 2014. There are a small percentage of disabled children attending independent schools and numbers have increased during 2010/11 to 2013/14, but these numbers are small. Children are placed in this provision when a child is at risk of exclusion from an existing school placement because the local authority has a duty to educate all school age children and young people.

The average placement costs per student have remained consistent between 2011/12 and 2013/14 with the exception of children and young people with Autistic Spectrum Disorder (ASD). The average placement costs per student accessing the SEN categories are significantly more for ASD resource panel placements.

This information and data relates to figures 9 and 10, and demonstrates which young people are involved, the extent of the prevalence and the continued need for transition planning.

5.2 CQC inspection Nottingham City

A CQC inspection pilot was carried out in July 2013 in Nottingham City CCG. This provides the most up to date local evidence around transition activity from a rigorous inspection and the feedback reflects the national trend and a similar picture in Nottinghamshire.

The inspection focused on transition from children's to adult's services for children and young people (aged 14 to 25 years) eligible for fully funded Continuing Care packages. In addition, a sample of cases that did not meet the continuing care thresholds was reviewed with the Children's Community Nursing and District Nursing services.

The CQC feedback was mainly positive. For example, the roll out of personal health budgets to children and young people and a transition pathway embedded in the Nottingham City Children's Continuing Care process received positive feedback. Although a young person had yet to transition through this pathway, it was felt that the pathway would work well. There were, however, a few areas requiring further focus:

- Transition plans for children and young people that fall below the threshold for Continuing Care did not exist
- It was unclear who the lead professional was for cases below the Continuing Care threshold and this was often confusing for involved professionals
- There were challenges regarding transition from children's to adult's services. Often the choice and availability of adult's services are less than that in children's services and families can be left feeling unsupported and confused.

5.3 Local Priorities in SEND: Designated Clinical Officer in Health Services

The Children and Families Act 2014 has made significant changes to the statutory responsibilities for Special Education Needs and Disability (SEND) to improve the outcomes for children and young people with Special Education Needs and Disability from 0-25years. The SEND Code of Practice recommends the identification of a Designated Clinical Officer to coordinate and support the implementation of the Education Health and Care Plan Pathway (EHCP).

As part of the on-going work in embedding the Education, Health and Care Plan (EHCP) into services commissioned and delivered to CYP the role of the Designated Clinical Officer (DCO), is currently being explored. The role of the DCO is to take a strategic lead for health on behalf of the CCGs within the local authority to support the embedding of this process, and to provide assurance to the CCG's that they will be meeting their statutory duties. One of the key priorities is to embed transition into the EHCP process within health.

5.4 NHS Provision

The Special Schools Nursing Service currently provided by NHS Nottinghamshire Healthcare Trust's Health Partnerships Division has a dedicated Transitions Nurse for the south of the county only.

The role of the Transitions Nurse

The transitions nurse facilitates a young person's move from children's health services into adult health services. The aim is to provide a seamless transition and ensure any placements are aware of and can support any health needs.

There is currently one identified transitions nurse who is based at Park House Health and Social Care Centre. The current role includes special schools only and provides a service to Ash Lea, Carlton Digby and Oak Field special schools. Orchard, Derrymount, Fountaindale, Yeoman Park, Beech Hill, Foxwood, Bracken Hill and Redgate special schools do not receive the service but the school nurse liaises around transitions as their workload allows. There is no remit to input into the transitions process in mainstream schools for children with disabilities.

The Specialist Transition Nurse supports young people from year 9 to year 14 and the caseload was 65 pupils in 2012/13, 76 pupils in 2013/14 and projected to be 78 pupils in 2014/15. The transition planning includes residential, college, day services, home, personal assistant, supported employment, short breaks in combinations tailored to the needs of the young person. See more detail in section 7.

What does this tell us?

6) What are they key inequalities?

- Parents of young people with complex needs often live with reduced personal resources for example they are more likely to be in part-time lower income jobs.
- Issues of access can be compounded by personal circumstances such as car ownership.
- It is not always clear to young people and their families, the different organisations and structures of education health and social care and the services available to them.

7) Where are the gaps in transition service?

- There is a mismatch between Children and Adult Services' access criteria and provision, and a different level of service in adulthood, although individual needs will remain the same or even deteriorate.
- In health specialist services there is a challenge associated with how services are organised and patients with co-morbidity (more than one condition) may find that they have many appointments with many different specialists and teams in many different locations to coordinate and manage.
- Development of transition services and support following the initial launch of The Nottinghamshire Multi-Agency Transition Protocol: Supporting Young People with SEN and Disabilities from Age 14 (Year 9) into Adulthood in 2010 has been absent. This is due to significant and on going changes arising from the Health and Social Care Act (2012) in the agencies responsible.
- There is no long term view of the young person's life; services are often reactive rather than proactive. A life course approach with longer term planning would be less anxiety provoking for children and families and would avoid crisis management and the need for the provision of emergency care. To summarise there are currently significant gaps in this work stream.
- There is one Transition Nurse based in special schools in the south of the county only and therefore the service is limited, demonstrating inequity of access for transition planning.

  The current NHS provider of transition support has offered the following suggestions as potential development of the role of Transitions Nurse in Special Schools Provision. It is not however a recommendation for Commissioning organisations as the provider clinical expertise would determine this. The role needs to provide an equitable service across all schools. There are two options that would sustain this.

  - The role of the transition nurse role remains the same not-with-standing changes required from current legislation, and is replicated across the school nursing services in both mainstream and special schools.
    The optimum caseload will need to be identified to allow the correct number of nurses to be recruited.
  - The existing school nurses are given the lead for transition within their caseloads. The transition role is not a school based role but relies on the ability to travel outside of the education setting. Support would be available from a transition's nurse who would also hold a caseload of those transition children with a disability in mainstream and those difficult and complex children but have training and 'clinical' support role. This option would require a change in special school nursing practice to fully facilitate this.

    Partners are currently required to work across Adult and Children's Healthcare, Social Care, the private sector and in Education and this represents a very

complex journey for parents. This will continue to develop with robust joint and integrated commissioning in the future – see Section 11, recommendation 2

8) Where are the gaps in knowledge?

Information is patchy and cannot be triangulated. We need to have reliable data around children and young people in independent schools and out of authority schools. This reflects the national position. Future integrated commissioning should include the collection analysis and reporting of data to inform good practice in service delivery.

Nottinghamshire currently supports transition planning for young people with the most complex needs, as per the target groups of young people previously mentioned. It would be useful in future iterations of the Joint Strategic Needs Assessment to widen the scope of research into support on transitions for all children and young people with SEN, for example children with dyslexia or young people moving into further education, training or employment, or those with long term conditions or life limiting conditions.

9) What are the risks of not delivering targets?

There are currently no targets or systematic approach across organisations in Nottinghamshire to identify and implement transition planning and this is both a gap and risk in managing this activity. However, risks of poor transition planning and support for young people and their families across the life course have been discussed earlier and throughout this document.

10) What is on the horizon?

Personalisation

The Children and Families Act 2014 requires significant reform in relation to how support across education, health and care is received by children and young people with SEND. The legislation includes a new requirement for local authorities to offer personal budgets to children with SEND.

The new requirements mean that where a local authority maintains an EHC Plan for a child or young person, they must offer a personal budget if asked to do so by the child's family or the young person themselves. Preparing a personal budget will require the authority to identify an amount of money which is required to meet a child or young person's identified needs, as specified in their EHC Plan. The Act extends the age range for EHC Plans up to 25 years old. In its current form, the legislation simply requires local authorities to identify a notional personal budget i.e. there is no requirement for the authority to pay all or any of the money directly to the family or young person until 1st September 2014.

Experience from elsewhere suggests that there is significant cost involved in the transition to personalisation. Six local authorities participated in the Individual Budgets pilot with expenditure of between £75,000 and £180,000 to establish a pilot scheme.

What should we do next?

11) Recommendations for consideration by commissioners

Many of the recommendations in the transitions section of the children's JSNA (2010) have been met; a strategic transition protocol has been developed to advise how local services work to meet the needs of disabled young people. This was accompanied by a local transition pathway to give the protocol operational detail and map how local services can work most effectively together and put in place transition reviews that lead to transition plans, which set out the wishes and aspirations of individual disabled young people, as well as the support that they need.

Recommendation 1: Review of existing Transition Planning strategy and practice
Existing Transition Planning strategy and practice now needs to be reviewed and updated in line with the statutory requirements in the Children and Families Act and SEND reforms.

Recommendation 2: Develop quality robust joint and integrated commissioning arrangements
It is essential that health services observe the requirement for joint commissioning in delivering the NHS England mandate for disabled children and young people. Transitioning from Children to Adult Services may require an examination of funding and budget levels with a well-managed 'push' for changes from Children Services and a reciprocal 'pull' from Adult Services. The transition planning should include activity which meets individual needs and reach into Adult Services and out of Children services.

In commissioning integrated services it is important to consider the transition between paediatric and adult health services for young people with less complex needs (i.e. no co-morbidity, but with long term health conditions, for example asthma or diabetes).

Recommendation 3: Ensure the collection of robust transition activity data and information
There is no systematic approach to collating robust information around transitions and service level activity. Information is patchy and it is difficult to correlate the information or conduct any meaningful analysis in order to inform service development. Additionally, transitioning from Children to Adult Services needs better data sharing, which is essential for forward planning, quality assurance and efficient commissioning.

Recommendation 4: Patient and families experience
Patient and families experience is at the centre of strategic decision making and planning as well as at operational and personal level. Young People and their parent/carers will be involved in the commissioning process shaping services through customer service feedback, consultation and coproduction of service provision and participation at the highest level.

Recommendation 5: Systematic approach to ensuring transition plans are in place
Effective transition starts at 14 years old for up to 5 years if needed and means identifying and tracking (from data systems), young people through key transition points in their life. Appropriate and timely support can be provided for young people only where data systems identify young people who are in need of help. This includes how agreements about the ways agencies will work together to support disabled young people and their families are set out in integrated transition protocols.

Recommendation 6: Committed resources to manage this work

Strategic level agreement and planning is essential to success at operational level. There should be designated leadership, time and capacity to maintain a focus on transition to inform service change and improvement. An effective multiagency steering group or Board should be developed to implement protocols and pathways.

Recommendation 7: The role of health and wellbeing boards in measuring the outcomes from transition planning
Health and Wellbeing boards should measure outcomes for children and young people in transition from children's to adult services, especially those with disabilities, palliative care needs and long term health conditions and consult with those young people. Their priorities should be reflected in the Health and Wellbeing strategy.

12) Additional references

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- 'You're Welcome': quality criteria for young people friendly health services *(*http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_126813)

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- Department of Health (2013) Children and Families Bill 2013: Contextual Information and Responses to Pre-Legislative Scrutiny. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/219658/Children_20and_20Families_20Bill_202013.pdf
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