Joint Nottinghamshire Integrated Community Children and Young People's Healthcare Programme

September 2013



This report is different…

NHS Nottingham City Clinical Commissioning Group

Nottingham City Council

Nottinghamshire County Council

NHS Nottingham North and East Clinical Commissioning Group

NHS Bassetlaw Clinical Commissioning Group

NHS Mansfield and Ashfield Clinical Commissioning Group

NHS Nottingham West Clinical Commissioning Group

NHS Newark and Sherwood Clinical Commissioning Group

NHS Rushcliffe Clinical Commissioning Group

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Joint statement from our Programme Sponsors

We are delighted to present this report for the Integrated Community Children and Young People's Healthcare programme. This has been developed in conjunction with commissioners, service providers, including third sector organisations and children, young people and families.

We know that there are increasing numbers of children with long term conditions, disability and complex needs surviving and thriving in Nottingham City and Nottinghamshire County and we want to ensure that our services meet their needs in the best way possible – efficient, effective and value for money.

There are legislative changes required to the commissioning, management and provision of statutory services and to the way that services are accessed by children, young people and families. At the same time there are financial challenges due to the global recession and national funding policy. This puts demands on commissioners and service providers but should not affect the quality and provision of healthcare services.

We have an excellent and wide range of high quality support services that have been established and evolved over time in response to need and available funding. There is no overarching strategy or management and planning for their delivery and development. Many services are currently uncoordinated and disconnected, operating independently of others. This gives rise to duplications and complications for families and there is opportunity for greater cohesion and integration.

Parents and carers want easy access to services and a proactive approach to planning for the future care of their children and how it impacts on their family life. Improvements can be made by having a flexible framework of care pathways and a flexible workforce, co-located and integrated services where possible and improved interlinking where this is not possible.

The findings and recommendations within this report provide the foundations for the next phase of this programme and a 'call to action' to enable us to develop and commission integrated services that meet the needs of children, young people and their families.



Dr Kate Allen
Consultant in Public Health
Public Health
Nottinghamshire
Nottinghamshire County Council



Teresa Cope
Director of Quality and Delivery
NHS Nottingham City
Clinical Commissioning Group

Endorsement

"I whole heartedly endorse this report for its innovation in approach, detail and design. The Large Scale Change required to drive and deliver the Integrated Children and Young People's Healthcare Programme can only be achieved through a vision, distributed leadership and by changing mind sets of ourselves as leaders, service providers, carers and service users.*

This report has embraced a new approach of using the power of public narrative to call to action all parties required to make this change happen, and is a great foundation to make it sustainable."

Alison Wheeler,
Director Good Squared,
Faculty member of NHS Institute – Large Scale Change Coach

*Public Narrative and Distributed Leadership

Transformation requires data and evidence of the problems, a vision and measures of success. Data itself is not enough; it engages our heads but fails to engage our hearts that we take action. It is the power of narrative, story telling, that engages and creates a commitment to transformational change. Distributed leadership means that people within a team and organisation lead each other. It can be defined as team leadership by more than only the 'appointed' leader.

Executive summary

Integrated Community Children and Young People's Healthcare (ICCYPH) Programme Phase 1 Report

This report was written during a period of great change within NHS as a result of the Health and Social Care Act 2012 and is as accurate as possible whilst 'dancing on a moving carpet'.

The number of children with long term conditions, disability and complex needs are increasing in Nottingham City and Nottinghamshire County in line with national trends. Legislative changes are required to the commissioning, management and provision of services and the way that services are accessed, at a time of financial challenge and the need to achieve more for less or within the same budget.

This programme has multi-professional focus and demonstrates collaborative arrangements between CCGs, local authorities, appropriate commissioning support and good partnership relationships with providers. It also includes good engagement with patients and the public, listening to what they say and reflecting their wishes.

Section 1 – Introduction

NHS Nottingham City and County CCGs (including Bassetlaw) and Nottingham City and County Councils are working together to improve ease and equity of access to and the integration of specialist community healthcare services for children and young people and their families.

The Vision

To enable children and young people with acute and additional heath needs, including disability and complex needs, to have their health needs met wherever they are. The services will support the child's life choices rather than restrict them and improve the quality of life for children and their families and carers.

The main focus of the programme is specialist community nursing and therapy services (occupational therapy, speech and language therapy and physiotherapy). The aims of the programme are to transform the current fragmented service provision, into an integrated network of health and care support, to reduce duplication and complications for families and services. This will be achieved using a phased approach reflecting the commissioning cycle as follows:

Phase 1 – Scoping, mapping and consulting
Phase 2 – Developing, planning, specifying, commissioning
Phase 3 – Implementation, evaluation, consolidation, monitoring and continual improvement

This report presents the findings from phase 1, the scoping phase of the programme.

There are many national policies and drivers relevant to the programme, referenced throughout the report. Particularly pertinent are:

- The Health and Social Care Act 2012 – places a duty on Clinical Commissioning Groups (CCGs) to promote integration.
- Disability and special educational needs green paper (2011) – includes the implementation of a new single assessment process and education, health and care (EHC) plan by September 2014
- An amendment to the Children and Families Bill (2013) – CCGs will, by law, have to secure services in education, health and care plans for children and young adults with special educational needs.
- Personalisation – the personal health budget (PHB) initiative is a key aspect of personalisation across healthcare services in England.

The NHS change model, created to support the NHS to adopt a shared approach to leading change and transformation has been applied throughout phase 1 and will continue to be followed in the next phase.

> The number of children with long term conditions, disability and complex needs are increasing in Nottingham City and Nottinghamshire County in line with national trends.

Section 2 - Children, Young People and Families

This report is different because it comes with a **'BIG ASK'**, a request to commit to change for improvement. This section gives a reflection of the current experience of children, young people and families.

Parents and carers are generally happy with services once they receive them, rating them very good and excellent – it is the process of accessing, the coordination and management that is not satisfactory. This section tells of the tireless 'fight' by parents and carers on behalf of their children to be listened to, to be understood, to obtain services and support to ensure they have their needs met and to have the best health they can so that they can enjoy and achieve in their lives.

Four fictional family scenarios, developed with parents and based on real life situations illustrate the diversity and complexity of needs of children with additional health needs and their families. Throughout the report the impact of the current fragmented system and the potential benefits proposed changes would have on these families are explored. In addition to the fictional scenarios there are two anonymised real case studies which illustrate the complications and duplications experienced by children and their families.



"Some children have complex medical or health needs which present a potential barrier to that child attending school and learning. The barriers can sometimes be about the complexity of a child's specific condition, but more often they are about the complexity of the organisational features and arrangements that are required. It may be more appropriate to rename the project, 'Children with health needs that require complex arrangements."

Source: Project to examine how we can best meet the needs of children and young people with complex health needs NCC Regional Innovation Project (2008)

Section 3 – Consultation and participation

Communication, consultation and participation was with a wide range of people: young people, parents and carers, and stakeholders including clinicians, GPs and professionals from health, education, social care, the third and independent sectors.

A 'Families' statement of expectations' was developed with parents from themes identified in the consultation work with young people, carers and parents. This shows that families are asking for respect and collaboration and for the system, processes and services to support and serve them in a way that enables them to enjoy as normal a family life experience as possible, like any other family.

Parents involved in the consultation and participation work undertaken in phase 1 of the programme were also keen to be involved in development phase 2 and in prototyping of proposed solutions.

Stakeholder consultations identified key themes and interdependent elements of an integrated model incorporating streamlined access, co-ordinated assessment and delivery of care, supported by shared information and key workers. Examples of good practice were also identified to share and build on in the development of an integrated model, for example the skills, expertise and experience of existing staff and their commitment and passion.

In a consultation survey of GPs almost half of respondents identified they would like to be more involved in the care of children with additional and complex health needs. A range of GP training needs were identified which reflect recommendations for good practice from the charity Contact a Family. A set of resources have been developed by Contact a Family to support GPs to enable families with children and young people with disabilities to access their services.

"In a consultation survey of GPs almost half of respondents identified they would like to be more involved in the care of children with additional and complex health needs.

Section 4 - Scoping and Mapping of current service provision

The ICCYPH programme includes the following four groups of children and young people:

Group 1 - Children and young people with acute and short term conditions, 0-19 years (updated from 18 years)

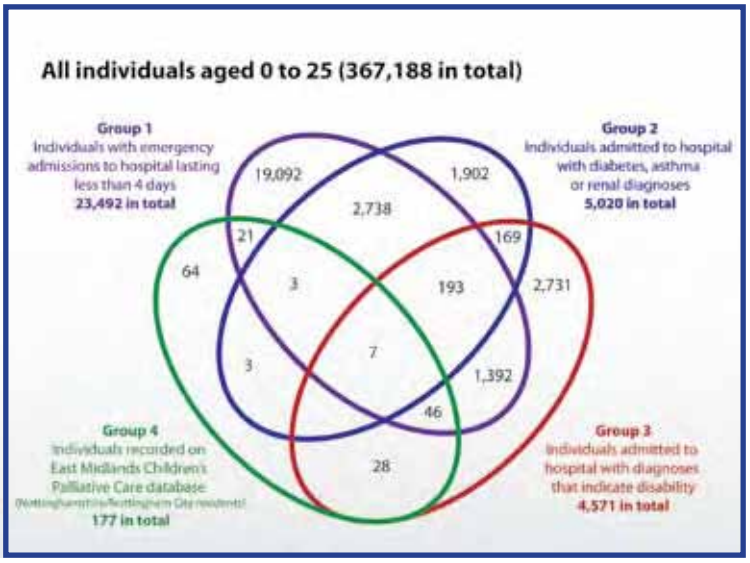
Group 2 - Children and young people with long term conditions, 0-19 years (updated from 18 years)

Group 3 - Children and young people with disabilities and complex conditions including those requiring continuing care and neonates, 0-25 years

Group 4 - Children and young people with life limiting and life threatening conditions and illness, including those requiring palliative and end of life care, 0-25 years

Scoping of conditions against the four groups shows that group 3 includes the widest range, however due to their complexity children and young people may and often do move between and overlap these groups as illustrated below:

Populations: how groups overlap: ages 0 to 25 years (Nottingham City and Nottinghamshire County CCG populations including Bassetlaw) - all numbers are counts of individuals



This chart represents the total number of individuals identified for analysis. Groups 1, 2 and 3 are derived from the number of individuals admitted to hospital from March 2011 to April 2013. Group 4 is derived from the East Midlands Palliative Care database and is the number of individuals resident in Nottinghamshire with a valid NHS number recorded.

Scoping and mapping of services shows that there is an excellent range of services but they are currently uncoordinated and disconnected. This gives rise to duplications and complications for families and there is opportunity for greater cohesion and integration, for example:

- Integration of children's community nursing services
- Integration of special school nursing with children's community nursing services
- Integration/interlinking of health and local authority services (OT, PT and SLT).

Section 5 – Population needs, service data and information

This section includes population data and data from a selection of children's community services. The data gives indications of current activity, trends and needs, providing evidence of increasing demands on services as children with additional and complex health needs are living longer.

Some key messages from the data, detailed in section 5 and the appendices include:

- Nationally the disabled population increased by 70% in 30 years (1976 –2006), the under 16 disabled population is growing fastest; local trends reflect this.
- From 2005 to 2011 the number of children having multi-disciplinary assessment and team around the child (TAC) coordination meetings in the Nottingham Children's Development Centre (CDC) almost doubled from 65 in 2005 to 120 in 2011.
- Activity data shows increased referrals and contacts with specialist paediatric community therapy services.
- Service activity data (2012/13) shows that 15-18% of children seen by specialist children's community services are seen by more than one service and some children are seen by at least three services. This indicates complexity of need and scope for integration.

Integrated working, with mobile working systems, a single point of access, shared records and assessments would reduce duplication for children, young people and families, improve communication and resource utilisation.

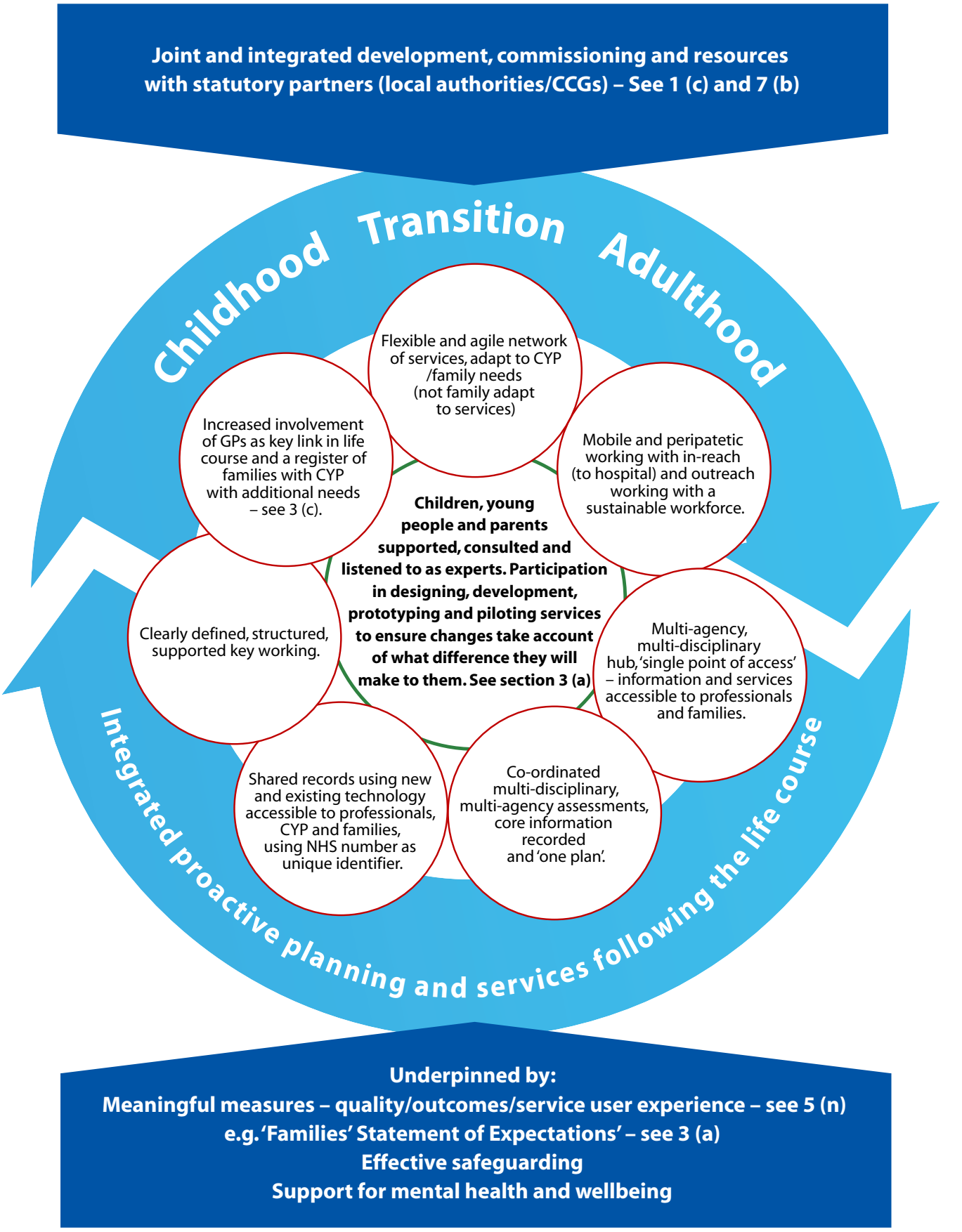
Key aim

A key aim of the development of an integrated model must be to remove unnecessary and wasteful complications from the system to enable resources to be focussed on meeting the complex needs of these children and young people.

Section 6 – Developing integration

There is no single care pathway for the groups of children within the ICCYPH programme. The challenge for effective integration is to develop a flexible model or framework that achieves a seamless journey for children and their families on the appropriate care pathway or pathways, delivered by the right people at the right time, in the right place.

The graphic below shows the essential interdependent elements of an integrated model of children's community health care that have been identified in phase 1 of the programme.



Development in phase 2 should include:

- A whole system approach, by adopting or adapting the Family Friendly Framework (FFF) to develop integrated service provision based on pathways and networks as units of service delivery, bringing together multiple commissioners and providers, putting children, young people and their families at the heart of what happens.
- Alignment of the ICCYPH programme in phase 2 with the SEND legislation development work in Nottingham City and Nottinghamshire County, to facilitate the wider development for all children and young people with additional needs, of:
  - Co-ordinated multi-disciplinary, multi-agency assessments and 'one plan', with core information captured once and shared.
  - Integration of information and communication technology (ICT) and development of mobile working, using the NHS number as a unique identifier, providing access to records, shared by services and children and families as enabled by appropriate information governance. There is potential for the Connected Nottinghamshire Programme to support ICT development
  - A single point of access for information and referrals to a multi-agency, multi-disciplinary 'hub' for co-ordinated and shared assessment of need to provide an entry point to appropriate information and services for children, young people and their families.
  - A key working model, including designated and non-designated key workers, with a clear definition and standards, structure and administration support,
- Increased use of assistive technology to bring benefits to individual children and young people, improved quality of life for families and reduced dependence on statutory services. This would enable savings to be invested to meet the challenges of an increasing population of children with complex needs for the same budget.
- Proactive transition pathways, planning and support, including personal health budgets, to enable young adults with additional needs to remain at home with their family, or for them to achieve independence.
- Mental health prevention, recognition, and early support and access to mental health services for any member of the family designed into an integrated model and service specifications which consider the mental health needs of the whole family.
- The principles of good safeguarding and early intervention to meet the Working together to safeguard children 'children's request for protection' statement embedded within the design, development, specification and delivery of integrated services.
- Tools and methodologies to help ensure engagement, consultation and participation of children, young people and families and other stakeholders in designing and developing an integrated model of service provision for example those provided by taking a community development approach.

Section 7 – Pilots, current and future developments

Describes a number developments across health, education and social care which are planned or in process in Nottingham City and Nottinghamshire County and which influence or support the ICCYPH programme. These are illustrated in the overview diagram appended to the programme brief (appendix 1) and include:

Nottingham City

- Disability and Special Educational Needs legislation (2011) development
- Personalisation: personal budgets and direct payments
- Children's Continuing Care and Case Management Service
- Early Support Pathway
- Autistic Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD) and Challenging Behaviour Pathway
- Nottingham City Council restructure of operating model for children's services

Nottinghamshire County

- Integrated Commissioning Hub for Children and Young People Services
- Disability and Special Educational Needs legislation (2011) development – 'One Project'
- Personalisation: personal budgets and direct payments
- Mid-Nottinghamshire NHS Integrated Care Transformation Programme (ICTP)
- Joint public health and social care Aiming High for Disabled Children (AHDC) occupational therapy pilot
- More recently (and not in the main body of the report) the Nottinghamshire ASD/ADHD/Challenging Behaviour pathway and the Bassetlaw ASD/ADHD pathway.

New and emerging policy and guidance

Together for Short Lives Commissioning children's palliative care: A guide for Clinical Commissioning Groups (CCGs), published 13 August 2013.

Section 8 – Call to action

A reflection on the report, what needs to be done, why it needs to be done and the commitment needed – an 'EVEN BIGGER ASK' – to fulfil the vision.

Section 9 – Glossary of acronyms, abbreviations and terms, references and bibliography

Section 10 – People and organisations

Summary of people and organisations involved in the phase 1 of the ICCYPH programme.

Recommendations

The recommendations, below, are in line with those in the Strategy produced by the Children and Young People's Health Outcomes Forum (2012) i.e.:

- Putting children, young people and their families at the heart of what happens
- Acting early and intervening at the right time
- Integration and partnership
- Safe and sustainable services
- Workforce, education and training
- Knowledge and evidence
- Leadership, accountability and assurance
- Incentives

It is clear from the recommendations from phase 1 that in phase 2 and 3 there will be actions to develop, implement and support an integrated model. This will require a series of work streams involving input from members from across the health community with specific knowledge and skills.

The recommendations for action are:

1. The 'Families' statement of expectations' should be used as guiding principles in the design, commissioning and provision of services and to develop standards to measure service user experience against.
2. Involve parents and young people in the development phase and prototyping of proposed integration.
3. Promote 'Contact a Family' resources for general practice and encourage GP practices to complete the self-assessment in order to identify key areas of focus. This will support GPs to enable families with children and young people with disabilities to access GP services and to reduce hospital admissions.
4. Develop education and training opportunities for GPs and practices.
5. Identify GP champions to raise the profile of the ICCYPH programme in phase 2.
6. Develop a Practice Specific Objectives target for 2014/15 (Nottingham City CCG) to update patient registers with specific categories (e.g. carers) and define some parameters of care which would help GPs to support children and young people with additional health needs and their families.
7. Develop and implement a mobile working system for children's community services.
8. Continue to monitor data to identify any further areas of work to focus on, in particular analysis of workforce data to assess competencies and skill mix to inform a workforce development plan.
9. Develop meaningful quality and outcome 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.
10. Adopt/adapt the Family Friendly Framework (FFF) in phase 2 of the ICCYPH programme to support the development of an integrated network model of children's community health services and pathways designed around the needs of children, young people and families, to reduce duplication, achieve seamless flow between services and good experience and outcomes.
11. Prototype shared records, assessments and care plans in children's community nursing services.
12. Align the ICCYPH programme with the SEND legislation development work in Nottingham City and Nottinghamshire County in phase 2.
13. Develop ICT functionality and compatibility across organisations.
14. Invest in increased use of assistive technology to address the individual needs of children and young people as part of the development of integrated services and support.
15. In developing a single point of access and multi-agency, multi-disciplinary hub ensure that the challenges and considerations identified in phase 1 are included.
16. Develop key working for families with children with additional needs in collaboration with SEND legislation development work in Nottingham City and Nottinghamshire County in phase 2.
17. Ensure that proactive transition pathways, planning and support, including personal health budgets, for all children with additional needs are included in the new integrated service network.
18. Build mental health prevention, recognition and early support and access to mental health services for any member of the family into an integrated model and service specifications, which considers the mental health needs of the whole family.
19. Embed the principles of good safeguarding and early intervention to meet the 'children's request for protection' ('Working together to safeguard children') within the design, development, specification and delivery of integrated services.
20. Ensure all work of the Mid-Nottinghamshire NHS Integrated Care Transformation Programme (ICTP) and ICCYPH Programme is aligned in phase 2 of the programme.

Are YOU interested?

If you read nothing else in this report for whatever reason, please skim the headlines and read the recommendations. This will enable you to see what is needed from you, as a parent or carer, a Councillor, a GP or clinician, a manager of service provision or a commissioner. Consider your position and make a commitment for change for improvement.

This change is long overdue.



Vision without action is merely a dream. Action without vision just passes the time. Vision with action can change the world.

Joel A. Barker[1]

What do YOU want from this report?

This is large scale change on a level quite unprecedented for these services. It is achievable if everyone understands 'the vision', is united in a common goal, with a consistent objective and is flexible, indeed positively agile and innovative at every level in their approach to achieve tangible change.

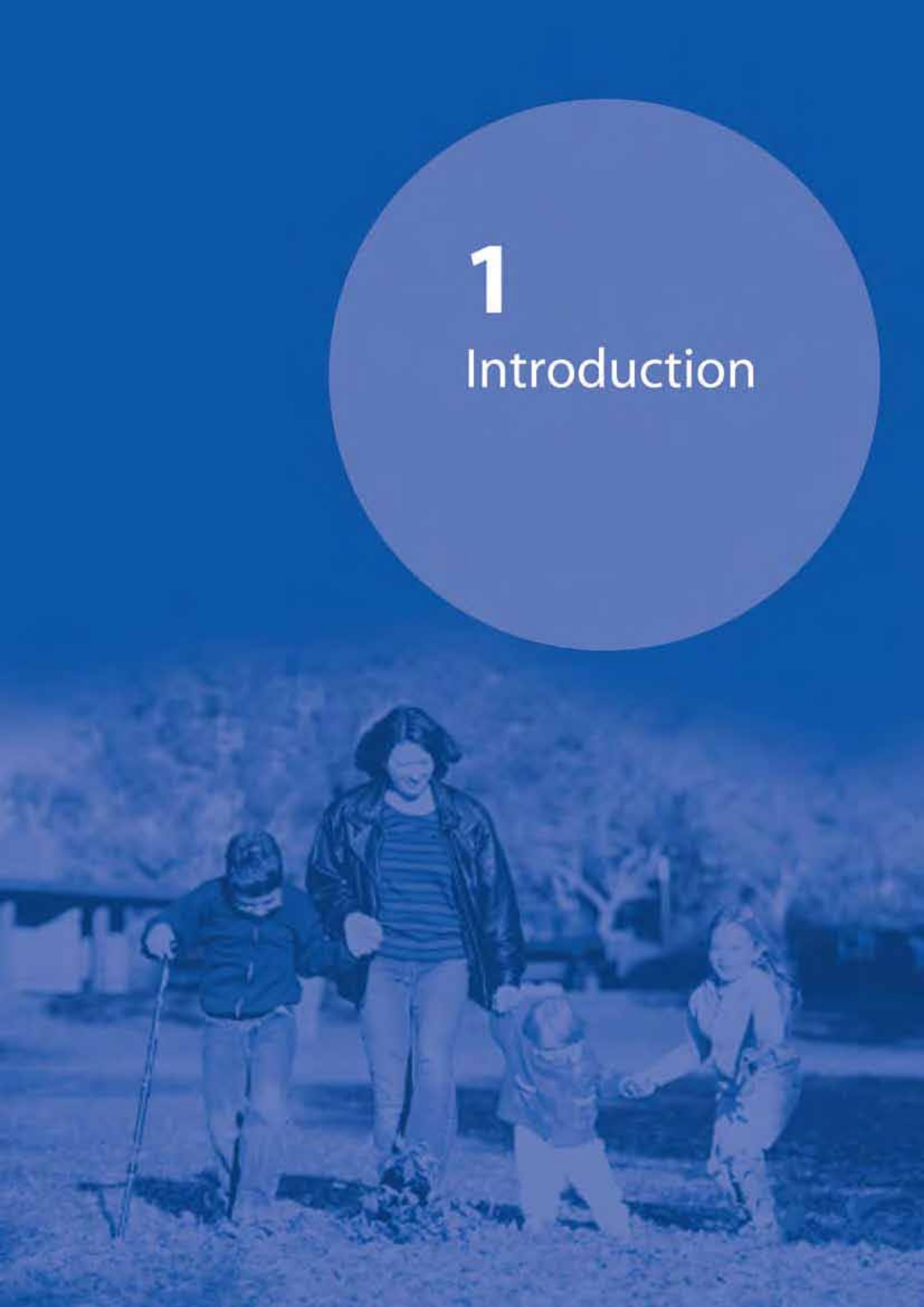
This report follows a colour coded presentation as follows:

If your interest lies with data and information look for the blue text/ headings and boxes

If your focus is on the human interest and the experience of children, young people and families or professionals look for the green text/headings and boxes.

If you are interested in recommendations and actions to be taken then look for the red text/ headings and boxes.

1
Introduction



1 (a) From fragmented to integrated Community Children's Services

NHS Nottingham City and County CCGs and Nottingham City and County Councils are working together to improve equity of access to and the integration of community healthcare services for children and young people aged 0-19 years (updated from 18 years) with acute and short term illness and long term conditions and aged 0-25 years with disability and complex needs, life limiting, life threatening conditions including palliative and end of life care and neonates.

Services have developed independently accessing different funding sources over time arising from policy, responding to need and availability of funding. Although services are well established they are now quite disparate and unconnected. Navigation by professionals and families through the services is challenging and gaps and duplication have resulted in a fragmented system of service provision.



The Vision

To enable children and young people with acute and additional heath needs, including disability and complex needs, to have their health needs met wherever they are. The services will support the child's life choices rather than restrict them and improve the quality of life for children and their families and carers.

The Programme brief outlines the aims and approach of the programme to transform current fragmented service provision into an integrated network of health and care support (see appendix 1)

This initiative started as a joint Nottingham City / Nottinghamshire County Integrated Children's Community Nursing (ICCN) project. The community nursing services had developed over time arising from identified need and available funding. This meant that there was no overarching strategy or management for delivery. Some services worked together, some knew of each other and would refer or signpost families to the services, others work quite independently. The services all have their own records, referral, assessment and review processes.

The aim of the project was to identify gaps in service and reduce duplication to develop a new, Nottingham City/ Nottinghamshire County jointly managed, integrated Children's Community Nursing service with a single point of referral and access.

In September 2012 the scope of the project was widened to include therapy services i.e. physiotherapy (PT), occupational therapy (OT) and speech and language therapy services (SLT). It became a phased joint Nottinghamshire-wide Integrated Children and Young People's Healthcare (ICCYPH) Programme. In November 2012 Bassetlaw also joined the Programme.

The scope of the ICCYPH programme is specialist community health services (nursing and therapy services), however the social care and educational needs of children are considered with the work in local authorities to meet the requirements of draft legislation on reform of provision for children and young people with special educational needs and disability.

Some potential risks are identified below:

Potential risks of not implementing the programme may include:

- Insufficient service capacity to meet increasing demand
- Long waiting times
- Negative impact on quality and co-ordination of services
- Deterioration of health and economic wellbeing of children, young people and their families
- Increased safeguarding risks
- Inconsistent and inequitable access to services
- Increased litigation and escalating compensation costs

Potential risks of implementing the programme may include:

- Not having a clear implementation plan and phased/ systematic approach
- Impact of organisational change and restructure on continuity and comprehensive support for implementation
- Potential to destabilise and de-motivate staff delivering services
- Inequities resulting from inconsistency of implementation across City and County
- Increased costs

Whilst Child and Adolescent Mental Health Services (CAMHS) are not within the remit of the ICCYPH programme, links with CAMHS and consideration of the mental wellbeing of children and parents/carers are considered.

Disabled children and those with complex needs are more vulnerable to poor safeguarding outcomes; fragmented service provision and communication can make the identification and tracking of potential safeguarding concerns more difficult. Integration and improved communication within health and across health, social care and education should enable better prevention of, identification of and response to safeguarding concerns.

1 (b) Impact of legislation: legal duties for CCGs, education, health and care plans and personalisation

There are many national policies and drivers relevant to the programme referenced throughout this report and listed in the references and bibliography in **section 9**. The following are highlighted as particularly pertinent.

The Health and Social Care Act 2012 places a duty on clinical commissioning groups (CCGs) to promote integration, with a view to *'…securing that health services are provided in an integrated way…' and '…provision of health services is integrated with the provision of health-related services or social care services…',* where this can improve the quality of the health services and outcomes and reduce inequalities[2].

In addition a new duty, with an NHS Mandate, is to be placed on CCGs in an amendment to the Children and Families Bill (2013)[3] such that they will, by law, have to secure services in education, health and care)EHC) plans for children and young adults with special educational needs. This ties health in to the requirements within the Disability and Special Educational Needs green paper (2011)[4] which includes the implementation of a new single assessment process and Education, Health and Care (EHC) plan by September 2014. This will include specialist services like physiotherapy, and speech and language therapy. The rationale behind this new duty is to help to ensure that local authorities, health professionals and volunteers come together to organise services and that health services work with education and care services[5].

Other reforms to the provision of services for children and young people with special educational needs should help to ensure that parents and their children are firmly in control e.g. through personal health budgets, the extension of support until the age of 25; more comprehensive health, education and care plans and better coordination between all the services that support children and their families. These reforms are being trialled in 31 pathfinder council areas, with up to £6m additional funding nationally from the Government to support the measures. This includes Nottinghamshire County (excluding Bassetlaw and Nottingham City).

The personal health budget (PHB) initiative is a key aspect of personalisation across healthcare services in England. The personal health budget pilot programme was launched by the Department of Health in 2009 after the publication of the 2008 Next Stage Review. Over 60 areas were involved in the pilot programme, including Nottingham City and Nottinghamshire County. Nottingham City was one of 20 sites which were part of the in-depth analysis reported in the evaluation, reported in November 2012. The others were part of the wider learning.

As the PHB programme moves from piloting to early rollout, all current pilot sites will continue to be able to offer personal health budgets. Nottingham City is one of nine Going Further Faster sites, the leaders who will push ahead and implement personal health budgets at scale, including for people with long-term conditions.

By April 2014 everyone in receipt of NHS Continuing Healthcare will have the right to ask for a personal health budget. Within the same time it is planned that the clinical commissioning groups will be able to offer personal budgets on a voluntary basis more widely[6].

During a speech to the Policy Exchange in January 2013 Health Secretary Jeremy Hunt set out a new ambition for the NHS to become paperless by 2018[7]. He also confirmed that NHS England had agreed that hospitals should be able to share digital data from April 2014, and to adopt paperless referrals from April 2015 – this is reflected in the document Everyone Counts: Planning for Patients 2013/14[8] which outlines the incentives and levers that will be used to improve services from April 2013, the first year of the new NHS, where improvement is driven by clinical commissioners.

These legislative changes and policy will have a significant impact and can only be delivered by creating integrated structures and services, using a whole systems approach. This has been recommended in the past but there is now an opportunity to do things differently driven by this legislation and national policy, supported by the recommendations within this report.



By April 2014 everyone in receipt of NHS Continuing Healthcare will have the right to ask for a personal health budget.

1 (c) Transformation of commissioning

Commissioning is an on-going process, illustrated in the commissioning cycle diagram below; it must assess need and ensure that services meet that need. Commissioning is 'the process of allocating public resources to achieve the greatest gains in health and well-being within a defined population' [9].



The commissioning cycle:

Joint commissioning involves developing joint needs assessment and shared priorities and needs a joint agreement of resource allocation and aligned budgets. This then enables joint design of service specifications and work on procurement and contracting.

Integrated Commissioning means responsibility for the whole commissioning cycle delegated to an integrated team through a pooled budget under section 75 arrangements of the NHS Act 2006. In Nottinghamshire County a new team has been developed to facilitate this; an Integrated Nottinghamshire Commissioning Hub (detailed in section 7).

Intelligent commissioning maximises value from the total local public sector budget and is outcomes driven with widespread use of behavioural change for better public health. It empowers service users in the local community with some community led commissioning and semi-autonomous personalisation. The phases of the ICCYPH programme reflect the stages in the commissioning cycle as can be seen in the programme on a page shown on page 14.

Intelligent commissioning

Commissioning [which is] "based on the knowledge of potential providers and desired outcomes, based on user needs. Intelligent commissioners should be able to make judgements such as whether contracts or grants are the right way to fund a service, how important price should be in determining who wins a contract, and whether there is scope for innovative methods of delivery"

(Public Services and the Third Sector: Rhetoric and Reality 2008)

The NHS Change model

The Health and Social Care Act (2012 heralds the biggest change in the NHS since it's creation in 1948. The ICCYPH programme reflects this and is large scale change. The NHS change model below demonstrates all the elements required to make it effective. These have been kept in mind throughout phase 1 of this programme and will continue to be followed in the next phase.

The NHS Change model was developed with hundreds of NHS staff at all levels who wanted to build energy for change across the NHS by using an approach to improving patient care that everyone agreed on and that was based on solid research. NHS England uses it as a framework for making change happen in the NHS.



There are eight component parts to the model – they have to be used together in equal measure to make change successful. The framework can be used on any change that matters, no matter how big or small[10].

This report presents the findings from the work undertaken in phase 1 of the ICCYPH programme:

- Communication and participation with young people, parents and carers and stakeholders, including clinicians and GPs.
- Scoping and mapping to identify local and national practice, current service provision and developments and models and development approaches which will influence the outcomes of the programme.
- Population and service data collection and analysis.

Programme on a page

Joint Nottingham City / Nottinghamshire County Integrated Children and Young People's Healthcare Programme

The vision...to enable children and young people with acute and additional health needs, including disability and complex needs, to have their health needs met wherever they are. The services will support the child's life choices rather than restrict them and improve the quality of life for children and their families

From fragmentation...

Lack of co-ordinated support for children and young people with complex needs and disability and their families leading to inequity of access and potential safeguarding risks

Multiple providers/ teams working to different processes, policies and procedures leading to duplication and lack of efficiency/effectiveness, having a negative impact on children, young people and families

Too many acute and emergency attendances and admissions for conditions that could be treated at home or avoided

Children staying in hospital for too long

Phase 1 – ends 31st March 2013

Scoping, mapping and consulting:

- Childrens Community Services like Nursing, Occupational Therapy, Physiotherapy, Speech and Language Therapy, Paediatricians, Short Breaks
- Children and young people: aged 0-18 years with acute and short term illness, and long term conditions; aged 0-25 years with disability and complex needs, life limiting, life threatening conditions including palliative and end of life and neonates
- Consulting and engaging children, families and professionals
- Population and service data collection, analysis and mapping

Post March 2013 (to be confirmed):

Phase 2

- Developing
- Planning
- Specifying
- Commissioning

Phase 3

- Implementation
- Evaluation
- Consolidation
- Monitoring and continual improvement

Our mission...to commission and provide co-ordinated, integrated community healthcare services for children and young people and their families which improve their health and wellbeing and their life chances

...to integration

Single point of access and co-ordinated assessment, treatment and review so that families experience a seamless service that is centred around the child / young person and family promoting independence and quality of life

Improved safeguarding outcomes

Children and young people and their families are enabled to lead as normal a life as possible

Improved access and equity of service provision with genuine choice for children, young people and their families

High quality, cost and clinically effective services with consistent staffing

Satisfied and highly motivated teams ensuring the right skills in the right place at the right time, every time.

2012.11.15 V2 (final) ICCH Programme on a Page

2

Children, young people and families



2 (a) Parents and families are frustrated: change and improvement is long overdue

This report is different to others because it comes with an **ASK**; it is asking you, the reader, as an individual, and as a representative of your family or organisation, to make a commitment for change – change to the funding, commissioning, management and delivery of services for children and young people with additional healthcare needs and their families.

It tells of the tireless 'fight' by parents and carers on behalf of their children to be listened to, to be understood, to obtain services and support to ensure they have their needs met and to have the best health they can so that they can enjoy and achieve in their lives. This is an ongoing concern for parents as shown in comments from as long ago as 1995. In the report 'The needs of disabled children and their families' [11] 47% of parents said *"I have to fight for everything my child needs." Sadly nothing has changed for them in 2012," At every stage we have had to fight for services – at one time even threatening legal action until we got our way. The whole process has been physically, emotionally and financially draining."* [12] Presenting quotations from parents from 1995 serves to illustrate an entrenched view from parents that should not be ignored. The cost to children and families on the quality of their lives and to services is on-going and clearly unacceptable.

Change is long overdue.

The frustration and exhaustion from that fight, in addition to the daily demands of being both a parent and an informal carer takes its toll on personal resources and resilience.

Parents say *"Looking after your child is a 24/7 job for parents, but there is no support for parents. I had three children all under 3 years of age of whom two had a disability. It drove me mad – I've gone mad and had to deal with it all on my own."* This has an effect on health *"the stress has got to me – I'm on medication myself for depression",* and on family relationships – partnerships, marriages and with siblings. It also has an impact on the economic activity of parents and on relationships and social development of siblings as a result of the perception of peers, and on educational attainment. [13]

47% of parents say "I have to fight for everything my child needs."

'The needs of disabled children and their families' by Bryony Beresford at the Social Policy Research Unit, University of York JRF (1995)

In families with children and young people who have long term conditions (LTC) disability and special educational needs or life limiting and life threatening and end of life (EOL) care needs the role of carer tends to fall to the mother. A high proportion of mothers are single parents and either work part time or are not in employment.

Some social groups are identified as particularly at risk of poverty, including for example families with children with disability, special educational needs (SEN) and those from gypsy traveller communities.[14] The average income per individual householder after tax, but including benefits, is £16,034 a year. In Nottingham City it is £10,834.[15] Nottingham City has 23% of children in severe child poverty, (East Midlands 14%, England 13%). This ranks Nottingham City as having the sixth highest level of child poverty in England. Nationally 29% of families with a disabled child are living in poverty. [16] Additionally many families with a disabled child attending special schools in Nottingham City and Nottinghamshire County live in an area with high Income Deprivation Affecting Children Index (IDACI),[17] which is a subset of the Indices of Multiple Deprivation (IMD), and combines statistics about the numbers of children in households receiving a range of benefits. Low income families face additional challenges, which in turn impact upon their health which means they are more likely to experience health inequalities. [18]

It is evident there is a case for change to improve the access and management of services, for a targeted approach for this group of families and informal carers for screening, early detection, intervention and health improvement initiatives.

When asked what a good service would look like, a parent said: *"…(a service) that looks at all the needs of the individual not only the person [child] medically but also socially, emotionally, economically and the whole family…(and)…it must take into account the specific needs of the family."*[19]

Personalisation through Personal Budgets and Direct Payments will give families more control, independence and freedom. It gives the opportunity to plan care around the child and family needs and within a family setting and routine rather than care delivered around service provision.



This report is different because it comes with **'A BIG ASK'**, a pledge to commit to change; to constructively challenge your role and to use your influence to effect and support change for children and families.

It is unusual and generally thought to be unacceptable to appeal to policy makers and managers to make a judgement and ask them 'to do the right thing' as there is conflicting opinion about whether that is politic or indeed what the right thing actually is. This report is different because it does this.

Proactive planning and prevention are needed rather than reactive service arrangements.

There are certain principles about the success of communities that are well established and understood: liberty, fairness, respect and family. The NHS Constitution[20] provides the health community with principles and core values. It states that everyone counts, that organisations and partners need to work together for patients [and families] to improve lives; that patients' have a right to privacy, respect and dignity and to commitment to quality care and compassion. Compassion is demonstrated through care and competence, good communication, courage and commitment. Success criteria are improvements in safety, improved clinical outcomes, and improved patient experience, achieved through innovation.

"People don't listen, they always know better....I know my child's needs better than anyone."

Nottinghamshire parent (2012)

Change is long overdue.

"....my daughter has a Common Assessment Framework (CAF) but the services are not joined up. All the assessments were separate and not joined up care. They don't work with each other or the parents... there is no parental involvement, no consultation, no joint decision making with parents – you're not invited to meetings – you're kept in the dark...we are the parents – we care for our children – they [health professionals] should be talking to us and finding out from experiences."

CQC Special Review (2012)

Better health outcomes for children and young people: Our pledge (2013)[21] stated that *'For the very first time, everyone across the health and care system is determined to play their part in improving health outcomes for children and young people.'*

This report is different because it appeals to you, the reader, to make a judgement to commit to the vision and the mission of this programme, to examine the evidence presented, consider the experience of children, young people with additional health needs and their families and decide what actions **you** will take to make changes for improvement. The **'BIG ASK'** is for you to care, to be compassionate and to be courageous, and communicate your commitment to meet the challenges in 'doing the right thing.'

The perception of families is that of one NHS and one service. The aim of this programme is to make that perception of 'one service' a reality.

One chance at childhood, one chance at parenthood...

2 (b) Meet some families...

Families with children and young people with additional needs are diverse. The **fictional scenarios** below, developed with local parent groups, illustrate this and are representative of many families who use the services. They have been used throughout this report as a reference to show the challenges encountered and the difference that the recommendations for change will make to them.



The Forrester Family

Mrs Forrester is a single parent with two daughters aged six years and eight years old. Her youngest daughter has complex needs arising from a genetic condition.

She is a full time mum and has lots of extended family support, preferring this as far as possible to statutory services. This means that she has little 'down time' as an individual, and is relatively isolated. She often feels tired and stressed and her level of resilience is reducing with each family crisis. She drives a family estate car.

Her youngest daughter has a genetic condition with neurological and orthopaedic symptoms. She has had orthopaedic surgical interventions requiring nursing support, physiotherapy, occupational therapy and equipment services. The family have occasional short breaks support.

Her other daughter has normal development and is healthy and thriving with well controlled asthma. The sisters love to go swimming together.



The Trent Family

Mrs Trent is a single parent with 3 children; a son and daughter from Mrs Trent's first relationship who are 9 and 7 years old and a daughter from a second relationship who is 16 months old. The family lives on state benefits as neither of the fathers of her children nor Mrs Trent are in employment. She doesn't own a car and relies on public transport or Third sector services.

Her son has complex needs and is physically disabled with orthopaedic problems and has orthotics and is an occasional wheelchair user. He attends Special School and receives nursing support, occupational therapy, physiotherapy and sees a dietician.

He has severe communication problems with orthodontic and speech and language therapy needs. He also has on-going sight and hearing difficulties and sees an audiologist and ophthalmologist.



The Sherwood Family

The Sherwood's are parents of a 2 year old son who is their only child. Their son has complex needs arising from a life limiting degenerative genetic condition.

Dad works full time on shift rotation and is a skilled manual worker. Mum was a teaching assistant in a local school but is now a full time mum, supported by statutory home care. Their son is a lively little boy who smiles a lot and delights in noisy and colourful toys. They have a family car primarily used by Dad for travelling to and from work; Mum has access to it on occasions, fitting around shift patterns.

Their son receives services funded from Continuing Care. He has learning difficulties with epilepsy and has a MIC-KEY button in situ for feeding and administration of emergency medication, under the supervision and support of community nursing services. He also has co-ordination problems requiring physiotherapy (including chest therapy), occupational therapy and equipment services, and visual impairment requiring ophthalmology. The family access short breaks and nursing service for overnight home and end of life care.



The Loxley Family

The Loxleys have two daughters who are 13 and eight years old. Their youngest daughter has physical disability arising from birth trauma and is a wheelchair user.

Dad is self-employed and has his own building company and Mum (not in the photograph) is a part time physiotherapist. They have private homecare - a nanny who carries out some personal nursing care and domestic cleaner and they have a well-managed home with adaptations.

They have their own transport; Dad drives a family car (in addition to the company builder's van if needed) and Mum drives a people carrier with adaptations.

Their youngest daughter has good cognitive skills, attends mainstream school with support and has integrated well. She has physiotherapy, occupational therapy and speech and language therapy.

Their eldest daughter has normal development and is healthy and thriving. She loves going shopping with her sister and they also enjoy computer games together. However she has begun to question why her sister has problems and she hasn't, is angry on behalf of her sister and frustrated because they are unable to share things together. She also feels guilty that she is healthy and able.

2 (c) A case for change – un-complicating the complexity



"Some children have complex medical or health needs which present a potential barrier to that child attending school and learning. The barriers can sometimes be about the complexity of a child's specific condition, but more often they are about the complexity of the organisational features and arrangements that are required. It may be more appropriate to rename the project, 'Children with health needs that require complex arrangements."

Source: Project to examine how we can best meet the needs of children and young people with complex health needs NCC Regional Innovation Project (2008)

There is a big difference between 'complexity' and 'complication'. Complexity is a matter of fact but complication is an unnecessary addition to complexity. Complication is frequently generated by poor management, inefficient processes, organisational silos, lack of skilled fresh talents, lack of timely and accurate information and an inefficient decision-making environment.[22] **Complication is waste.**

For example over time, processes can become burdened with rules and considerations that, although introduced with good intent, often end up complicating those processes for services, families and children. Some of the consequences of these complications can be seen in the two anonymised summary case studies on page 20. Whether a child's needs are complex like Alice or less complex, like Emma, the process of accessing services and support is unnecessarily complicated and disruptive to family life.

As highlighted in the comments from Alice and Emma's parents', parents and carers are generally happy with services once they receive them, rating them very good and excellent – it is the process of accessing, the coordination and management that is not satisfactory.

These case studies quantify the complications in terms of contacts and interactions with organisations, professionals, assessments and services. They highlight that parents are not only parenting but are carers and also managers and co-ordinators of services. They do not detail the affect this has on marital and family function, the effect on economic activity, health and wellbeing and the resultant health inequalities.

Un-complicating the complexity

A key aim of the development of an integrated model must be to remove unnecessary and wasteful complications from the system to enable resources to be focussed on meeting the complex needs of these children and young people.

"Parents are not only parenting but are carers and also managers and co-ordinators of services.

Special educational needs (SEN) and moderate health needs	Special educational needs and disability (SEND) and complex care needs
Emma* (born 1992) 13 years in education health and care	**Alice*** (born 2003) 10 years health and social care support, six years in education (mainstream and special)
Primarily neurological and developmental condition	Congenital, respiratory, neurological, ENT and orthopaedic conditions
Used six statutory and two private services also two private funding sources for support to meet needs not met by statutory provision	Used over 50 statutory services, three private services and three voluntary sector offering additional family support
44 assessments completed and some of those are on-going	Over 55 initial assessments. Completed. 34 services still active and assess/ review six monthly
19 Professionals involved	Currently over 28 Professionals involved, this has varied over the years
10 organisations involved	55 organisations involved
Emma's parent said: "The most frustrating thing for me was that when she was around seven years old I knew something wasn't quite right for Emma and I knew it was associated with school. She was great during school holidays. I knew my child well: she has a strong character and was an intelligent, articulate child capable of discussion, negotiation and reaching understanding and compromise. Over a period of time I noticed that she had become impatient, easily frustrated and short tempered. She was, in plain language, unhappy. I couldn't find out from her what was troubling her. I spoke to her teacher at school about it on three occasions but felt fobbed off and not taken seriously. I later had the same experience with teachers at secondary school, the family GP and the practice nurse. I am an intelligent, well educated professional used to being listened to, but found myself in a position where I was not being treated seriously and what I had to say was meaningless. **I learned almost immediately that I had to fight to be listened to and heard. I became a warrior parent and Emma has learned to do the same and we haven't stopped fighting yet."**	In one month Alice missed 12 school days attending a variety of health, social care and education appointments and her parent wanted to share the following thoughts: "The services my daughter receives are generally excellent but when it comes to information, I do not know who holds what, where it is held and with whom it is shared. At times the volume of appointments and coordination of services can feel like a full time job. I often provide the same information to different services, which can be frustrating. I know about the services my daughter receives but I do not know what else might be available. Other parents are generally the best source of information for this. Professionals are often too busy to take on the role of key worker or lead professional which then places further pressure on parents to coordinate services. **I should stress that the care received is good; it is the organisation that gets in the way!"**





3

Consultation and participation



Communication, consultation and participation were with a wide range of people: young people, parents, carers, and stakeholders including clinicians, GPs and professionals from health, education, social care and the third and independent sectors.

3 (a) Parents, families and young people consultation and participation

Previous (2008-2012) national and local consultation findings were reviewed and the following new joint Nottingham City / Nottinghamshire County engagement and participation work was undertaken as part of phase 1 of the ICCYPH Programme (see appendix 2 for details).

From November 2012 to April 2013 there were six consultation events with young people and their families and carers at various venues including Barnardo's Butterfly Project, Carin4Families at Nottingham University Hospitals NHS Trust (NUH), Portland College Oak Field School and APTCOO, seeking their experiences of using services.

The following 'Families' statement of expectations', was developed from themes identified from the consultation and participation work with parents, families and young people and with reference to the values developed by the Children and Young People's Inter-Agency Group (CIAG)[23] and the UN Conventions on the Rights of the Child,[24] and on the Rights of Persons with Disabilities.[25]

As you can see families are asking for respect and collaboration and for the system, processes and services to support and serve them in a way that enables them to enjoy as normal a family life experience as possible like any other family.

What they are asking for is not extraordinary or unrealistic. The message is simple and only what we may wish for ourselves.



The **BIG ASK** is 'Can we do better?'

Families' statement of expectations

Our values are…

1. Respect
2. Collaboration
3. Continual improvement

My family's expectations will be met when…

1. We are consulted and listened to, heard and treated with respect as experts on our/our child's condition and have our views taken into account at all times.
2. We can easily get information, advice and guidance, and the services and supplies that we need, when we need them, so that our family can enjoy the best possible health and fulfilling lives. This should enable and support our roles, lifestyle choices and aspirations.
3. There is collaborative, joined up and timely planning and service delivery, with all parts working as a whole across all organisations and agencies involved in every aspect of our children's care.
4. Each of our children is treated as an individual.
5. There is timely communication and shared documentation including core essential information about our children, their condition and their support between all those who need to be involved.
6. We are confident that there are enough staff, who have the right knowledge, skills and expertise for what they are there to do, and they demonstrate this by empathy and understanding in all contacts.
7. Our children are supported to achieve responsibility for themselves as adults and the family is supported during this period of transition to adulthood and reduced dependence on the family.
8. We can see that everyone involved in our children's care is committed to continually improving what they do.
9. Our children are seen in age appropriate environments furnished and equipped to meet their needs, this takes account of chronological and developmental age.
10. At all times our children are protected from harm.

Parents involved in the consultation and participation work undertaken in Phase 1 of the programme were keen to be involved in the development phase and in prototyping proposed solutions. In addition The Nottinghamshire County Health and Wellbeing Board has agreed and signed a Nottinghamshire Disabled Children's Charter, as per The Children's Trust, Tadworth (see appendix 3). This is under review in Nottingham City.

Recommendations

1 The 'Families' statement of expectations' should be used as guiding principles in the design, commissioning and provision of services and to develop standards to measure service user experience against.

2 Involve parents and young people in the development phase and prototyping of proposed integration.

3 (b) Multi-agency, multi-professional stakeholder consultation events

Two stakeholder consultation events were held, in July 2012 (Integrated Community Nursing Project event) and in February 2013 (Right place, right time, every time: from fragmentation to integration event

The stakeholder consultations identified key themes and interdependent elements of an integrated model incorporating streamlined access, co-ordinated assessment and delivery of care, supported by shared information and key workers. Key themes from the consultation are shown in the table on the following pages.

Key themes from the stakeholder events and the implications for children young people and families

The stakeholder consultations highlighted that streamlined access, co-ordinated assessment and delivery of care, supported by shared information and key workers with a clearly defined, structured role are inseparable components of an integrated model of care.

Key themes from stakeholder events

	Key themes to support integration	What would this mean to children, young people and families?	Family example
1	Collaborative integrated commissioning and resources with statutory partners. Potential integration with statutory partners' SEND legislation projects / programmes.	Parents don't need to know which pot of money funding for care comes from – can focus on meeting needs. 	The **Sherwood family** are parents with additional carer roles. The first few years of parenting is always challenging, with a lot to learn and many changes to absorb. Having a child with complex needs exacerbates this and parents need support at this time to navigate the system of support provided and available. Collaborative integrated commissioning of services would reduce the number of interactions to have their child's needs met.
2	Single point of access / specialist hub for information and access to services – accessible to professionals and families. Local offer to be developed.	One stop shop for information and access to services. Better co-ordination of contact with different services – in same place, same time. Proactive planning for life course. 	The **Loxley family** already has additional personalised support to meet the family needs. It would be useful for them to have access to information about all services available which they can access or arrange with confidence using either Direct Payments or independent finance. This is particularly useful in preparing their daughter for future independent living and transition planning. They could also seek help to support their older daughter come to terms with her emotions of having a sibling with additional health needs.
3	NHS Number as unique identifier. Shared records using new and existing technologies – accessible to professionals and parents/young person. Web based tool.	Not having to constantly repeat child and family's story. Parents and CYP know what information is held on them. More awareness and control over content and how, when and with whom records and information are shared. Increased safety with one record (i.e. one copy which will always be the current copy) – consistent information available to all who need it. Enables data protection requirements to be met.	This would be of benefit to **all families** and would enable more control and clarity over whom or what services get what information. At the moment there is no way for families to track this. Families say they want to share core information about their child's needs and the way their families live so that services can be designed to ensure as normal a life as possible. They also say that they would like additional specific information shared with specific services on a need to know basis. This means they retain control dignity and privacy in the same way that other families do. 
4	Clearly defined, structured and supported key workers that would liaise with lead professional and SEND navigator role – this may be a dedicated role or part of existing roles (to be explored).	Clear and consistent support and advocacy from key workers with capacity to undertake the role. Parents only need to be key worker if choose to, not because they feel they have to.	The **Forrester Family**, and particularly Mrs Forrester who, as a single parent, is fiercely independent and feeling stressed as a result is likely to benefit most from a stable and supportive relationship with a key worker. If Mrs Forrester is well supported the family as a whole will benefit.
5	Co-ordinated multi-disciplinary, multi-agency assessments, core information recorded and one plan which includes a single plan or an EHC plan.	Reduced duplication of information. Specialist assessments contribute to one plan. Increased safety and reduced time spent during assessments with single plan.	This would especially benefit both the **Trent and Sherwood families** as their children have particularly complex needs. Mrs Trent's son has additional social care needs and the Sherwoods' son will need additional palliative care services over time. Currently both receive multiple and complex assessments and plans, co-ordinating and collating them in one place would reduce duplication and complication.

	Key themes to support integration	What would this mean to children, young people and families?	Family example
6	Network model based on Family Friendly Framework, with network management – life course approach from birth to adulthood – not a linear model. Generic and specialist tasks with 365 day support to prevent emergency admission. Parents consulted and listened to as experts.	Seamless access to proactive services, effective planning and reduced disruption to child's education and the family's economic and social functioning. Reduced anxiety and disruption from unplanned admissions and discharge arrangements. Services planned around the life course means ease if transition to adult services.	Again, both the Sherwood and Trent Families would benefit from this. Mrs Sherwood has restricted access to transport. Mrs Trent has no transport and attending appointments is a significant undertaking for a single mum with three children and a limited income. An integrated network of flexible services with staff with generic skills in addition to specialised skills and roles would reduce the amount of appointments to attend and the related travelling and the related disruption on school and economic activity. A life course approach and pro-active planning would ensure a smooth transition to adult services.
7	Increased GPs' education, knowledge, involvement and awareness of this group of children.	Improved early support and communication between healthcare professionals involved in care. Local access to understanding general medical services for 'normal' childhood illnesses, avoiding special trips to specialist paediatric services or having to resort to visit to emergency services. Less anxiety at transition when GPs become more involved in care as GPs already know the child and family.	**All families.** It would enable them to normalise the usual childhood illnesses, growing up and becoming independent adults and leading as normal lives as possible.  
8	Flexible and agile services adapt to meet CYP/family needs not CYP/family adapt to service needs.	Right support available at the right time in the right place – follows the child. Families able to live as normal family life as possible.	**All families** would benefit from this. CYP and families would be enabled to live a normal family life in spite of their complex needs, rather than being restricted because of them.
9	Integrated services where possible and interlinked provision. 	Fewer services and professionals to deal with. Easier co-ordination of services and less time spent on arranging and following things up. More family time.	All families but the **Forrester family** and the **Trent family** in particular as there would be less to manage resulting in reduced demands and more down time for self and family. An increase in quality family time and satisfaction that as parents they are making the most of their opportunity to parent well – one chance at childhood, one chance at parenthood.
10	Mobile workers, working or based in various places on rotation or for relatively short periods to facilitate – in-reach (to hospital) and outreach working (in the community). 26 27	Increased confidence that the child and their specialist needs are known and will be met during inpatient spells without parent having to be there 24/7. Better continuity of care and individualised knowledge of the child. Child's personal and specialist needs safely met wherever they are.	**All families** will benefit and can be 'visiting parents' instead of 'in hospital carers'. Admissions to hospital would be less frequent and for less time and discharge planning would be better coordinated and managed. A seamless service that would feel less disruptive as children passed through hospital care rather than 'going in and out' of hospital. Less disruption to economic activity and family life.

Many examples of existing good practice were also identified to continue doing/hold on to which could be shared, spread and built upon when developing a new model of service delivery. These include:

- Liaison posts that prevent admissions and facilitate discharge
- Skills/expertise/experience of existing staff and their commitment and passion.
- Early support pack/start box (blue box) – needs to be embedded into universal services (e.g. health visiting and children's centres)
- The integrated models that already work in localities e.g. special schools. Families benefit from a 'one-stop shop' (single point of access). During consultation stakeholders used the terms 'single point of access' and 'one-stop shop' interchangeably
- Hold onto and build on strengths and quality of current services. Clinical, hands on delivery with children…more capacity for it
- Unified documentation (in some areas)
- Continuing care framework and assessment
- Parents network and parent and carer support forums.
- Specialist support services e.g. information library, CDC, HV coordinator
- CAF is the vehicle to integrated seamless assessment/ care planning. Needs to be embedded across all services.
- Specialist pool of knowledge that can deliver training to frontline staff.
- Voluntary sector (e.g. Butterflies, Rainbows etc.)

3 (c) GP online consultation survey

During March and April 2013, an online survey was circulated to 778 GP's – 279 in Nottingham City and 499 in Nottinghamshire County (not including Bassetlaw) – to gain an understanding of their awareness of children with additional health needs and disability, whether they proactively identify carers and siblings in their records and what they see as their development needs in this area.

> 50% of parents say "They (professionals) do not know what it's like to look after my child."
>
> *'The needs of disabled children and their families' by Bryony Beresford at the Social Policy Research Unit, University of York, JRF (1995)*

Due to the small number of responses (25) and inconsistencies in some responses from some GPs from the same practices relating to practice systems the results are of limited quality or validity. Of those that responded only 20% felt confident or very confident about supporting children and young people with acute and additional health needs and almost half (48%) would like to be more involved in the care of the children and young people in this programme.

Training and development needs identified included training to gain confidence in communicating with children with speech, language and communication difficulties and children and families where there are palliative or end of life care needs. Also training to gain confidence in clinical management of children with complex needs and information on access to resources e.g. support groups, social care support, palliative support for families and bereavement support. This is one of the recommendations in the CYP Outcome Forum recommendations.[28]

> "I have struggled to find a GP who understands my child's condition and needs."
>
> *Parent, Nottinghamshire (2012)*

There were concerns that resources in practices are already stretched and this is a barrier to GPs becoming more involved in the care of these children and young people. Some specific issues were also identified in university practices around supporting students and children of students with complex needs and disability.

One GP suggested developing a Practice Specific Objectives Target (part of a Nottingham City incentive scheme) for GPs to update patient registers with specific categories (e.g. carers) and define some parameters of care which would help GPs to support children and young people with additional health needs and their families with more holistic care.

Local and national findings from consultation demonstrates that parents, professionals and young people with additional health needs and disability want more involvement of and better communication with GPs as a key link in the life course of individuals and families and to avoid having to resort to emergency hospital and specialist services for 'normal' childhood illness.

The charity Contact a Family has produced a set of resources[29] to support GPs to enable families with children and young people with disabilities to access GP services and to reduce hospital admissions. This includes a practice self assessment questionnaire to baseline and identify key areas of focus.

Recommendations

3 Promote 'Contact a Family' resources for General Practice and encourage GP practices to complete the self-assessment in order to identify key areas of focus. This will support GPs to enable families with children and young people with disabilities to access GP services and to reduce hospital admissions.

4 Develop education and training opportunities for GPs and practices.

5 Identify GP champions to raise the profile of the ICCYPH programme in phase 2.

6 Develop a Practice Specific Objectives target for 2014/15 (Nottingham City CCG) to update patient registers with specific categories (e.g. carers) and define some parameters of care which would help GPs to support children and young people with additional health needs and their families.

4

Scoping and mapping of current service provision



4 (a) Scoping – groups of children and conditions

The ICCYPH programme includes children and young people with acute or additional health needs including disability and complex needs. These include the following four groups:

Group 1 - Children and young people with acute and short term conditions, 0-19 years (updated from 18 years)
Group 2 - Children and young people with long term conditions, 0-19 years (updated from 18 years)
Group 3 - Children and young people with disabilities and complex conditions including those requiring continuing care and neonates, 0-25 years
Group 4 - Children and young people with life limiting and life threatening conditions and illness, including those requiring palliative and end of life care, 0-25 years

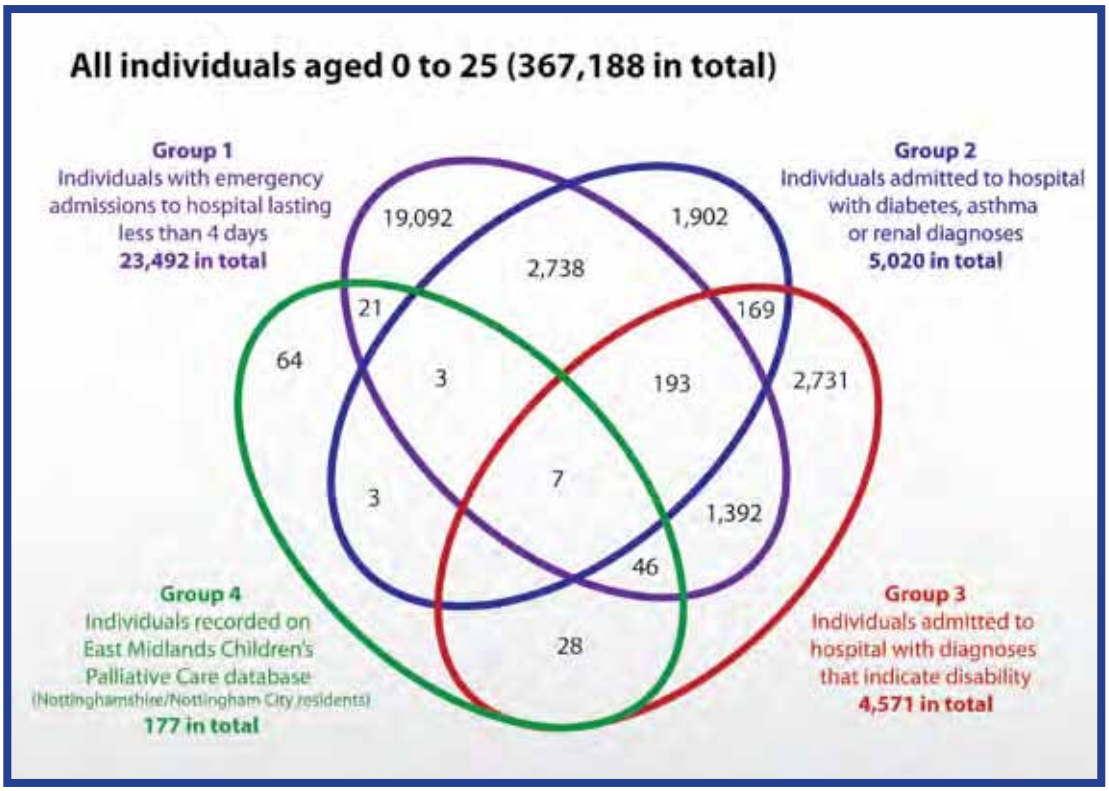
The mapping/list of conditions against the four groups of children shows that group 3 includes the widest range of conditions (see appendix 4). During their development and/or the progression of their condition or illness individual children and young people may and often do move between and overlap these groups, for example many disabilities and complex conditions (group 3) are life limiting or life threatening (group 4). This is illustrated in the graphic below, which highlights the complexity of need that this programme is addressing:

Integrated teams and a flexible framework of services and pathways are required to meet the needs of these children and young people; linear pathways do not meet the complexity of needs. The recommendations made and detailed throughout this report are in line with those in the Strategy produced by the Children and Young People's Health Outcomes Forum (2012).[30] Appendix 5 gives a summary of these recommendations, by groups 1 to 4.

4 (b) Scoping – services

A detailed scoping exercise was undertaken to map the current specialist community health services for children with acute and additional health needs and disability, including complex needs in Nottingham City and Nottinghamshire County (not including Bassetlaw), against a number of criteria including location of service delivery, referral sources and geographical coverage. Various sources of information were used including review of service specifications and consultation with providers. An extract of the detailed service mapping document can be seen in appendix 6. Note: whilst care has been taken to present an accurate representation of the information/ data ongoing changes may have taken place.

Populations: how groups overlap: ages 0 to 25 years (Nottingham City and Nottinghamshire County CCG populations including Bassetlaw) – all numbers are counts of individuals



This chart represents the total number of individuals identified for analysis. Groups 1, 2 and 3 are derived from the number of individuals admitted to hospital from March 2011 to April 2013. Group 4 is derived from the East Midlands Palliative Care database and is the number of individuals resident in Nottinghamshire with a valid NHS number recorded.

On page 31 is a snap shot mapping of services for children and young people with acute and additional health needs, including disability and complex needs, in Nottingham City and Nottinghamshire County (excluding Bassetlaw as this was not available).

The main focus is on specialist community health services which are core to this programme, with some key secondary care, social care and education services and reference to third sector services, groups and organisations that families may access.

This is a snap shot and as such is not intended as a complete picture of the many services available. It is an attempt to illustrate the number of individual services and complexity of the service landscape for this group of children and their families to navigate.

In addition to the services shown in the service mapping there are a range of other local and national third and sector organisations which provide services and support for children, young people and families, including equipment and resources. They often work in partnership with statutory organisations and play an important role in protecting and supporting a child and their family. Third sector organisations also have an important role in providing information and resources to the wider public about the needs of children and young people.

The detailed scoping exercise and snap shot mapping together have highlighted that:

- Many service specifications require updating, to be more clearly defined without being prescriptive.
- Specifications use different age ranges and definitions – these need to standardised to be consistent across the system as appropriate.
- The majority of health services provide care to Nottingham City and Nottinghamshire County populations – this supports the joint programme in phase 2.
- Similar services are being delivered in the same settings e.g. children's community nursing services; health and social care occupational therapy services – this suggests potential for streamlining / integrated working to release clinical resources and reduce duplication.
- There are a wide range and number of individual services – this shows potential for co-location and integration (e.g. co-ordination or interlinking of therapy provision for children and young people with multiple problems).
- All the services have their own referral and assessment processes – this creates duplication and repetition for children and families and referrers.
- Many services have what they describe as a 'single point of access' – this is confusing.

The service mapping exercises provide further evidence of fragmentation, duplication and potential opportunities for integration for example:

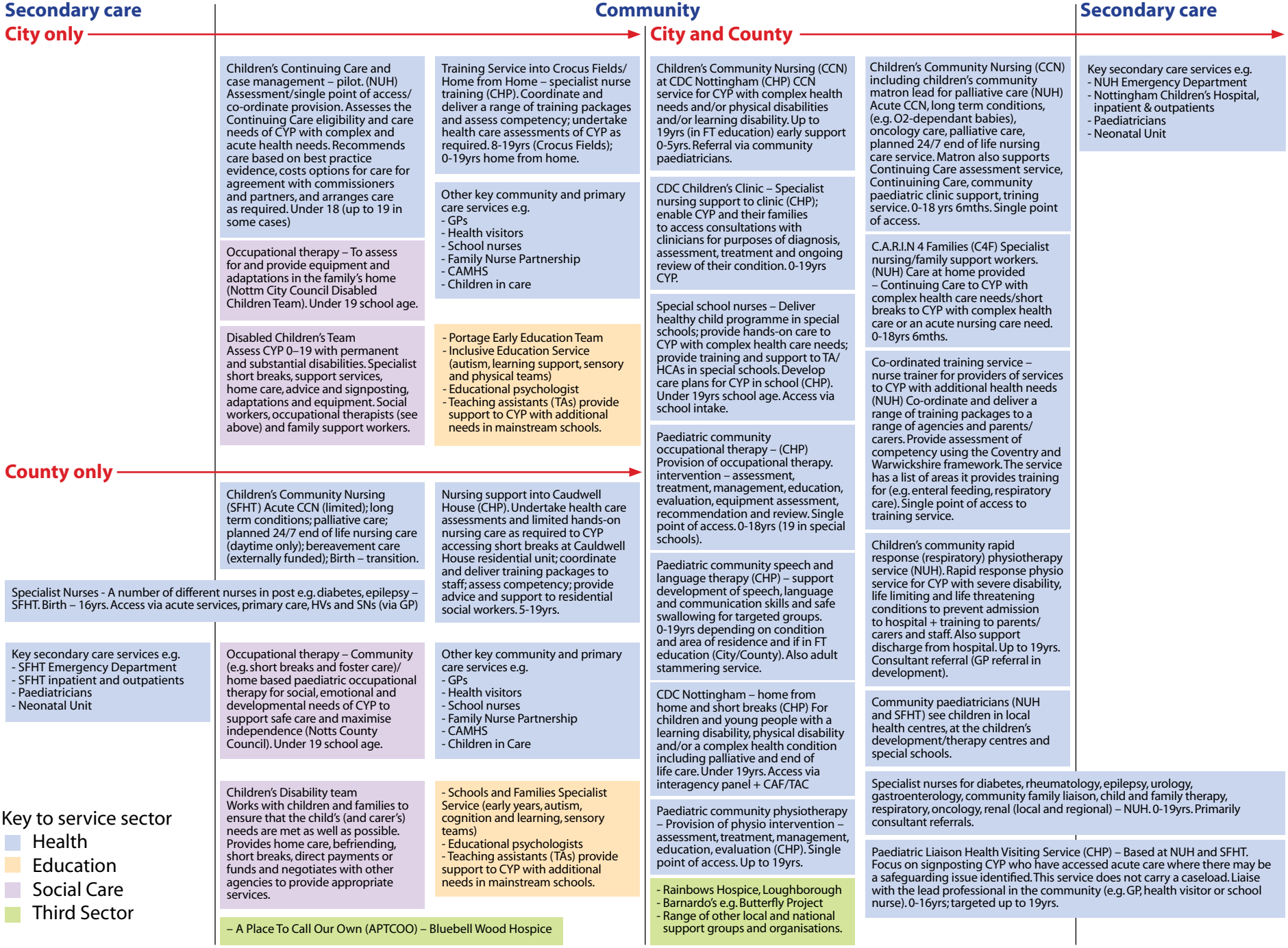
- Integration of children's community nursing services
- Integration of special school nursing with children's community nursing services
- Integration/interlinking of health and local authority services (OT, PT and SLT). A Nottinghamshire County OT pilot (2009-11) showed favourable results in reduced waiting times, improved service, understanding of roles and integrated working.

Snap shot service map

Key to acronyms and abbreviations

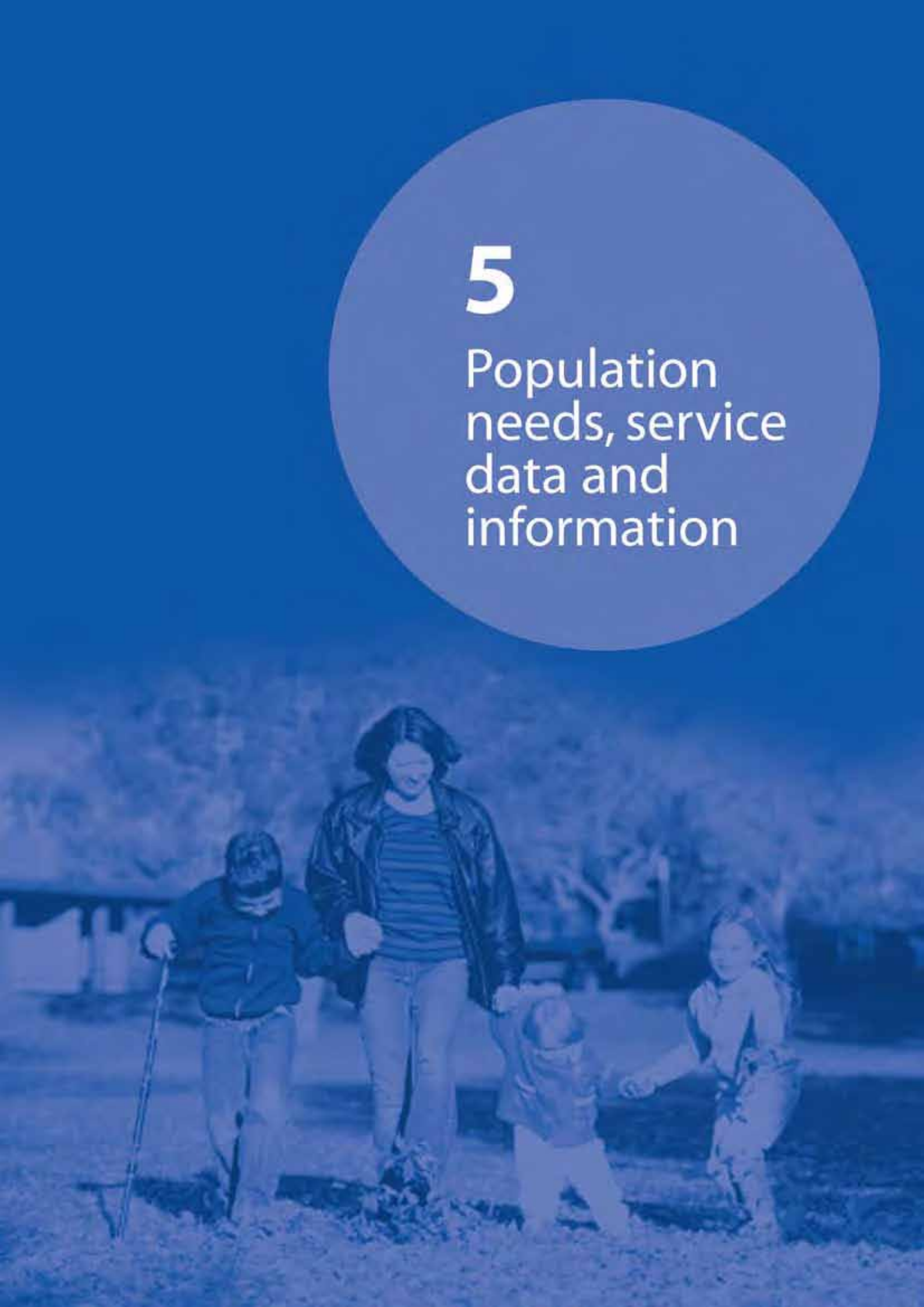
CAF	Common Assessment Framework
CAMHS	Child and Adolescent Mental Health Service
CCN	Children's community nurse/nursing
CHP	Nottinghamshire County Health Partnerships
CYP	Children and young people
FT	Full time
GP	General practice / general practitioner
HCA	Health care assistant
HV	Health visitor
Nottm	Nottingham
NUH	Nottingham University Hospitals NHS Trust
Physio	Physiotherapy
SFHT	Sherwood Forest Hospitals NHS Foundation Trust
SN	School nurse
TA	Teaching assistant
TAC	Team around the child

Snapshot service map



5

Population needs, service data and information



5 (a) Joint Strategic Needs Assessments (JSNA)

Joint Strategic Needs Assessments (JSNA) 2010
The Children's chapters of both the Nottingham City JSNA (2010) and Nottinghamshire County JSNA (2010) are currently being revised to the same format and updated. Publication is due later this summer.

Nottingham City (JSNA) 2010
The Nottingham City population of 0 to 19 years is approximately 57,900. Of this there are estimated to be 4,000 disabled children, of which 900 are severe. The disabled population has increased by 70% in the last 30 years (1976 –2006). The fastest growing section of the disabled population is the under 16 age group. The number of children born with complex needs and surviving into adolescence and beyond is also increasing.[31]

School census data shows an increase of 28% within all disability groups and 48% within groups with higher needs between 2004 and 2009. This is a greater increase than was recorded in the last JSNA, although it is over a longer time period of five years.

It would appear that the incidence of young people with SEND is rising rapidly in Nottingham, and this increase is greater for those young people with the most complex needs. Figures generated to support the Building Schools for the Future (BSF) programme predict a rise of over 15% in demand for special school places by 2019 (Nottingham City JSNA, 2010). [32]

> There are between 7,000 and 12,000 children and young people who experience some form of disability in Nottinghamshire.

5 (b) Nottinghamshire Joint Needs Assessment for children and young people with disability and SEND (2012)

Key messages from the disability and SEND needs assessment:[33]

- There are between 7,000 and 12,000 children and young people who experience some form of disability in Nottinghamshire. The prevalence of severe disability amongst children and young people is increasing because of higher survival rates of children and babies with complex needs. Even if disability prevalence remains constant, the number of children with disabilities will continue to increase as the population of children and young people is forecast to grow.
- Children who experience poverty have increased rates of disability and ill health. Nationally 29% of disabled children live in poverty.
- There has been a 60% rise in young claimants (aged 0-24) of Disability Living Allowance in Nottinghamshire over the last decade.
- The number of children and young people with life limiting and life threatening conditions has doubled over the last decade.
- Disabled children and young people have many of the universal needs of their non-disabled peers.
- Substantial inequalities persist between disabled children and young people and their peers e.g. health, education and access to opportunities.
- Transition to adult services can also be particularly challenging.
- More children have choice and access to a wide range of short breaks.
- The number of children with disabilities accessing children's centres has increased.
- The number of children and young people with disabilities receiving a direct payment has greatly risen since 2007/8.
- Over the last 10 years there has been a 72% increase in the number of accepted UCAS applications for disabled young people compared to a 16% rise in non-disabled peers.
- There is a lack of coordinated data on disabled children and young people and performance information from the services that they access.
- Consultation with local families in 2009 indicated that services on offer do not always help with the complex 'juggling act' of looking after a family with a disabled child and that it is also difficult to find out what services are available.

5 (c) Health needs within special school settings

Key messages from the disability and SEND needs assessment:

There are a number of schools across Nottingham City and Nottinghamshire County for children and young people with disability and special educational needs. Children and young people are admitted at various ages dependent on their needs (many have multiple needs that would be met at a specific school) and location. Schools' population health needs assessments have been completed at a number of the schools and have identified the following as levels of high need requiring specialist interventions:

Activities of daily living

- Airway and breathing support
- Consciousness e.g. seizures
- Eating and drinking, including feeding via oral and enteral routes
- Eliminating, including continence support
- Maintaining a safe environment
- Medications – various routes
- Mental health and wellbeing
- Mobilising – aids (e.g. wheelchair)
- Rest and sleep
- Socialising (interaction and behaviours)
- Speech, language and communication difficulties including hearing, vision, and assistive technology
- Washing and dressing including personal choice and gender identity
- Working and playing

Health support in special schools includes:

- Child and Adolescent Mental Health Services (CAMHS)
- Community dentistry
- Community paediatricians
- Occupational therapy
- Physiotherapy
- Special school nursing
- Speech and language therapy

Commissioners across health and the local authorities are working together to develop a process that will lead to each child and young person receiving a joint assessment to identify education, health and care needs. This will be developed into a single education, health and care (EHC) plan to ensure all of their needs are met via a single seamless process. The implementation of jointly commissioned and integrated services will further strengthen and enable this process.

Reviews of health provision are in place or programmed to commence at a number of the special schools in order to ensure equity of access to services that support the health needs identified.

Issues to be addressed include special school nursing activity, where 90% of contacts and 33% of time recorded is spent on administering medication (including enteral feeds). This is from 2012/13 data supplied for Nottingham City and south Nottinghamshire (see appendix 7*) but the picture is likely to be the same or similar in the rest of the county. The data also suggests that considerable time is taken up with administration. Reducing duplication by integrating records, care plans and assessments across community nursing services (as illustrated in the case study in appendix 8), would contribute to reducing the administrative burden on all the community nursing services to free up resources to focus on care delivery. This would support the integration of special school nursing with the specialist community nursing services.

*Note: this data is subject to variation because the activity codes are so 'loose' that staff input the same activity under different headings due to different interpretation.

"Not everything that counts can be counted...and not everything that can be counted counts."

Source: Albert Einstein (1879-1955)



5 (d) Numbers of children and young people educated otherwise than at school (April 2013)

As at April 2013, around 500 children and young people on the local authority rolls were listed as being educated otherwise than at school, including those at the Nottinghamshire Learning Centre. There were 393 children registered as being home educated, of whom 31.0% were identified as having a special educational need, and 16.5% were Gypsy, Roma and Traveller children. See table below:

District	Number of children	Percentage of total
Ashfield	65	13.0%
Bassetlaw	88	17.6%
Broxtowe	70	14.0%
Gedling	40	8.0%
Mansfield	69	13.8%
Newark & Sherwood	107	21.4%
Rushcliffe	42	8.4%
City/other	19	3.8%

A flexible framework of community services which follow the child should ensure that children educated at home receive the care they need, where they may otherwise miss out on access to services that are provided, for example within special school settings.

5 (e) Childhood chronic diseases (long term conditions)

The table below shows the estimated number of children with chronic diseases (long term conditions) in the under-19 population in Nottingham City, Nottinghamshire County and Bassetlaw.

These estimations of the number of chronic diseases were calculated by applying the prevalence data to the local population. These prevalence data were mostly retrieved from the national website of the specific chronic disease. It is estimated that the rate of sickle cell anaemia is much higher in some urban areas – about one in 300. Crohn's disease is more prevalent in White people than in Black and Asian people. It normally presents in adolescence and early adulthood with the median age of diagnosis at about 30 years old.[34] Therefore the figure on Crohn's disease is an over estimation since Crohn's disease normally occurs after 16 years old.[35]

Asthma is the most common of the chronic diseases in the under-19 population, with a prevalence of almost ten times that of epilepsy, the next most common disease, and high estimated numbers of children with asthma.

Every 18 minutes a child is admitted to hospital in the UK because of their asthma.

Diagnosis	Prevalence (per 1000)	Nottingham City (Population: 74,062*)	Nottinghamshire (Population: 141,415*) (Excluding Bassetlaw)	Bassetlaw (Population: 24,145*)
Cystic fibrosis[36]	0.4	30	56	10
Sickle cell anaemia[37]	0.42	31	59	10
Crohn's disease[38]	1.45	107	205	35
Diabetes mellitus[39]	1.18	87	166	28
Childhood cancer[40]	2	148	283	48
Asthma[41]	91	6734	12856	2195
Epilepsy[42]	9.7	719	1373	234

*Population figure based on the GP registered patients: NHIS datawarehouse: January 2013

5 (f) Children with additional health needs and disability trends

The numbers of children with additional health needs and disability have been rising locally in line with national trends.

Evidence of this includes:

- The number of children on home enteral feeding seen by community paediatricians at the Nottingham Children's Development Centre (CDC) and Nottingham Special Schools (not including North Notts) increased from 34 in 2000 to 98 in 2012. (These do not include all children enterally fed for example it does not include CF, oncology, renal and children managed by the hospital.)
- Numbers on the caseload of community children's nurses based at the CDC have increased from around 30 in 2002 to around 100 in 2012.
- From 2005 to 2011 the number of children having multi-disciplinary assessment and team around the child (TAC) coordination meetings in the CDC almost doubled from 65 in 2005 to 120 in 2011.
- At May 2012 the number of children and young people on the database with life limiting and life threatening conditions with an NG postcode aged 0-4 years was 207, aged 5-15 years was 185 and 16+ years was 61.

Continuing Care Funding

There are currently 41 children funded by Nottingham City CCG for Continuing Health Care Services via the Children's Continuing Care Service. 18 of these are children in care with Nottingham City identified as responsible commissioners.

In Nottinghamshire County, across all five CCGs (excluding Bassetlaw CCG) 45 children with continuing health care needs are currently funded either fully or jointly with social care and education. This includes children who are children in care and where the Nottinghamshire CCGs have been identified as the responsible commissioner. Additionally, via Continuing Care, Nottinghamshire County CCGs also fund support for 29 children with health care needs within mainstream schools.

5 (g) Population data

There have been significant challenges obtaining data for this population group, services and workforce in both Nottingham City and Nottinghamshire County. This reflects a national picture: the Children and Young People's outcomes forum report highlights *'one of the biggest barriers to improving outcomes for this group of CYP is paucity of robust and comprehensive data'.* One of the recommendations in this report is to address this issue and improve the quality and quantity of data collected in a uniform way in order that it can be used to make useful comparisons and contribute to planning and development to meet future needs.

Public health population data is available for the children and young people who are the subject of this report by group (for example age or gender) and by CCG. Further analysis is required in phase 2 of the programme to determine activity and emerging themes and generate individual care scenarios. This will help the understanding of what services and changes mean to children, young people and their families.

5 (h) Nursing and therapy services workforce data

Further work is needed on this data in phase 2 of the programme as it is both incomplete and incompatible, making it challenging to assess workforce skill sets and mix in teams. This information is pivotal in understanding teams and services to begin working on integrating services.

5 (i) Utilisation review of paediatric beds

NHS Nottingham City and Nottinghamshire County CCGs commissioned the East Midlands Procurement and Transformation (EMPACT) Utilisation Review Team to undertake a snapshot utilisation review (UR) of paediatric beds at Nottingham University Hospitals NHS Trust (NUH) and Sherwood Forest Hospitals NHS Foundation Trust (SFH).

The purpose of the review was to provide commissioners and providers with data on how their paediatric beds are being utilised in order to assess effectiveness and identify opportunities for future service development.

The onsite review took place over four weeks from 1 to 26 April 2013 using the records of patients occupying beds at the time. Additional reviews were collected from ward E40 at NUH in June 2013.

A total of 775 reviews were completed, 337 admission reviews and 438 continued stay reviews (to assess whether or not ongoing inpatient healthcare is required or the current healthcare institution continues to be the most adequate solution for an individual's need). Information was collected on referral source along with six patient characteristics – disability, long term condition, oncology, acute illness, trauma, planned surgery.

The following questions were addressed in the review:

- What level of care does the patient require?
- Is the patient in the right level of care for their needs?
- If the patient is not in the right level of care what is preventing the transfer?

Summary of key findings

Admissions

- Almost all admissions into paediatric beds were appropriate with only 5% of 337 patients reviewed not meeting criteria for admission (SFH 11%; NUH 3%). Reasons included: alternative level of care does not exist; clinical/professional override; family/carer choice; awaiting tests.
- 64% of admissions occurred between Monday and Wednesday. Admissions were received from A&E (30%), GPs (18%), other acute hospitals (11%) and a range of other sources.
- The most common characteristic at admission was acute illness (52%) and the least common was disability (5%); 24% had a long term condition. The majority (78%) of patients had one characteristic. For those with more than one characteristic the most common combination (38%) was long term condition and acute illness.

Continued stays

- Of the 438 continued stay reviews completed 78% had been in the service for less than 10 days at the time of the review. 72% were aged up to four years at admission.
- 22% did not meet the criteria for continued stay, resulting in 34 (51% of total) bed days being used inappropriately at SFH and 61 (16% of total) at NUH.
- The top three reasons for inappropriate continued stay were: alternate level of care does not exist; clinical/professional override; family/carer choice.

Overall the UR review findings were positive, for example the low level of inappropriate admissions. The review team made a number of recommendations as follows:

Commissioner recommendations

- Raise GP awareness of alternatives to hospital care to prevent inappropriate admissions.
- Consider the feasibility of service redesign to create opportunities for step down medical care outside of the acute hospital environment.
- Consider introducing utilisation management/case management for paediatric patients in Nottingham.

Provider recommendations

- Review and align referral criteria and admission processes across King's Mill Hospital and Queen's Medical Centre beds.
- Investigate whether the latest data on admission patterns reflects that of the study and, if so, consider the reasons why to help manage capacity and demand.
- Investigate the spread of planned versus unplanned admissions across the week.
- Review multidisciplinary team discharge planning and processes across all sites to highlight best practice and ensure a consistent approach.
- Ensure discharge planning from day one of admission, using estimated date of discharge to prepare patients and families for discharge.
- Explore individual reasons for clinical/professional override.
- Explore individual reasons for family/carer choice.
- Use utilisation review to support clinical decisions and ensure an evidence-based consistent approach to patient management and discharge.
- Explore reasons for longer lengths of stay based on day of admission.

NHS commissioners in Nottingham City and Nottinghamshire County plan to review the findings and to consider future priorities in response to the recommendations from the utilisation review. This will impact on the ICCYPH programme, particularly around CYP group 1 (acute and short term illness).

5 (j) County Health Partnerships paediatric therapy and children's community nursing activity data – Nottingham City and Nottinghamshire County (excluding Bassetlaw)

Analysis of activity data (contacts and referrals) was undertaken for paediatric therapy services provided by County Health Partnerships (CHP) to the population of Nottingham City and Nottinghamshire County (speech and language therapy (SLT), occupational therapy (OT), physiotherapy (PT) and children's community nursing (CCN) services).

Limited data was available from the following sources:

- CHP service data (Q1 – Q4 2012/13) for under 25 years, from the NHIS Data Warehouse, supplied by Nottingham City Public Health for Nottingham City and Nottinghamshire County.
- Data from Nottingham City Q4 performance report (April 2012 to March 2013) supplied by CHP for Nottingham City only.

Key findings include:
(See appendix 9 for full details)

Nottingham City

- Overall increase of 23% in referrals to paediatric therapy services in 2012/13 compared to 2011/12, mainly due to increase in OT referrals.
- Three-year trends show increase in OT and SLT referrals.
- Marked increase in OT contacts at 42% in 2012/13 compared to 2011/12.
- Average monthly therapy referrals increased from 127 to 142 in 2012/13 compared to previous year.
- 75% therapy referrals are to SLT; 18% of these are multiple referrals of the same child.
- Fewer than 5% of referrals come from GPs. The majority of referrals to OT, PT or CDC nursing come from paediatricians and other consultants. SLT receives referrals from a much wider spread of referrers.
- 41% of contacts (all services) and 63% of therapy referrals are for children under five years with little activity around transition. 3% of contacts are in the 16-18 years age range.
- A total of 2,567 individual children were seen in 2012/13 across therapies and CDC nursing. Of these 15% were seen by more than one service. Of these 5.3% were seen by all three therapy services, and accounted for 24.7% of contacts with them, and as such are likely to be more complex cases. A small proportion also received CDC nursing.
- Figures for paediatric therapy referral rates/1000 population aged 0-24 years from Nottingham City CCG are 12.5 including university practice populations or 17.9 excluding university practice populations (there are very low numbers using services in the relevant age range for university practices).



Children and young people who are seen by more than one service are small in number but have higher needs.

Nottinghamshire County

- No year on year comparable data available, however there appears to be a slight increase in overall referrals and contacts with OT and SLT during 2012/13.
- Average monthly therapy referrals 272 in 2012/13.
- 68% of therapy referrals are to SLT; 20% of these are multiple referrals of the same child.
- Fewer than 5% of referrals come from GPs. The majority of referrals to OT, PT or CDC nursing come from paediatricians and other consultants. SLT receives referrals from a much wider spread of referrers.
- 40% of contacts (all services) and 64% of therapy referrals are for children under five years with little activity around transition, with 5% of contacts in the 16-18 age range.
- A total of 4,528 individual children were seen in 2012/13 across all therapies and CDC nursing. Of these 18% were seen by more than one service. Of these 6.2% were seen by all three therapy services and accounted for 33.2% of contacts with them, and as such are likely to be more complex cases. A small proportion also received CDC nursing.
- Paediatric therapy referral rates/1000 population in the 0-24 years age group show the highest need in Mansfield and Ashfield CCG (20.5) and the lowest in Nottingham West (13.19) in 2012/13.

Referral rates show a higher level of need for paediatric therapy services in Nottingham City and Mansfield and Ashfield CCGs.

The issue of multiple referrals of the same child requires further examination to determine the underlying reasons, including referral management, client choice, source and quality of referrals, to identify potential for improved resource utilisation.

The above data is only for the CHP specialist paediatric therapy and CDC nursing services. The proportion of children seeing more than one service is likely to be higher if other health services including special school nursing and social care services are included.

Children and young people who are seen by more than one service are small in number but have higher needs. They will be assessed by and have to repeat their stories to each service, creating unnecessary complications and disruption for them and their families. Integration including a single point of access and shared records and assessments would reduce duplication for children, young people and families, improve resource utilisation and communication and support effective safeguarding.

5 (k) Children's Community Nursing (CCN) Audit

A comprehensive audit of daily activity was undertaken between November 2012 and January 2013 by the children's community nursing teams based at the Children's Development Centre (CDC) Nottingham, Children's Hospital Nottingham (NUH) and Sherwood Forest Hospitals NHS Foundation Trust (SFH).

A considerable volume of data was collected during the audit and detailed analysis is in progress. A brief snapshot from the initial findings from the data analysis of client-based activity (face-to-face and non-face-to-face) is shown in appendix 10. Non client-based activity analysis is currently unavailable.

Some key findings include:

CDC team

- Four staff; two band 6 nurses, one healthcare worker (WTE not known).
- 102 children seen over three months, over 490 client-based events, 69% face to face, mainly seen by band 6 nurses.
- Over 50% of face-to-face activity is for assessment/review/discharge, gastronomy cares and supplies. 42% of face-to-face activity is delivered in the home setting with a significant proportion at the CDC (City), school and hospital.
- Over 40% of non-face-to-face activity is for support; a significant proportion is for administration and supplies.

NUH team

- Twelve members of staff; all nurses – 10 band 6, one band 5, one band 7; WTE 11.8 (1.0 WTE band 7, 9.8 WTE band 6, 1.0 WTE band 5)
- 157 children seen over the three months. Over 940 client-based events, 80% face-to-face, mainly seen by band 6 nurses.
- Over 40% of face-to-face activity is for oncology blood taking. 75% of face-to-face activity is delivered in the home setting, others include school and hospital.
- Nearly 50% of non-face-to-face activity is for administration. A significant proportion is for supplies or assessment/review/discharge.

SFH team

- Two members of staff; both nurses, one band 6 and one band 7; both 0.8 WTE.
- 69 children seen over three months, over 340 client-based events, 95% face-to-face, evenly spread between the nurses.
- Over 50% of face-to-face activity is for oxygen reviews, PORT/CVL flushes, support and gastronomy cares. 71% of face-to-face activity is delivered in the home setting; others include school and hospital.
- The amount of non-face-to-face activity recorded is low, and where recorded is for administration.

Staff within each team don't know whether the client has been seen by other teams. The CCN audit allows a view across teams and it appears that a small number of children (<20) are seen by staff from different teams (i.e. NUH and either SFH or CDC). None were seen by staff from all three teams. In addition a number of children with complex needs are likely to also receive care from Special School Nursing Services in special school settings and a range of other health services (e.g. therapies, paediatricians) and social care and education services. Integrated working with a single point of access, shared records and assessments would reduce duplication for children, young people and families, improve communication and support effective safeguarding.

The data also suggests some potential for improving resource utilisation for example by exploring whether tasks currently undertaken by nursing staff could be undertaken by others with the relevant skill level or using alternative systems (e.g. administration, oncology blood taking) in order to release nursing capacity to meet increasing demands without increasing costs.

Mobile working

Mobile working is the ability to work anywhere, irrespective of place and time, enabling staff to access and update information and communicate on the go, using mobile devices (e.g. tablets or laptops with mobile access) which provide community clinicians with real time access to valuable resources at the point of care.[43] There is no current evidence to suggest that practitioners are operating in a mobile working system or that providers are developing this for the children's community services.

Mobile working is not just about geographical mobility but also includes the use of mobile technology. This means that practitioners use devices that enable them to record interventions in real time in partnership with other practitioners and the child/young person and their family. Combined with shared access to records across services, it aids communication and efficient use of time and avoids delays and misunderstandings.

Recommendation

7 Develop and implement a mobile working system for children's community services.

5 (l) CARIN4Families (NUH)

The CARIN4Families (C4F) team is a team of family support workers and children's nurses, providing short and long term care to children with complex health and nursing care needs. They provide care in the home, other community settings and in hospital. The team won the national Well Child Award for Best Medical Team 2013.

CARIN4Families total care hours delivered in 2012/13		
Care hours	**Nottingham City**	**Nottinghamshire County**
Continuing Care day	3486	5403.75
Continuing Care night	0	446
Respite/short breaks day	1048.5	218.25
Additionally funded (day)	444	11013.5
Additionally funded (night)	992	12233.5
Total number of children cared for during year	16	33
Total care hours	5970.5	29315
Total caseload at 31/03/13	15	73

Whilst the number of children on the caseload is small, the number of hours of care provided by the service illustrates their high level of nursing care needs. These children will also be receiving care from other nursing and specialist services, for example therapy services and special school nursing. Integrated working with a single point of access, shared records and assessments would reduce duplication for children, young people and families and improve communication and resource utilisation.

5 (m) Rapid response physiotherapy service (NUH)

Following a successful pilot from July 2010 to June 2011 a community-based rapid response physiotherapy service was mainstreamed in 2012/13. The service is for children with severe disability, life limiting, and life threatening conditions and focuses predominantly on CYP who have spent prolonged periods in hospital with chest infections in the past. The pilot covered patients registered with NHS Nottingham City and in the south of NHS Nottinghamshire County and the evaluation estimated that there were approximately 80-100 CYP across Nottinghamshire who would benefit from the service.

Additional investment was made to increase access overall and to expand the service to patients registered with GPs in north Nottinghamshire in 2012/13 (excluding Bassetlaw).

The aim of the service is to assess and treat children's acute respiratory conditions in the community in order to prevent hospital admissions.

During the pilot phase the services prevented 88 admissions across Nottingham City and south Nottinghamshire. This increased to 120 in 2012/13 and 166 including north of Nottinghamshire (from September 2012) (see below).

This service helps to keep CYP out of hospital, enabling them and their families to lead more ordinary lives.

Rapid Response Physiotherapy Service – summary data		
Populations	**Pilot Jul 10 - Jun11**	**Apr 12 - Mar 13**
Nottingham City	55	61
Nottinghamshire County (South)	33	59
Nottinghamshire County (North) from Sept 2012	0	46
	88	166

Reducing admissions to hospital for this vulnerable group minimises risks of acquiring further infections.

The service also provides training to parents/carers and a range of staff, to enable children to continue to access other activities, including education and short breaks. The service provides information to parents on when to access their GP rather than Emergency Departments, which together with the training provision may result in further prevented admissions not reflected in the data above.

This demonstrates the effectiveness of services targeted at specific groups vulnerable to hospital admissions for acute episodes as a result of their complex condition.

What does this mean for The Sherwood Family?



A community-based, rapid response integrated physiotherapy service would mean that families like the Sherwoods would have earlier intervention for respiratory treatment for their son and in their own home. This would prevent the need for admission to hospital and the resultant upset and disruption to family routine and economic activity. This would also mean less stress for children and parents and contribute to calmer home environments preserving relationships and personal reserves for living with the challenges of caring for a child with additional and complex healthcare needs. Mobile working means that records can be completed and updated in partnership with families in real time and provides a seamless service for children and families.

5 (n) Future data needs

Data has a key role to play in the planning and commissioning of future services. The data analysis for the ICCYPH programme has shown that there is a wealth of data from a multitude of sources. Translating the data into information to inform the programme and gain knowledge about services, trends and needs has been challenging and there is no specific data readily available on outcomes.

What is needed is relevant data to track trends over time in a reliable and meaningful way to inform commissioners, providers and service users about the quality of access, patient experience and services and outcomes achieved. This process should be integral to the design and development and clearly reflect the outcomes and intended benefits to be achieved from the services and integration.

Recommendations

8 Continue to monitor data to identify any further areas of work to focus on, in particular analysis of workforce data to assess competencies and skill mix to inform a workforce development plan.

9 Develop meaningful quality and outcome 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.

6
Developing integration



6 (a) Evolution of thinking – fragmentation to integration

There is currently a combination of service models. However these models have evolved for many reasons into a practice which looks at a child's needs and then matches it to service provision rather than ensuring that services meet the child's needs. Additionally, to meet gaps in provision processes have been developed reactively, often resulting in a fragmented approach and complicating provision for services and the children, young people and the families that they aim to support.

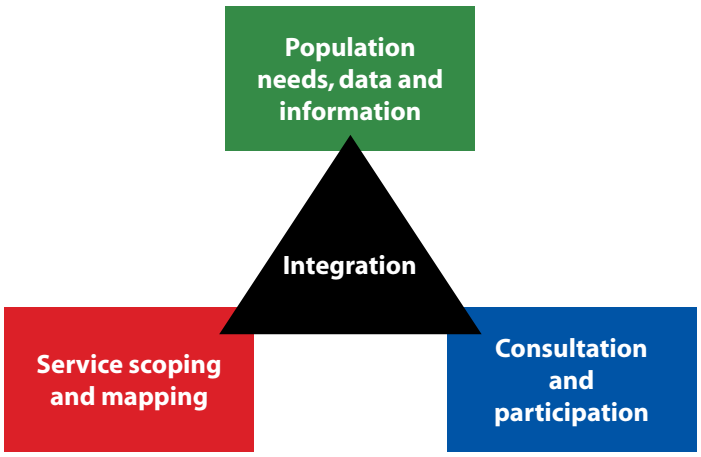
Much work has been done around care closer to home, outreach and community services but there has been little development of the expertise in the community being used in an in-reach (to hospital) capacity. There is a clear need to move from the current fragmented provision to achieve consistency, flexibility and sharing of expertise across primary, secondary and tertiary care.

The importance of integration

"The quality and productivity gains we need to make lie not within individual NHS organisations but at the interfaces between primary and secondary care, between health and social care, and between empowered patients and the NHS. At the heart of this is the importance of transforming patient pathways, leading to the integration of services and in some cases, the integration of organisations. Where organisational change takes place, it is not necessarily one organisation taking over another, but creating new services with patients and their needs at the centre."

DH (2009) the Operating Framework for the NHS in England 2010/11

6 (b) Developing an integrated model

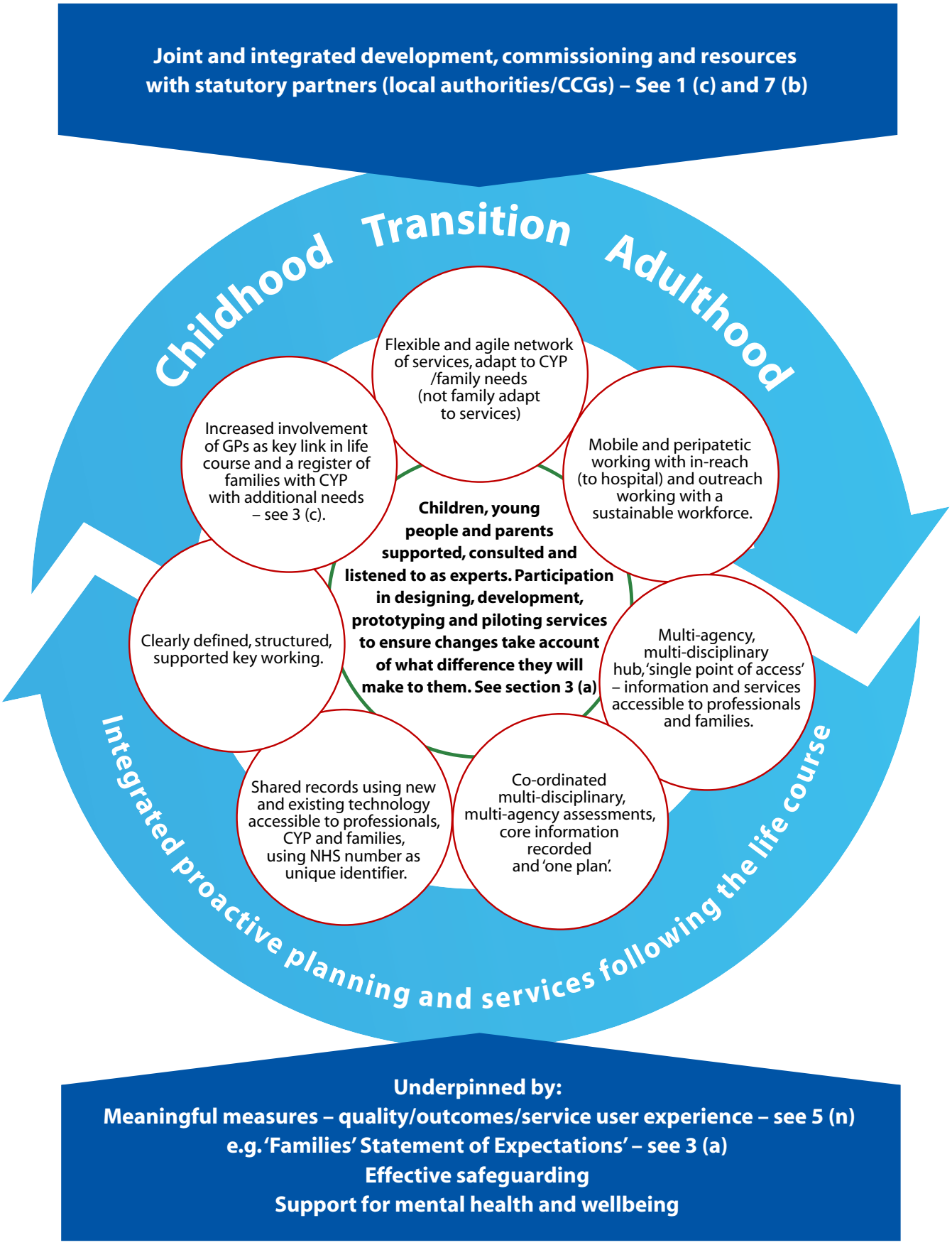


The content of the preceding sections provides triangulated evidence to support the development of an integrated model with streamlined access, co-ordinated assessment and delivery and shared information and records, supported by clearly defined, structured key working.

A programme of integration must focus on removing unnecessary and wasteful complications from the system and any cost savings can be reinvested to meet the increasing demand arising from this population of children who are surviving, thriving and living longer.

"There is a clear need to move from the current fragmented provision to achieve consistency, flexibility and sharing of expertise across primary, secondary and tertiary care.

The following have been identified as essential, interdependent elements of an integrated model of children's community health care in phase 1 of the ICCYPH programme. These are explored in more detail in this section:



There is no single care pathway for the groups of children within the ICCYPH programme. The challenge for effective integration is to develop a model or framework that achieves a seamless journey for children and their families on the appropriate care pathway or pathways, delivered by the right people at the right time, in the right place. These all need to be considered within a whole system approach to the development, commissioning and delivery of an integrated model.

A whole system approach:

- Incorporates the consideration of a range of perspectives and conditions.
- Acknowledges that problems in one part of the system cannot be resolved in isolation from their impact on other parts of the system. [44]
- Ensures that children and young people are not seen in isolation from their families or their social environment or communities.[45] This includes for example transport, housing and adaptations, technology and equipment.
- Requires a system wide cultural change, leadership and empowerment of front line staff enabling shared (or distributed) leadership wherever they are in an organisation.[46]

> "You can't solve problems with the same thinking that created those problems."
>
> *Source: Albert Einstein (1879-1955)*

To match the complexity of needs of the children and young people a cohesive, 'positively agile' network model is required. This should include hospital in-reach and community out-reach that seamlessly wraps around the child/young person and their family following their life course, supporting change, crisis and transition to adulthood. A good example of this is the Family Friendly Framework.



6 (c) Family Friendly Framework – an integrated service network

The Family Friendly Framework (FFF)[47 48 49] is a whole system approach developed by the British Association for Community Child Health in response to concerns about the fragmentation of commissioning compounded by an increasingly competitive marketplace of multiple providers.

The FFF is based on pathways and networks as units of service delivery:

- A **pathway** is a description of the best management of a concern/condition. For a short term condition it links four component parts: prevention, recognition, assessment and interventions. For a long-term condition these component parts are replicated into a programme of care consisting of the initial pathway (up to diagnosis and treatment), a review pathway (living with the condition) and transition pathway (back to normal, onto adult services or into end of life services).
- A **network** comprises all the teams that deliver component parts of the pathway and are involved with the management of a group of conditions. Ideally collectively strive for continuous improvement and are commissioned, managed and regulated as a network.

The journey that an individual child and their family take through services may be a life course pathway, using universal services, or a condition-related service pathway when there are concerns or problems, or a combination of these.

Bringing multiple commissioners together – a better use of collective capacity

The implications for commissioners are that by explicitly describing each of the components of a pathway, each component can be allocated to the most appropriate commissioner. This should ensure less fragmentation, duplication or omission and therefore better value. The development of networks and devolution of decision-making, will create clearer lines of accountability and bring decision-making closer to clinicians and the users of services.

Service providers may be responsible for a whole pathway, parts of a pathway or some components. They have a responsibility to work collaboratively with other providers who contribute to the whole network in order to generate continuous improvement. Each component part needs to be based on best evidence, delivered by a competent team, in the right place and at the right time.

Putting children, young people and their families at the heart of what happens

Improved outcomes (and better experience) depend on all the parts being in place and working well together from the perspective of a child and their family, including prevention and safeguarding. The system should be able to adapt both to new knowledge (research) and from information generated by families through creating feedback based on experience.

The use of a whole system approach based on innovation and learning gives all stakeholders a voice in the improvement process. This means a system that offers value for money, ensures all the parts are in place and working well together, and encourages constant learning from new evidence, feedback from users and service-based innovations.

This work has long been on the agenda for service improvement and this is a great opportunity to move from fragmentation to integration. A network model of services based on the Family Friendly Framework would fulfil that purpose.

Recommendation

10 Adopt/adapt the Family Friendly Framework (FFF) in phase 2 of the ICCYPH programme to support the development of an integrated network model of children's community health services and pathways designed around the needs of children, young people and families, to reduce duplication, achieve seamless flow between services and good experience and outcomes.

6 (d) Shared records, assessments, care plans and technology

Shared records, assessments and care plans

Currently each service or team undertakes its own assessments, develops its own care plans and holds its own records for individual children. For children who require the input of multiple services this results in duplication for CYP and families and multiple contacts with services for the duplicated activities. These activities do not add value for the family and involve additional travel time and cost. This is disruptive to, for example parents' work commitments and the child's attendance at school. For services this means time and resources (capacity) taken up with duplicated, non-value adding activity and potential for inconsistencies in information, which could lead to safeguarding concerns being overlooked.

Case study

The 'Integrating Community Services Nursing Documentation' case study – appendix 8 – illustrates the complications arising from the current fragmented system and the benefits to be gained from an integrated approach to assessments, care plans and records for nursing services within a single provider.

Consultation shows that service users' perception is of 'one service' and this is entirely reasonable. Therefore a seamless service between statutory organisations and between different parts of statutory organisations is essential and would meet expectations. Services should be integrated where it is possible and interlinked where it is not. Using the NHS number as a unique identifier, access should be provided to records, shared by services and children and families as enabled by appropriate information governance. To achieve this would require integration of information and communication technology (ICT) and development of mobile working - see section 5(k).

Information and communication technology

In the Information Revolution White Paper (2012),[50] the Secretary of State for Health Andrew Lansley, said that:

"High quality health and care services depend on good information. The right person having the right information at the right time can make all the difference to the experience of a patient, service user or carer. Good information also enables care professionals to make the process of care safer and more efficient. Information is a health and care service in its own right: it must be freely available to all who need it. Good information is also the basis for genuine shared decision-making: no decision about me, without me."

The SEND legislation requires statutory organisations to undertake multi-agency assessments and produce joint education, health and care (EHC) plans. This will require collaborative working between professionals and children, young people and their families, facilitated by ICT systems. Alignment of the ICCYPH programme with the SEND developments in Nottingham City and Nottinghamshire County (see section 7) will facilitate the wider development of co-ordinated multi-disciplinary, multi-agency assessments and 'one plan' for all children and young people with additional needs, with core information captured once and shared.

In phase 2 of the ICCYPH Programme there is potential for the Connected Nottinghamshire Programme to support ICT development. The objectives of this programme are:

- Improved sharing of health information to support business transformation
- Improved sharing of health and social care information to support business transformation
- Collaborative working between health and social care IT providers

It is important to include service staff and clinicians and children, young people and families who will use the systems in their development. Young people understand digital media and use it in their day-to-day lives. They should be included in developing new health resources, feeding in their thoughts about how the full potential of new technology should be harnessed in a way that creates trust and credibility

Assistive technology
Assistive technology is a broad term that includes assistive, adaptive, and rehabilitative devices for people with disabilities. It enables people to perform tasks that they were formerly unable to do or had great difficulty doing, promoting confidence and greater independence. It provides enhancements to, or different methods of interacting with, technology to perform activities of daily living.

A local project[51] has shown that there are considerable benefits to be gained from appropriate use of assistive technology.

These include:
- Individual self efficacy-increased independence and control.
- Increased quality of life and reduced stress in families.
- Increased mental health and wellbeing.
- Reduced dependency on statutory support services e.g. short breaks.

As well as the benefits to the individual child and family the cost savings from reduced dependency on services will enable investment to meet the challenges of this increasing population of children with complex needs, effectively providing more support for more children for the same budget.

Recommendations

11 Prototype shared records, assessments and care plans in children's community nursing services.

12 Align the ICCYPH programme with the SEND legislation development work in Nottingham City and Nottinghamshire County in phase 2.

13 Develop ICT functionality and compatibility across organisations.

14 Invest in increased use of assistive technology to address the individual needs of children and young people as part of the development of integrated services and support.

6 (e) Single point of access ('one-stop shop') and multi-agency hub

A single point of access for information and referrals to a multi-agency, multi-disciplinary 'hub' for co-ordinated and shared assessment of need would provide an entry point to appropriate information and services for children, young people and their families.

Benefits to children and families include:
- One place to go for information and signposting.
- Fewer inappropriate referrals into services, right place first time.
- Reduced duplication of assessments and attendance at appointments through better co-ordination and shared assessments.
- More responsive and timely access to information and services.

Benefits to services include:
- Streamlined, efficient referral process which includes triage/prioritisation, assessment of need and care planning.
- Less time spent by the referrer in identifying and arranging appropriate care.
- Improved awareness of and access to a range of services.
- Communication of agreed plan back to the referrer and to the GP (if not the referrer)
- More effective utilisation of resources, fewer erroneous referrals and less duplication of activity.

> "It is important to include service staff and clinicians and children, young people and families who will use the systems in their development.

Challenges and considerations
Challenges and considerations for phase 2 of the ICCYPH programme for the development of a single point of access (SPA) and multi-agency, multi-disciplinary hub include:

- Alignment with the SEND legislation development work.
- Consideration of access to health services for children and young people and their families who do not have SEND or social care needs.
- Assurance that the SPA does not create a delay to access to services for children and young people with less complex needs and those requiring for example referral to just one service.
- Consideration of an effective triage and prioritisation system, including developing clear referral criteria, processes and local services offer.
- Co-location of and virtual teams.
- Geographical differences between City and County – with locality teams
- Multi-skilling, generic tasks and roles and workforce development.
- Technology requirements – new and existing, including cloud technology for multiple access including children and families.
- Contact, communication and access for professionals and families.
- Consultation and participation of children, young people and families in the design and development to ensure their needs are met, as well as professionals/ service providers.
- Ensuring purpose and function are clearly understood and defined before the developing roles and structures.
- Prototype before pilot involving all relevant parties.
- Learn from the experience of other areas, for example Doncaster, Derby, Leicester, Newcastle, Scotland and Southampton.

Recommendation

15 In developing a single point of access and multi-agency, multi-disciplinary hub ensure that the challenges and considerations identified in phase 1 are included.

6 (f) Key working

Key working is for children and young people who have additional needs (birth to adulthood) and their families. The overall aim of key working is to provide a single point of contact and co-ordinate the provision of holistic care and support to meet the individual needs of the child or young person and their family. Every child, young person and family who would benefit from key working support should get access to it.

The SEND legislation highlights the importance of key working for families and the impact that it can make. Key workers may be non-designated (workers who key work with a few families in addition to their normal professional role) or designated (those employed specifically as full-time key workers).[52] An integrated service model will require a mix of both designated and non-designated key working, depending on the nature and complexity of the needs of children and families. The key worker model will require a clear definition and standards, structure and administration support to enable key workers to focus on supporting families effectively within a streamlined system (i.e. they should not be an alternative to reducing complications within the system). See also section 7(b).

Recommendation

16 Develop key working for families with children with additional needs in collaboration with SEND legislation development work in Nottingham City and Nottinghamshire County in phase 2.

> The overall aim of key working is to provide a single point of contact and co-ordinate the provision of holistic care and support to meet the individual needs of the child or young person and their family.

6 (g) Transition

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.

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 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. This is likely to be a national trend.

While the CQC inspection was undertaken in Nottingham City only, 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

Young people's complex needs and disabilities do not become less as they move into adulthood. It is the complications in the system which can cause age to become a barrier to access to services and support.

Lack of support to enable a young adult to remain at home with their family, or for them to achieve independence, may result in them having to go into a residential placement, with the associated cost to commissioners and social and quality of life implications for the individual and their family.

Recommendation

17 Ensure that proactive transition pathways, planning and support, including personal health budgets, for all children with additional needs are included in the new integrated service network.

6 (h) Mental health and wellbeing

Good mental health or mental wellbeing is about feeling good about life and being able to cope with problems when they happen. Good mental health and resilience are fundamental to a person's physical health, relationships, education, training and work and to achieving their potential.[53]

Children with disabilities can experience social isolation in some settings, and feelings of frustration, which can contribute to mental health and behavioural difficulties. The many challenges faced by a family which cares for a child with a disability can also lead to experiences of isolation for the family or individuals within it. This can be due, for example, to the limited opportunities for social interaction outside the family and/or a lack of understanding of the family's situation by others. The challenges of accessing services and support, demands of day to day caring and the see-saw of emotions experienced all have an impact on the mental well-being of parents and families.[54]

Siblings of children with disability and additional needs can also experience social isolation, experiencing feelings of jealousy and resentment and feeling that their needs come second to that of their brother or sister. This can have a negative impact on their self esteem, academic performance and behavioural and emotional development.[55]

"I don't want my personal carers to change when I move to adult services."

Young person, Nottinghamshire (2012)

The focus of many policy documents in the past has been mainly on the support needed from parents to achieve the desired outcomes for children, rather than the support needed for parents in carrying out their roles as parents. The National Service Framework (NSF)[56] for Children is close to an outcomes-focused approach for parents with disabled children. Standard 8 of the NSF defines the standard to be achieved by services for disabled children and their families as follows: 'Children and young people who are disabled or who have complex health needs [should] receive co-ordinated, high-quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, enable them and their families to live ordinary lives'.[57]

'No Health without Mental Health' (2012) is the Government's strategy for improving mental wellbeing and outcomes by embedding prevention, early recognition and early interventions across all health services. This includes providing training to non-mental health professionals and raising awareness of mental health problems to ensure that clinical and other staff are able to recognise those at risk of developing mental health problems, to spot the signs of mental ill health and know how to get specialist support when required. This should include streamlined access to CAMHS for children where appropriate.

Recommendation

18 Build mental health prevention, recognition and early support and access to mental health services for any member of the family into an integrated model and service specifications, which considers the mental health needs of the whole family.

6 (i) Safeguarding

The Munro Review of Child Protection in 2011[58] identified helping a wide range of professions to work well together as a major challenge in building a responsive child protection system. This requires communication and co-ordination between the many services and professions that are involved with helping children and families, to build an accurate understanding of what is happening in a child or young person's life, so that the right help can be provided, to prevent and reduce abuse and neglect and to reduce inefficiencies and omissions.

The findings of the Munro Review reflect the earlier findings in the enquiry report following the death of Victoria Climbié in 2000, which highlighted that a number of long standing problems, repeatedly raised by child abuse enquiries over the previous 30 years, had not been resolved. These included:

- Poor co-ordination between services
- Failure to share information between agencies
- Absence of anyone with a strong sense of accountability
- Front-line workers trying to cope with staff vacancies, poor management and inadequate training[59]

These factors are consequences of fragmented working across services. Fragmentation therefore can contribute to lapses in safeguarding in terms of poor communication and co-ordination.

Working together to safeguard children guidance (2013) responds to the recommendations in the Munro report and describes key principles[60] of good safeguarding:

- Safeguarding is everyone's responsibility: for services to be effective each professional and organisation should play their full part; and
- A child-centred approach: for services to be effective they should be based on a clear understanding of the needs and views of children

The guidance also describes what children themselves say they need, to protect them from harm. These needs are underpinned by a range of legislation, national and local policy and procedures for safeguarding.

Children's request for protection

Children say they need:

- **Vigilance:** to have adults notice when things are troubling them
- **Understanding and action:** to understand what is happening; to be heard and understood and to have that understanding acted upon
- **Stability:** to be able to develop an on-going stable relationship of trust with those helping them
- **Respect:** to be treated with the expectation that they are competent rather than not
- **Information and engagement:** to be informed about and involved in procedures, decisions, concerns and plans
- **Explanation:** to be informed of the outcome of assessments and decisions and reasons when their views have not met with a positive response
- **Support:** to be provided with support in their own right as well as a member of their family

Source: Working together to safeguard children

Good safeguarding practice applies to all children, however evidence shows that children with disabilities are more vulnerable to abuse and poor safeguarding outcomes[61 62] and extra vigilance is required using heightened awareness and communication skills.

Early intervention is critical in preventing poor safeguarding outcomes. The Nottingham Children's Partnership Early Support Pathway (2011)[63] and Nottinghamshire County Pathway to Provision (2012)[64] support a multi-agency approach to early intervention to prevent problems increasing and the need for protective services. These pathways rely on high quality assessments. The Common Assessment Framework (CAF) provides a systematic and purposeful approach for agencies working with children and young people to understand what is happening to the child/young person and their needs.

The Common Assessment Framework is a four-step process whereby practitioners can identify a child's or young person's needs early, assess those needs holistically, deliver coordinated services and review progress. The CAF process is voluntary and requires informed consent. It is not a 'referral' process but a 'request for services' and should be offered to children who have additional needs that cannot be met by universal services. The CAF enables practitioners to assess needs, so that appropriate support can be identified, however it is not a risk assessment for safeguarding.[65]

Recommendation

19 Embed the principles of good safeguarding and early intervention to meet the 'children's request for protection' ('Working together to safeguard children') within the design, development, specification and delivery of integrated services.



Good safeguarding practice applies to all children, however evidence shows that children with disabilities are more vulnerable to abuse and poor safeguarding outcomes.

6 (j) Community development approach to integrating services

Large scale change needs large scale culture change and this can be achieved by using a community development approach. The following are some examples of tools and methodologies which could be used to help ensure engagement, consultation and participation in designing and developing an integrated model of service provision in phase 2 of the programme.

Appreciative inquiry
Appreciative inquiry (AI) is an organisational development method applicable to organisations facing rapid change or growth. It focuses on increasing what an organisation does well rather than on eliminating what it does badly. Through an inquiry which appreciates the positive and engages all stakeholders it seeks to renew, develop and build on a situation.

Role modelling
Promote good examples of families, managers, teams and services as role models. These can be used as aspirational examples of good practice.

Experiential learning
Experiential learning is the process of making meaning from direct experience. Policy makers and managers can learn by experiencing a day in the life of a child a parent or a clinician.

Soft systems methodology (SSM)
SSM is a whole system approach which enables structured open and challenging thinking in a collaborative way about the real world from different perspectives. It elicits information and ideas and world views in complex situations and enables best fit solutions to problematical situations rather than a solution to a problem. It acknowledges the fact that many situations will always be problematic, as complexity is a matter of fact but complication is not. It gives the opportunity to untangle the complications, address multiple goals and multiple perspectives, identify recurring themes and take preventative action and plan and manage proactively.

The application of SSM in the development phase of the ICCYPH Programme would be beneficial as there are so many stakeholders and 'world views' involved.

7

Pilots, current and future developments



Pilots, current and future developments

There are a number developments across health, education and social care which are planned or in process in Nottingham City and Nottinghamshire County and which influence or support the ICCYPH programme. These are illustrated in the overview diagram appended to the programme brief (appendix 1). Some key areas are described in more detail in this section. There is an opportunity for the statutory organisations in Nottingham City and Nottinghamshire County to share learning experience for the benefit of service users.

7 (a) Nottingham City specific

Disability and Special Educational Needs legislation (2011) – local context

Nottingham City Council is in the early stages of planning for the various strands of the legislation within one overall programme management approach. There are two elements to the work, looking at the roll out of social care individual budgets and moving towards combined social care, SEN and health personal budgets and a larger piece of work which involves the delivery of the single EHC plan. A launch event for key stakeholders is planned in September 2013.

Personalisation: personal budgets and direct payments

Direct Payments are available for children aged 0-19 years. They are payments made "In Lieu" of social care services. They put families in control of deciding on their own support and services, as an alternative to receiving direct social care services like home care, sitting services and other short breaks services. The chosen support and/or services must be considered to meet the individual's assessed social care needs (appendix 11).

Nottingham City's Disabled Children's Team/Short Breaks Team has recently completed a small pilot project which gave a personal budget to a small cohort of young people in transition. The learning from this pilot, together with the evaluation from six national pilots, has informed the decision that Nottingham City Council (NCC) will continue to develop this as an offer for all young people. This will include a cohort of young people with jointly funded packages of care.

NHS Nottingham City was identified as one of 20 personal health budget pilot sites in October 2009. The results of this pilot, which were published in November 2012,[66] informed the decision by NHS Nottingham City to continue to offer personal health budgets to a wide range of adults and children with long term conditions. This is in line with the policy announcement by Norman Lamb in November 2012, on the roll out of personal health budgets for everyone eligible for continuing healthcare.

NHS Nottingham City CCG and Nottingham City Council will continue to work closely to ensure that processes are as efficient as possible and that CYP and their families receive a holistic service that ensures they are at the centre of any decision-making process. This will enable personalisation so that CYP and their parents/ families will have more choice and control over all of the support they receive.

NHS Nottingham City CCG's aim is to deliver better quality care, especially more responsive care, by enabling children, young people and their families to take control over the way in which money is spent on their health and social care.

"For the first time in my daughter's life I felt peace... my daughter came home from school with work she had done and not work done by her assistant...the school says she has made so much progress... their eyes have been opened and they have been shown the way to unlock her potential. Since then I have been able to let go, I have been able to get involved with the local parents forum where I can put my experience to good use. I would like to return to work and since having a personal budget I can, for the first time envisage a future for me too."

Children's Continuing Care and Case Management Service – Nottingham City
A children's Continuing Care pathway has been implemented in Nottingham City to provide support for children and young people with Continuing Care needs in line with Department of Health guidance. A Continuing Care need may arise from a number of factors such as congenital conditions, long-term deteriorating conditions, accidents or effects of serious illness or injury. It refers to instances where children and young people's needs cannot be met by existing universal and specialist services.

The children's Continuing Care Service carries out a health-led multi-agency assessment which includes consideration of health, education and social care needs. The assessment is carried out in conjunction with the wider multi-disciplinary team and at its core are the needs and wishes of the child or young person and their family. The service makes recommendations for an appropriate package of care to meet these assessed needs. The package is agreed by a multi-disciplinary panel of commissioners, and the service is then responsible for implementing, case managing and reviewing the agreed package of care. The pathway has been operational from January 2013 and as of August 2013 there are 35% more packages of Continuing Care in place with referrals steadily increasing.

Early Support Pathway – Nottingham City
An early support pathway was developed in November 2012 for children born with severe neurological / multiple problems leading to lifelong profound disability and complex health needs. This development was in response to an identified need to have a co-ordinated, multi-disciplinary, multi-agency approach to proactive early identification of needs and service planning to support timely and safe entry to school placements for the small but growing number of children in this group. The pathway was developed with and incorporates relevant health, social care and education services and links into the children's Continuing Care Pathway (above). The pathway is currently being tested.

Autistic Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD) and Challenging Behaviour Pathway
Commissioners, the public health directorate, social care and education, service providers and the clinical leads have worked together to develop a care pathway which incorporates challenging behaviour, ADHD and ASD. The pathway promotes a primary health care team referral approach and reflects Nottinghamshire safeguarding policies and procedures. It offers an opportunity to create coherence and consistency across the City. The approach to assessment has the potential to create further consistency within specialist services such as community paediatrics. Many of the services included in the ICCYPH programme are involved in the care of these children.

Nottingham City Council restructure of operating model for children's services
Nottingham City Council is in the early stages of planning to restructure it's operating model for children's services, to include single point of access and multi-agency assessments. This work programme will align with the ICCYPH programme in the future.

7 (b) Nottinghamshire County specific

Integrated Commissioning Hub for Children and Young People Services
The joint commissioning hub offers a single point of accountability and co-ordination for children's health related joint commissioning, on behalf of Nottinghamshire County Council, Nottinghamshire clinical commissioning groups and NHS England Area Teams and will be based on the alignment and pooling of commissioning resources.

It will be accountable to the Health and Wellbeing Board through the Nottinghamshire Children's Trust Executive and will be line managed via the corporate director for children, families and cultural services with clinical direction and supervision via the director of public health.

The Hub will take ownership of the JSNA and its importance in informing intelligent commissioning and provides the opportunity for children's health services to be effectively aligned with wider children's services.

This will be effective from September 2013 and will enable a whole system approach to planning and commissioning with clearer accountability. It will offer the opportunity for clearer processes and participation with children young people and their families.

It will integrate public health approaches to prevention, reduce silo working and duplication, add value and greater savings, make the best use of available resources and build strong partnerships (see appendix 12).

Disability and Special Educational Needs legislation (2011) development
The Nottinghamshire County Special Educational Needs and Disabilities (SEND) pathfinder project is being extended for a further 18 months until September 2014. Known locally as the **'One Project'** it forms part of the government's national SEND pathfinder programme. Funding of £150,000 has been received from central government to support this. During this extension phase the 20 pathfinders will help to shape and inform the Children and Families Bill (containing the new special educational needs legislation and new SEN Code of Practice) as it progresses through Parliament in 2013.

Key points from the Bill for children and young people with SEND are:

- Statements of SEN (for under 16 years) and learning difficulty assessments (for over 16 years) will be replaced with a new single birth to 25 years education, health and care (EHC) plan extending rights and protections to young people in further education and training and offering families personal budgets so that they have more control over the support they need.
- Improved cooperation between all the services that support children, young people and their families and particularly requiring local authorities and clinical commissioning groups (CCG's) to work together.
- A requirement for local authorities to involve children, young people and parents in reviewing and developing provision for those with special educational needs and to publish a 'local offer' of support.

Whilst it is expected that the new legislation will not be implemented in England until September 2014, a condition on all the pathfinders is that they will introduce their new arrangements in advance of this date. In Nottinghamshire County it is intended that this is undertaken as a phased roll-out starting from 1 September, 2013 so that arrangements are fully operational across the local authority area by January 2014. An EHC plan pathway is currently being developed.

Key working is a cornerstone of support for families. The 'One Project' has adopted the recommendations that support the SEND reforms to develop key working.[67]

Personalisation: personal budgets and direct payments

Children's Disability Services in NCC have a short term project to support 60 children and young people stepping out of social care on the pathway to provision. These children have had an assessment by a social worker and have packages mainly of short breaks including direct payments. Two workers are working with families using a person centre tool to produce a support plan owned by the family and base on their current package. Where possible and with family agreement this will be linked to the child's statement of special educational need where one exists working with the SEND pathfinder project staff. The cost of the package is included in the plan.

What does this mean for The Forrester Family?



Personal budgets mean that families like the Forrester family can benefit by having more independence more control and a better quality of life. This is an example from a pathfinder authority where an EHC plan and funding for a personal assistant in school has been brought into an existing personal budget provided by social care (2013). It also means that staff provide a better service and have pride and satisfaction in their work and will mean a more stable workforce which benefits everyone.

> "I thought I worked with parents well and understood participation. I have learned so much from the co-production approach. I would never go back to how I did things before: this is about trust and really putting the child and family at the heart of what we are doing."
>
> *Professional from a pathfinder area (2013)*

Mid-Nottinghamshire NHS Integrated Care Transformation Programme (ICTP)

The health needs of the population of Mid-Nottinghamshire are changing. A combination of an ageing population, the shifting expectations amongst citizens around the time and type of care they receive, an emerging evidence base of the benefits of care closer to home, and a predicted increase in demand, will all place additional pressures on this health and social care economy.

Significant financial constraints also exist, with health budgets only seeing small increases and social care budgets decreasing in real terms.

In light of this, the five organisations involved in the delivery of health and social care in this area (Newark and Sherwood Clinical Commissioning Group, Mansfield and Ashfield Clinical Commissioning Group, Nottinghamshire Healthcare NHS Trust, Sherwood Forest NHS Foundation Trust and Nottinghamshire County Council) agreed to work together to design a blueprint for the future delivery of services that would meet the needs of the population both now and in the future, and do so whilst operating under the financial constraints that exist.

There are four care design groups within the ICTP one of which is the Women and Children's Group. The ICCYPH Programme has been adopted under this work stream.

Recommendation

20 Ensure all work of the Mid-Nottinghamshire NHS Integrated Care Transformation Programme (ICTP) and ICCYPH Programme is aligned in phase 2 of the programme (County only).

Joint public health and social care Aiming High for Disabled Children (AHDC) occupational therapy pilot
The Joint public health and social care AHDC OT pilot (2009-11) responded to the concern that children with additional needs could be seen by up to five different children's occupational therapists throughout their development. Each OT has a specific and specialist role, but there was duplication of skills in respect of equipment provision and delivery, and specifically surrounding 'seating'.

This small pilot aimed to encourage more collaborative working between health and social care and to develop a common knowledge base, this included:

- Joint training – Delivery of specialist training in postural care and sensory modulation
- Short term loan equipment scheme – Provision of equipment to support access to community activities and holidays
- Occupational therapist post – For a period of six months to facilitate timely intervention on health referrals.

Outcomes and improvement achieved were:
- Service users benefited from a more timely response to referral requests.
- Service users have had a consistent message on the use of equipment and a better understanding of the different OT roles.
- Earlier intervention has eliminated the need for ongoing support in some cases.
- Improved communication and better working relationships between health and social care OTs.
- Children/young people enabled to access wider community activities or holidays, through short term equipment loan.
- Improved management of social care assessments resulting in earlier discharge from hospital.
- Collaborative working has supported a more seamless transfer of cases between health based and social care based OT.

It is envisaged that the financial savings of a more collaborative service will be realised in the long term i.e. a more timely and consistent approach regarding postural care and its importance will reduce the need for more complex and costly intervention later in a child's life. Working collaboratively reduces the likelihood of duplication on assessments and is therefore more cost effective.

The recommendations from the pilot were:

- Develop joint health and social care training, assessments tools and assessment reports/care plans to ensure clear and consistent communication.
- Develop a 'buddy system' between health and social care to gain increased knowledge of respective roles.
- Develop protocol /process in respect of fast tracking provision of specialist equipment
- Develop staff induction programme to incorporate aspects of both health and social care setting.
- Further promote the short term loan scheme and widen access to hospital discharge and short break services.

This is an example of good practice and consistent with the requirements of the SEND legislation for single education, health and care plans.

7 (c) New and emerging policy and guidance

Together for Short Lives Commissioning children's palliative care: A guide for Clinical Commissioning Groups (CCGs), published 13 August 2013.[68]

This is a resource to help CCGs to effectively commission Children's Palliative Care (CPC) services including recommended actions around commissioning partnerships with local authorities and neighbouring CCGs, designing pathways, specifications and procurement, delivery and improvement.



Develop joint health and social care training, assessments tools and assessment reports/ care plans to ensure clear and consistent communication.

8 Call to action



"The case for change is clearly outlined in this report. We first need the key leaders to embrace that change with hearts and minds. There is such a great opportunity to make a difference to the lives of children, young people and their families.

Please do not ignore the case for change. Please make it happen."

Rachel Tyler, parent (2013)

8 (a) Call to action

This report is different…

This report is different because it draws together, for the first time data, information and experience of services and their interaction with each other. This has helped to shape and focus the core values and beliefs of the steering group to drive change for improvement. This is a 'call to action' to the health community who serve this group of children young people and families.

The members of the ICCYPH steering group have roles in the commissioning, monitoring and provision of services. From previous reviews and reports, including consultations, we understand the needs and frustrations of families and staff working in the current services. These frustrations are the result of a lack of cohesion with other related services, for example in education and social care. Particular concerns have been highlighted around transition from children's to adult services. Large scale change is required now and the need for action is made more urgent by the current legislative drivers.

The Steering Group has the capacity and statutory responsibility to make best use of resources, to act and lead on this change as it represents a wealth of knowledge skill and experience from commissioners and providers of services and in working with education, third sector organisations and parent groups represents the views and opinions of service users and their families. During consultation with stakeholders we have been inspired by the commitment and excellence of clinicians and practitioners impassioned in their roles, the services and care. There have been specific moments when there was a glimpse of the unfailing dedication of parents – 'warrior women' – and families to fight for services for their children and to function like any other family. This is a call to action to do more and better.



"Any intelligent fool can make things bigger, more complex.... It takes a touch of genius - and a lot of courage - to move in the opposite direction."

Source: Albert Einstein (1879-1955)

This programme requires large scale change on an unprecedented level to achieve a joint vision without compromising quality of care. Large scale change needs large scale culture change from commissioners and statutory partners, service providers, managers and their teams and children, young people, parents and families.

This change is long overdue.

BIG ASK

ASK - BIG ASK - EVEN BIGGER ASK

The steering group would like to demonstrate that there is leadership, support and commitment for this programme at strategic, management and operational levels and from children, young people and families to be effective and to ensure that the vision of this programme becomes a reality.

The Vision

To enable children and young people with acute and additional heath needs, including disability and complex needs, to have their health needs met wherever they are. The services will support the child's life choices rather than restrict them and improve the quality of life for children and their families and carers.

It is clear from the recommendations from phase 1 that in phase 2 and 3 there will be actions to develop, implement and support an integrated model. This will require a series of work streams involving input from members from across the health community with specific knowledge and skills.

Be part of this change: Are you, for example, a member of a Health and Wellbeing Board, a GP, a clinician, a manager or a parent? Are you in a position to influence, to support and take action to implement the recommendations within this report to bring about large scale change and improvement to children's community services across Nottingham City and Nottinghamshire County? If so please advise the contacts below of your offer to champion, endorse or pledge support.

Ann Berry ann.berry@nottscc.gov.uk and Sarah Everest sarah.everest@nottscc.gov.uk in Nottinghamshire County or Jane O'Brien jane.obrien@nottinghamcity.nhs.uk and Deborah Hooton deborah.hooton@nottinghamcity.nhs.uk in Nottingham City.

9

Glossary of acronyms, abbreviations and terms, references and bibliography



9 (a) Glossary of acronyms, abbreviations and terms

Glossary of acronyms and abbreviations used in this document

ACT – The Association for Children's Palliative Care
ADHD – Attention deficit/hyperactivity disorder
Age groups – Age Group is defined as follows; 0 - 19 years – this includes all children and young people up to their 19th birthday at which point they would be discharged from children's service provision i.e. as soon as they become 19 years old. 0 - 25 years - this includes all children and young people up to their 25th birthday at which point they would be discharged from children's service provision i.e. as soon as they become 25 years old.
APTCOO – A place to call our own
ASD/ASC – Autistic Spectrum Disorder/Autistic Spectrum Condition
AVECO – Association of Chief Executives of Voluntary Organisations
BACCH – British Association for Community Child Health
CAF – Common Assessment Framework
CAMHS – Child and adolescent mental health service
CAS – Clinical Assessment Service
CBC – Clare Bale Consultancy
CC – Continuing Care. The National Framework for Children and Young People's Continuing Health Care (DH 2010) sets out a process for assessing eligibility for NHS healthcare funding for children and young people under the age of 18 years. It is for those who meet the eligibility criteria for NHS continuing healthcare and where statutory service cannot meet the needs of the individual, packages of care will be commissioned and care needs regularly reviewed.
CCN – Community Children's Nursing
CCQ – Care Quality Commission
CDC – Children's Development Centre
CHP – Community Health Partnerships
CIAG – Critical Incident Analysis Group
CQC – Care Quality Commission
CYC – City of York Council
CYP – Children and Young People
CYP HOF – Children and Young People Health Outcomes Forum
DE – Department of Education
DH – Department of Health
ECL – Executive Community Leadership
EHRC – Equality of Human Rights Commission
EoL – End of Life
FFF – Family Friendly Framework (BACCH)
HCP – Health Commissioning Portal
HMG – Her Majesty's Government
HNA – Health Needs Assessment
HV – Health Visitor
IMD – Indices of Multiple Deprivation
ITFH – Information Technology Feedback and Health
JCHC – Journal of Child Health Care
JRF – Joseph Rowntree Association
JSNA – Joint Strategic Needs Assessment
LA – Local Authority
LAC – Looked After Children
LCC – Lincolnshire County Council
LGIU – Local Government Information Unit
MH&WB – Mental Health and Wellbeing
NCCity – Nottingham City Council
NCCounty – Nottinghamshire County Council
NCH – Nottinghamshire Community Health
NCT – National Childbirth Trust
Neonate – An infant from birth to 4 weeks of age
Newlife – Newlife Foundation for Disabled Children
NHS – National Health Service
NHS CCG – NHS Clinical Commissioning Group. There are 7 groups involved in this programme; 1. Ashfield and Mansfield 2. Bassetlaw 3. Newark and Sherwood 4. Nottingham North and West 5. Nottingham East 6. Rushcliffe 7. Nottingham City
NHS LBC – National Health Service Leading Better Care
NICE – National Institute of Health and Care Excellence formerly National Institute of Health and Clinical Excellence
NIHR – National Institute for Health Research
NSCP – Nottinghamshire Strategic Commissioning Plan
NUH – Nottingham University Hospital
OT – Occupational therapy
PC – Palliative Care
PE – Policy Exchange
PH – Public Health
PH Nottingham City – Public Health Nottingham City
PH Nottinghamshire – Public Health Nottinghamshire
PHE – Public Health England
PPI – Patient and public involvement
QW – Quality World
QCC – Quality Care Commission
RCGP – Royal college of General Practitioners
RCN – Royal College of Nursing
SLT – Speech and language therapy
SEBD – Social, emotional and behavioural difficulties
SEN – Special educational need
SEND – Special education needs and disability
SFHT – Sherwood Forest Hospital Trust
SLA – Service Level Agreement
SPA – Single point of access
STC – Severe Child Poverty
TCTT – The Children's Trust Tadworth
TMR – The Marmot Review
UNICEF – United Nations Internationals Children's Emergency Fund
WHO – World Health Organisation
WTE – Whole Time Equivalent

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Participating Organisations

NHS Clinical Commissioning Groups

Nottingham City
Ashfield and Mansfield
Bassetlaw
Newark and Sherwood
Nottingham North and West
Nottingham East
Rushcliffe

NHS Providers
Nottinghamshire Healthcare NHS Trust
(includes County Health Partnerships and
Bassetlaw Health Partnerships)
Nottingham University Hospitals NHS Trust
Sherwood Forest Hospitals NHS Foundation Trust

Local Authorities
(Including Public Health)
Nottingham City Council
Public Health Nottingham City
Nottinghamshire County Council
Public Health Nottinghamshire

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Oak Field School Parents Group, Nottingham
Portland College Post-16 years Student Group, Mansfield

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Children, young people and families
The steering group consists of commissioners and providers. There is currently no parent-member or representative on the steering group. Instead a collective decision was made for the programme leads, Ann Berry and Jane O'Brien, to engage and facilitate wider participation of parents, young people and carers throughout phase 1 of the programme.

Appendices



Appendices

1 Integrated Community Children and Young People's Healthcare Programme – Programme Brief

2 Phase 1 Engagement, Consultation and Participation Summary Report

3 Tadworth Children's Trust Disabled Children's Charter for Health and Wellbeing Boards

4 Scoping – groups of children and conditions and pathways

5 The children and young people's health outcome's forum (summary of recommendations)

6 Extract from service scoping and mapping exercise

7 Special Schools Nursing data

8 Integrating Community Services Nursing Documentation case study

9 County Health Partnerships (CHP) paediatric therapy and children's community nursing activity data – Nottingham City and Nottinghamshire County (excluding Bassetlaw) – key findings

10 Children's Community Nursing (CCN) Audit - key findings

11 Personal Budgets and Direct Payments

12 Project on a Page: Integrated Commissioning Hub for Children and Young People (Nottinghamshire County)

Appendix 1

Nottinghamshire Integrated Community Children and Young People's Healthcare Programme

Programme Brief

May 2013 (V2)

Note: NHS Bassetlaw PCT/CCG position to be determined

Glossary of acronyms and abbreviations used in this document	
ADHD	Attention deficit/hyperactivity disorder
APTCOO	A place to call our own
ASD	Autistic spectrum disorders
CAMHS	Child and adolescent mental health service
CAS	Clinical Assessment Service
CCG	Clinical Commissioning Group
DH	Department of Health
HNA	Health needs assessment
JSNA	Joint strategic needs assessment
LAC	Looked after children
NICE	National Institute of Health and Clinical Excellence
NNE	Nottingham North and East
OT	Occupational therapy
PPI	Patient and public involvement
SEBD	Social, emotional and behavioural difficulties
SEN	Special educational need
SLT	Speech and language therapy

Version control
The final version was produced in November 2012.
Logos only updated in May 2013 to reflect the changes in commissioning organisations from 1st April 2013.

Programme Brief
Integrated Community Children and Young People's Healthcare Programme

Introduction

The purpose of this programme is to develop a Nottinghamshire wide integrated and sustainable model of children's care delivery via a network of community based services. This will include in-reach and out-reach, for children and young people with acute or additional health needs including disability and complex needs. Key elements will be a single point of access and co-ordinated assessment, treatment and review processes implemented across integrated care pathways.

The vision is to enable children and young people with acute and additional heath needs, including disability and complex needs, to have their health needs met wherever they are. The services will support the child's life choices rather than restrict them and improve the quality of life for children and their families and carers.

Stakeholder engagement will be fundamental to informing the programme. Equality and quality impact assessments will be undertaken on developments.

Policy and drivers

National

There are many national policies and drivers relevant to the programme e.g.:

- NHS at Home: Community Children's Nursing Services (DH, ref 15106, 2011)
- Healthy lives, brighter futures: The strategy for children and young people's health (DH, ref 094397, 2009)
- Disability and Special Educational Needs green paper (2011)
- Framework for children and young people's continuing care (DH, ref 116469, 2010)
- ACT (2009) Right people, right time, right place: planning and developing an effective and responsive workforce for children and young people's palliative care
- NICE guidance for related paediatric conditions

Local

- NHS Nottingham City Transformational Change in Specialist Children's Nursing Services in the Community, GP Commissioning Executive Committee. June 2012
- Nottinghamshire County Joint Strategic Plan, Children's Trust Board. Feb 2012

Scope

This is a joint NHS Nottingham City and NHS Nottinghamshire County programme for children and young people with acute or additional health needs including disability and complex needs. These include the following four groups:

1. Children and young people with acute and short term conditions (0-18yrs)
2. Children and young people with long term conditions (0-18yrs)
3. Children and young people with disabilities and complex conditions including those requiring continuing care and neonates (0-25yrs)
4. Children and young people with life limiting and life threatening conditions and illness, including those requiring palliative and end of life care (0-25yrs)

During their development and/or the progression of their condition or illness individual children and young people may and often do move between and overlap these groups.

Needs

Nottingham City 0 to 18 years population – approx 57,900. There are approx 4,000 disabled children of which 900 are severe.

- Nottingham City JSNA, 2010 – refresh currently in progress.
- Disabled Children's Ofsted inspection 2012 (publication pending).

Nottinghamshire County 0 to 18 years population - approx 180,000. There are estimated between 7,000 to 12,000 disabled children of which more than 2,500 are severe.

- Nottinghamshire County JSNA for children and young people 2010.
- Nottinghamshire County HNA for children and young people with disability and SEN, including HNA for children and young people in special schools, 2011.

Issues

- There is a lack of co-ordinated support for children and young people with complex needs and disability and their families.
- There is an increase in demand and a need to demonstrate value for money as well as ensuring equity of access and service provision, whilst taking account of City/County differences e.g. population needs, geography, finances.
- More children with a severe disability and complex needs are living longer (Healthy Lives, Brighter Futures 2009), due to new interventions and technology.
- Disabled children and those with complex needs have higher safeguarding needs.
- There are multiple providers/teams working to different processes (e.g. assessments, care plans), policies and procedures and different IT systems resulting in duplication / lack of efficiency and effectiveness (negative impact on children, young people and families)
- There are too many acute and emergency attendances and admissions for conditions and illness that could be treated at home or avoided.
- There are too many children staying in hospital for too long, particularly those who are vulnerable to hospital acquired infections.

Current service provision

Current health providers and partners

- NHS County Health Partnerships
- NHS Nottingham University Hospital Trust
- Nottingham City Council – Education, Social Care and Public Health (from April 2013)
- Sherwood Forest NHS Hospital Foundation Trust
- Nottinghamshire County Council – Education, Social Care and Public Health (from April 2013)

Core services

- General practice
- Hospital services
- Universal community children's services
- Education
- Social services

Supported by specialist community services (not an exhaustive list)

- Children's Community Nursing, including special school nursing, short breaks and training provision
- Paediatricians
- Speech and language therapy
- Physiotherapy
- Occupational therapy
- Looked after children health services
- Safeguarding
- Local Authority specialist services e.g. short breaks services, special educational needs team, disabled children team, looked after children services

Interfaces and linkages with CAMHS will be considered within the programme, however they are not specifically included within the development scope.

Benefits

Benefits include:

Children young people and their families

- A single point of access and co-ordinated assessment, treatment and review will mean that parents and families experience a co-ordinated seamless service that is centred around and personalised to the individual child and family promoting independence and quality of life.
- Improved safeguarding outcomes due to improved co-ordination of services.
- Parents and carers are able to put being parents first and health care providers second and are enabled to do ordinary family activities.
- There is genuine choice of end of life care, acknowledging the preferences of the child or young person and their families.
- Children and young people are admitted to hospital or stay in hospital only when it is clinically inappropriate to care for them in the community.
- Children and young people who are vulnerable to infection are protected from health care-acquired infection.
- Children and young people are enabled to lead their vision of a normal a life as possible with minimum disruption to their every day lives.
- Improved access and equity of service provision.

Services

- High quality and cost effective services
- Consistent staffing from satisfied and highly motivated teams.
- A cohesive coordinated network model will ensure that there is utilisation of the right skills in the right place at the right time every time.

Commissioners

- Quality services and value for money would be achieved through re-focussing resources where the need is.
- Improved performance management of service delivery.

Risks

A detailed risk assessment and actions to mitigate risks will be undertaken by the Programme Steering Group, including clear communication and consultation with stakeholders. Some potential risks are identified below:

Potential risks of not implementing the programme may include:

- Insufficient service capacity to meet increasing demand
- Long waiting times
- Negative impact on quality and co-ordination of services
- Deterioration of health and economic wellbeing of children, young people and their families
- Increased safeguarding risks
- Inconsistent and inequitable access to services
- Increased litigation and escalating compensation costs

Potential risks of implementing the programme may include:

- Not having a clear implementation plan and phased/systematic approach
- Impact of organisational change and restructure on continuity and comprehensive support for implementation
- Potential to destabilise and de-motivate staff delivering services
- Inequities resulting from inconsistency of implementation across City and County
- Increased costs

Summary Timeline - phase 1
Integrated Community Children and Young People's Healthcare Programme

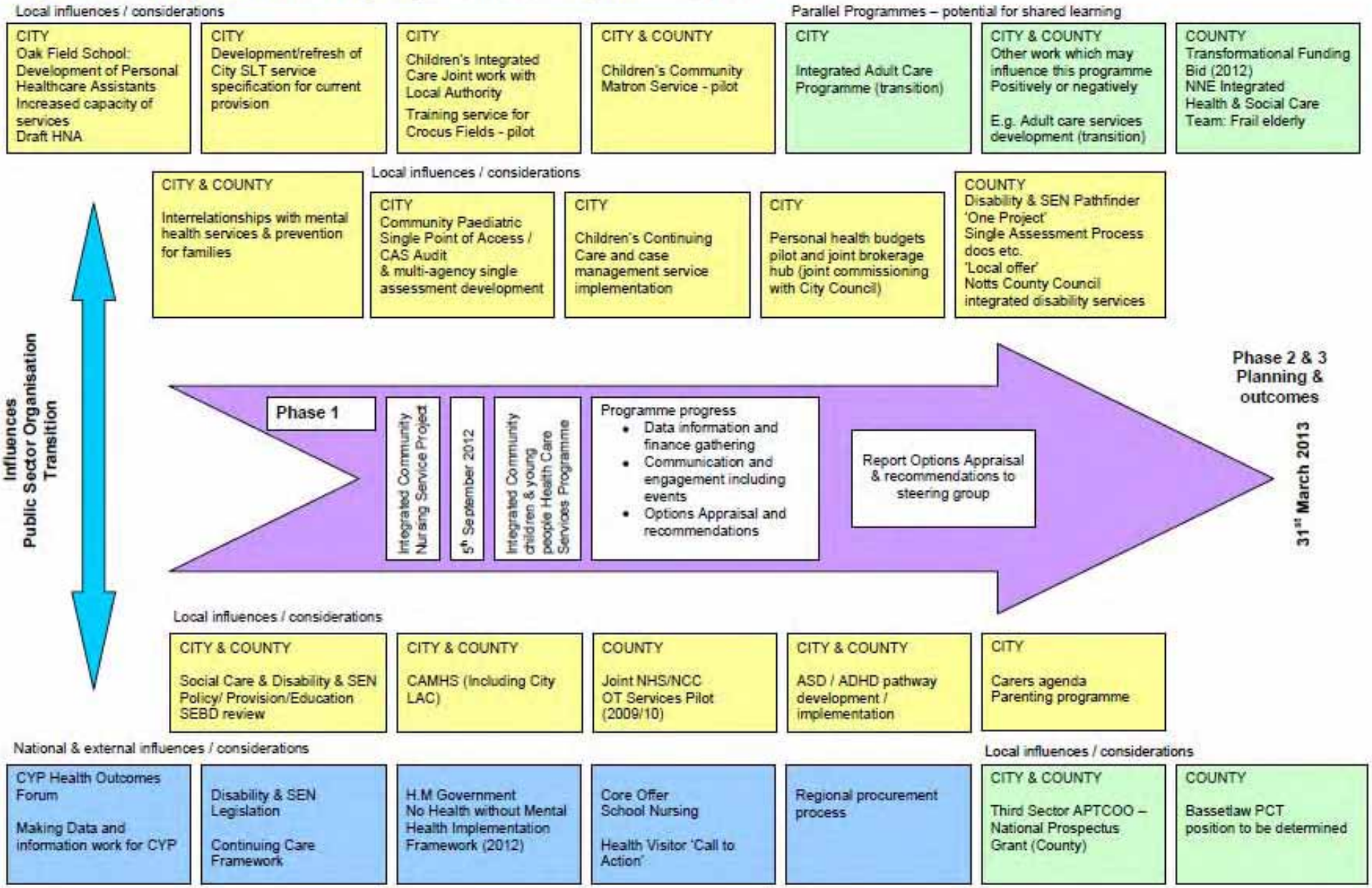
Date	Key milestone
August 2012	Establish steering group • Develop project controls
September 2012	Programme signoff • City CCG Clinical Council • County – Joint Commissioning Group Special Educational Needs and Disability • County Cross CCG Children Commissioning Group
September/October 2012	Initial set up of programme task and finish groups: • Communications and engagement o Development of communications plan o Involvement of provider PPI/Commications leads • Data, information and finance o Contract activity o Health needs
September – January 2013	Programme scoping: • Four Groups: o Children and young people with acute and short term conditions o Children and young people with long term conditions o Children and young people with disabilities and complex conditions including those requiring continuing care and neonates o Children and young people with life limiting and life threatening conditions and illness, including those requiring palliative and end of life care • Engagement on pathways with healthcare professionals and service users • Current contracts: o Activity o Cost o Outcomes • Health needs: o JSNA outcomes o Other health profiling o Population projections o Transition Purpose – to outline the programme of work required to implement an integrated children's services.
March 2013	Report with option appraisal and recommendations to be presented to CCGs

Overview diagram

The diagram below is an overview of the Integrated Children and Young People's Healthcare Programme showing local and national factors and current developments (as at time of writing) which may influence the outcomes of the programme.

V1 (22/11/12)

Integrated Community Children and Young People's Healthcare Programme - Overview



Appendix 2

Nottinghamshire Integrated Community Children and Young People's Healthcare Programme (ICCYPH)

Phase 1
Engagement, Consultation and Participation Summary Report

April 2013

1) Engagement, consultation and participation work undertaken

Previous national and local consultation findings were reviewed and the following new joint Nottingham City / Nottinghamshire County consultation and engagement work was undertaken as part of phase 1 of the ICCYPH Programme:

a) Consultation with parents, families and young people

- November 2012 – engagement with parents at a parent's coffee morning held by the Barnardo's Butterfly Project in Nottingham City. the aim to gain an insight into which services they have used, what was good about their experience and what could be improved.
- October – December 2012 – parent questionnaires used to interview parents by Barnarodo's Butterfly Project staff to gain feedback on services. Also used by the team leader for Carin 4 Families at Nottingham University Hospitals NHS Trust.
- December 2012 Focus group work with a group of 8 young people aged 16-19 years from Nottinghamshire County and Nottingham City at Portland College, Mansfield. The aim was to gain an insight into the experience of young people with disability, acute and additional health needs in accessing and using services, which services they have used, what has worked well and where there is room for improvement.
- February 2013 – work with small group of parents at APTCOO (A Place to Call Our Own), Mansfield, using themes and feedback from previous consultation to develop a Families' Statement of Expectations.
- April 2013 – Consultation with a group of parents at a parent's coffee morning at Oak Field School to review and comment on the draft Families' Statement of Expectations, ask if it reflects their views and expectations and if they support it.

b) Multi-agency, multi-professional stakeholder events

- July 2012 – Integrated Community Nursing Project Event
- February 2013 – Right place, right time, every time: from fragmentation to integration. Integrated Community Children and Young People's Healthcare Programme Event

c) GP online survey

- March – April 2013, online survey circulated to GPs in Nottingham City and Nottinghamshire County to gain an understanding of their awareness of children with additional health needs and disability, whether they proactively identify carers and siblings in their records and what they see as their development needs in this area.

2) Summary of feedback and themes from consultations

a) Parents and carers

Positives:

Services are generally good once received. Many organisations received complementary feedback about the staff e.g. Community Physiotherapists, Occupational Therapy, End of Life, C.A.R.I.N 4 Families, short breaks, hospital nursing care, CDC, Thornberry and Barnardo's Butterfly Project, Rainbows Hospice, APTCOO.

Room for improvement:

Training / awareness for professionals and parents / carers

- Frustrations accessing mainstream services for 'normal' childhood illness – e.g. difficulties in finding a GP with an understanding of children with additional / complex health needs and disability, often end up going to hospital or paediatrician.
- GP's as commissioners when they seem to have little knowledge or experience working with children and young people with additional need.
- Moving and handling issues and use of equipment in mainstream schools – inadequate training / updates.
- Knowledge and skills of staff on children's hospital wards – lack of adequate care for specialist needs.
- Better staff education and training
- Poor / inadequate training for use of equipment at home leading to risk of injury to CYP / parent / carer – and/or reluctance to use equipment.

Planning

- Supply of equipment (long waits) and lack of anticipation of changing needs as child grows / condition progresses.
- Delays in delivery of equipment means longer stays in hospital.
- Want long term planning rather than services based in a time limited provision.
- Want clear and long term planning for the future.
- Need proactive planning between services and agencies e.g. planning for discharge from hospital to home/community.
- Need to consider logistics and challenges of travelling to and managing to attend appointments with disabled children. This is particularly difficult where there is more than one disabled child with limited mobility in a family. Need to take a whole system approach.

Communication and access to information

- One stop shop for information
- Clear information about services available
- Need shared documentation and assessment for ease and improved communication and to prevent repeating child and family history time and time again

Service / organisation design and management

- Duplication e.g. having to see health OT and social care OT
- Simplified system to access services – a single point of access
- Lack of adequate key worker support for children and young people with emotional needs
- More joined up working between health, social care and education

- Need to be less service focussed and more family focussed – support for siblings and family oriented services and activities
- Negative impact of operational management issues on families e.g. lack of cover for staff absence.
- Location of hospice provision means lots of travelling for those living in the middle of the county

Transition

- Transition from children's to adult services – concerns about continuity of care, communication, forward planning, loss of support and resources, loss of established relationships and having to form relationships with new team. Age an artificial barrier to accessing care.
- Concern about hospice care post transition.

Funding

- Direct payments – mixed feelings – positive in giving more choice but examples of difficulty recruiting suitable carers and carers not being willing/able to undertake some tasks. Also concerns about liability as employer – and another role for parent to take on.
- Personal health budgets - mixed feelings as with direct payments - positive if enabled continuity of the same care team across transition from children's to adult services.
- Clarity about funding sources for equipment and supplies.

b) Young people

Positives:

All agreed that the services they received were good. They valued honesty from all areas of staff on treatments waiting times etc

Room for improvement

Training/awareness

- Education and training for doctors and others – to improve their skills in working with children and young people with disabilities and additional health needs and have greater awareness and understanding of their conditions.

Service/organisation design and management

- Waiting times at clinics – kept waiting for ages, with nothing to do, then have too short a time with health professional when called in – use technology to manage waiting times and provide something to do during waits.

Transition

- Transition to adulthood – health professionals talking to parents instead of young person. Young people want to be supported to be more independent and in control to make own decisions.

Privacy and dignity

- Privacy and dignity – want to be treated as individuals and have choice of being seen on their own for all or part of a consultation – without parent or others e.g. students.

c) Families' statement of expectations

A *Families' Statement of Expectations,* below, was developed from themes identified from the consultation and participation work with parents, families and young people and with reference to the Values developed by the Children and Young People's Inter-Agency Group (CIAG)[1] and the UN Conventions on the Rights of the Child[2], and the Rights of Persons with Disabilities[3].

The recommendation is for the *Families' Statement of Expectations* to be used as a set of guiding principles in the design, commissioning and provision of services and in developing service user experience measures. It also has the potential to be used to develop a framework of standards against which quality of services could be assessed.

Families' Statement of Expectations

Our values are…

1. Respect
2. Collaboration
3. Continual improvement

My family's expectations will be met when…

1. We are consulted and listened to, heard and treated with respect as experts on our/our child's condition and have our views taken into account at all times.
2. We can easily get information, advice and guidance, and the services and supplies that we need, when we need them, so that our family can enjoy the best possible health and fulfilling lives. This should enable and support our roles, lifestyle choices and aspirations.
3. There is collaborative, joined up and timely planning and service delivery, with all parts working as a whole across all organisations and agencies involved in every aspect of our children's care.
4. Each of our children is treated as an individual.
5. There is timely communication and shared documentation including core essential information about our children, their condition and their support between all those who need to be involved.
6. We are confident that there are enough staff, who have the right knowledge, skills and expertise for what they are there to do, and they demonstrate this by empathy and understanding in all contacts.
7. Our children are supported to achieve responsibility for themselves as adults and the family is supported during this period of transition to adulthood and reduced dependence on the family.
8. We can see that everyone involved in our children's care is committed to continually improving what they do.
9. Our children are seen in age appropriate environments furnished and equipped to meet their needs, this takes account of chronological and developmental age.
10. At all times our children are protected from harm

[1] Values developed by the Children and Young People's Inter-Agency Group (CIAG) http://www.ncvys.org.uk/UserFiles/Policy/CIAG_ServingChildrenAndYoungPeopleBetter_Oct09.pdf
[2] UN Convention on the Rights of the Child (1989) http://www.unicef.org.uk/UNICEFs-Work/Our-mission/UN-Convention/
[3] *UN Convention on the Rights of Persons with Disabilities http://www.equalityhumanrights.com/human-rights/our-human-rights-work/international-framework/un-convention-on-the-rights-of-persons-with-disabilities/*

Parents involved in the consultation and participation work undertaken in Phase 1 of the programme were keen to be involved in the development phase and in prototyping proposed solutions.

d) Multi-Agency, multi-professional stakeholder events

July 2012 event:

The primary aim of the event was to engage stakeholders (nursing services) in the proposed integration. To listen to their input on what currently works well, what is not working well, and their opinions on what opportunities exist.

Aspects of an integrated nursing model which were considered to be most important by participants:

Training / awareness for professionals and parents / carers

- A comprehensive education/training programme - systematic and strategic; competency based with targeted resources.

Planning

- A service that is proactive and not reactive
- Early identification mechanisms; pre and post natal, and using Common Assessment Framework

Communication and access to information

- Shared records
- Care plans based on agreed outcomes with child and family (lead prescription)
- Develop a easily accessible service map / directory

Service / organisation design and management

- Aligned policies and paperwork
- A clear pathway / pathways - ageless and endless, service users should be able to dip in and out of provision. It needs to be flexible.
- A One-stop shop/Single point of access, available 24/7 which is multi-level.
- Lead professional/key worker per child
- Involvement of third sector
- The role of the GP could be central and they could have a register of patients
- Service users should be able to easily access resources and supplies including continence and equipment.
- Develop family capacity and include siblings
- Service users should have options and choice
- Needs of Children in Care should be specifically considered

Funding

- Personal Health Budgets - should be considered within integration

What do we need to continue doing/hold onto?

- Liaison posts that prevent admissions and facilitate discharge
- Skills/expertise/experience of existing staff
- Early support pack/start box (Blue box) - needs to be embedded into universal services (e.g. Health visiting and Children's Centres).

- The integrated models that already work in localities e.g. special schools. Families benefit from a one-stop shop
- Hold onto and build on strengths and quality of current services
- Unified documentation (in some areas)
- Continuing care framework and assessment
- Parents network, but need to support it better
- Specialist support services e.g. Information library, CDC, HV coordinator
- CAF is the vehicle to integrated seamless assessment/care planning. Needs to be embedded across all services.
- Local community based services
- Parent and carer support forums
- Clinical, hands on delivery with children…more capacity for it
- Specialist pool of knowledge that can deliver training to frontline staff
- Service quality/innovation in Nottinghamshire
- Commitment and passion of the workforce in Nottinghamshire
- Voluntary sector (e.g. Butterflies, Rainbows etc.)
- Keep and build on continuing care support
- Keep and build on the End of Life Team

February 2013 event:

The purpose of the day was to provide an update on the Integrated Children and Young People's Healthcare Programme, learn from a collective parents' perspective – presented by a parent representative, and to give delegates an opportunity to generate ideas for key elements of an integrated and interlinked network model (Access, Assessment, Integration) for development in the next stage.
Key highlights from the workshops:

Key worker role
The key worker role came across very strongly as key to bringing all the elements of an integrated model together.

Possible options for a key worker structure included:

- Dedicated key worker service. Leicester model (provided by Menphys) put forward as an exemplar.
- Include key working in all service specifications as integral part of all staff roles
- A key worker support / administration service to support key workers in their role.
- Whatever Key worker model is used key workers require admin/information support and a structured model.
- SUSTAINABILITY must be considered

Essential elements of a key worker role (from parent representative)

- **Signpost** families to other services and information that they may not be aware of.
- Provide an objective **thinking partner** to empower families and help them make decisions and remain in control.
- A **navigator** and **enabler** to help parents to understand and negotiate the complex arrangements that may be in place.

Shared records and communication
Supported by Government policy - i.e. hospitals should be able to share digital data from April 2014, and to adopt paperless referrals from April 2015. The NHS to become paperless by 2018

- Use of 'new' technologies and systems – e-cloud - and use of existing technologies and systems or combination of these.
- Use videos to illustrate how to undertake key tasks.
- Learn from work taking place already.

- Family led permissions to control access, not led by individual agencies. Tiered access. Multi-discipline and multi-agency access
- Information Governance perceived as a barrier – but should be an enabler – parents assume that their child's records and information are already shared by the professionals involved in care.
- Analyse current cost of duplicated work – potential for re-focussing resources.
- Better use of existing information technology to speed up communication between e.g. consultants to community, currently communicated on paper

Access, assessment and integration

Integrated model incorporating streamlined access, co-ordinated assessment and delivery of care, supported by shared information and key workers.

- Access – hub and spoke model - central access hub – multi-disciplinary / multi-agency teams – co-located and virtual. One front door, single branding. Based away from hospital
- Joint (health/social care) assessments where possible or separate assessments at the same time as education
- Share, trust and accept information and assessments already undertaken to avoid duplication
- Trust parents/carers – treat parents as experts
- Use of existing technology for virtual discussions where appropriate to reduce the number of meetings that families have to attend, with flexibility to fit around the family's needs rather than service needs.
- Collaborative commissioning *and* provision for health and social care / Nottm City and Notts County
- Join access and assessment together as one project
- Join health with SEND development work in County and City
- Commission for joined assessments or requirement for multi-agency/multi-disciplinary assessment and multi-agency action plans
- Example of models from elsewhere – Derby model – Multi-agency hub; Nottingham - CDC acts as hub for pre-school children; Oak Field School, Nottingham – one stop shop for children attending the school

Quick wins

- Combined appointments for children who now have to see more than one clinician on separate occasions.

- Pre-appointment phone call with parent/child to find out their questions/concerns so that relevant information and answers can be available at the appointment. This would make the appointment time more productive for the clinician and family and less likely for family to have to attend again to see someone else or to get the answers.

- Greater trust and confidence in parents as expert carers and greater use of telephone consultations – particularly those that the child does not need to attend.

- Development of an integrated approach to working from nursing teams, including common nursing assessment and single care plan co-ordinated by a lead nurse was considered a 'quick win'. Nursing services which all have access to System1 should be able to implement shared care plans and assessment documentation. Barriers to enabling this to happen need to be analysed and overcome.

The stakeholder consultations highlighted that streamlined access, co-ordinated assessment and delivery of care, supported by shared information and key workers with a clearly defined, structured role are inseparable components of an integrated model of care, illustrated in the diagram on the right.

Many examples of existing good practice were also identified which could be shared, spread and built upon when developing a new model of service delivery

e) Summary of key themes identified from stakeholder consultations:

	Key themes to support integration	What would this mean to children, young people and families?
1	Collaborative integrated commissioning and resources with statutory partners. Potential integration with statutory partners' SEND Legislation projects / programmes.	Parents don't need to know which pot of money funding for care comes from – can focus on meeting needs.
2	Single point of access / specialist hub for information and access to services – accessible to professionals and families. Local offer to be developed.	One stop shop for information and access to services. Better co-ordination of contact with different services – in same place, same time. Proactive planning for life course.
3	NHS Number as unique identifier. Shared records using new and existing technologies – accessible to professionals and parents/young person. Web based tool (e.g. Wikki – One Project)	Not having to constantly repeat child and family's story. Parents, CYP know what information is held on them. More awareness and control over content and how, when and with whom records and information are shared. Increased safety with one record – consistent information available to all who need it. Enables data protection requirements to be met.
4	Clearly defined, structured and supported key workers that would liaise with Lead Professional and SEND navigator role – this may be a dedicated role or part of existing roles (to be explored)	Clear and consistent support and advocacy from key workers with capacity to undertake the role. Parents only need to be key worker if choose to, not because they feel they have to.
5	Co-ordinated multi-disciplinary, multi-agency assessments, core information recorded and 'one plan'.	Reduced duplication of information. Specialist assessments contribute to one plan. Increased safety and reduced time spent during assessments with single plan.
6	Network model based on Family Friendly Framework, with network management – life course approach from birth to adulthood - not a linear model. Generic and specialist tasks with 365 day support to prevent emergency admission. Parents consulted and listened to as experts.	Seamless access to proactive services, effective planning and reduced disruption to child's education and the family's economic and social functioning. Reduced anxiety and disruption from unplanned admissions and discharge arrangements. Services planned around the life course means ease if transition to adult services.
7	Increased education, knowledge, involvement and awareness of GPs of this group of children.	Improved early support and communication between healthcare professionals involved in care. Local access to understanding general medical services for 'normal' childhood illnesses, avoiding having to resort to visit to A&E. Less anxiety at transition when GPs become more involved in care as GPs already know the child and family.
8	Flexible and agile services adapt to meet CYP/family needs not CYP/family adapt to service needs.	Right support available at the right time in the right place – follows the child. Families able to live as normal family life as possible.
9	Integrated services where possible and interlinked provision	Fewer services and professionals to deal with. Easier co-ordination of services and less time spent on arranging and following things up. More family time.
10	Peripatetic workers, working or based in various places for relatively short periods to facilitate - in-reach (to hospital) and outreach working (in the community)	Increased confidence that child's specialist needs will be met during inpatient spells without parent having to be there 24/7. Better continuity of care and individualised knowledge of the child. Child's personal and specialist needs safely met wherever they are.

f) GP online survey

To gain an insight into the awareness and views of general practitioners as key primary healthcare providers a short online survey was circulated to individual general practitioners in Nottingham City and Nottinghamshire County at the beginning of March 2013, and reminders sent during April 2013.

The survey consisted of five questions:

1. GP practice code
2. Do you know how many children and young people registered with your practice have:
    a) a disability? Y/N
    b) complex health needs? Y/N
    c) a long term condition? Y/N
    d) palliative or end of life care needs? Y/N

3. Do you proactively identify in your patient register
    a) Carers e.g. parents, of children with additional health needs including disability and complex health needs and those with palliative and end of life care needs (Y/N/don't know)
    b) Siblings of children with additional health needs including disability and complex health needs and those with palliative and end of life care needs (Y/N/don't know)

4. How confident do you feel about supporting children and young people with acute and additional health needs including disability and complex health needs and those with palliative and end of life care needs and their parents and carers? (Very confident/confident/neither confident or unconfident/unconfident/not confident at all)

    a) Would you like to be more involved in the care of these children? (Y/N)
    b) What are yours and your practice's training and development needs to help with this?

5. Please give us any other comments:

Results

Q 1 Responses were received from 25 GPs in total, some responses were received from more than one GP in the same practice:

Area	Number of GPs	Number of Practices
City	13	11
County	7	4
Not stated	5	
Total	**25**	15+

Q1 & 2 Due to the small number of responses received and inconsistent answers given to questions 2 and 3 by different GPs from the same practices the results from these two questions are of limited quality or validity.

The results do suggest that children with palliative or end of life care needs are more likely to be identifiable from practice registers (64% positive responses) than the other three groups (44% to 56% positive responses). The results also indicate that parents are more likely to be

proactively identified in practice registers as carers of children with additional health needs (72% positive responses) than are siblings (24% positive responses).

Q4 Only 20% of GPs responded that they felt confident or very confident about supporting children and young people with acute and additional health needs including disability and complex health needs and those with palliative and end of life care needs and their parents and carers. The majority (60%) felt neither confident or unconfident.

Q4.a. Almost half (48%) of the GPs who responded would like to be more involved in the care of these children (36% would not and 16% did not answer this question).

Training and development needs identified

Information on access to resources e.g. support groups, social care support, palliative support for families and bereavement support.

Training to gain confidence in clinical management of children with complex needs.

Training to gain confidence in communicating with children with speech, language and communication difficulties and children and families where there are palliative or end of life care needs.

Information on what services are available.

Other comments

Communications from specialists/consultants (to GPs) is good but feedback from MDTs poor and communications between teams poor.

Initiating help and treatment is difficult. Difficult for GPs to get adequate support.

Updating registers and targeting support would make a good Practice Specific Objectives (PSO) i.e. a target to update registers of the specified relevant categories and define a few parameters of engagement of care which would keep GPs in the loop and deliver more holistic care.

Concern that resources in practices are already stretched and this is a barrier to GPs becoming more involved in the care of these children and young people.

Specific issues highlighted in University practice. Issues of Transition and new entrants to the system. University practice predominately focussed on 18-25 year olds - some students arrive with significant and complex needs - sometimes with no prior warning which is a challenge - as is working around the fact they spend a significant time both in Nottingham but also at 'home'. Covers physical issues but even more so mental health issues. University has services and mechanisms to help but need to ensure link closely with wider health and social care system. Increasingly also have children of international students with complex needs - either born here or arrive with family - creates issues of culture and language - sometimes the main carers in these families can be relatively isolated, and they also have little understanding of NHS. As the carers usually are not the one's studying at the University the University network/ response can be less robust.

More psychological support and co-ordination of services for teenagers who fall short of the need for CAMHS but have significant difficulties such as low mood, anorexia, difficulties arising from low self esteem and sexuality. Also more psychotherapy required for teenagers.

Appendix 3

Disabled Children's Charter for Health and Wellbeing Boards

The ..... **Health and Wellbeing Board** is committed to improving the quality of life and outcomes experienced by disabled children, young people and their families, including children and young people with special educational needs and health conditions. We will work together in partnership with disabled children and young people, and their families to improve universal and specialised services, and ensure they receive the support they need, when they need it. Disabled children and young people will be supported to fulfil their potential and achieve their aspirations and the needs of the family will be met so that they can lead ordinary lives.

By [date within 1 year of signing the Charter] our Health and Wellbeing Board will provide evidence that:

1. We have **detailed and accurate information** on the disabled children and young people living in our area, and provide public information on how we plan to meet their needs
2. We **engage directly with disabled children and young people** and their participation is embedded in the work of our Health and Wellbeing Board
3. We **engage directly with parent carers** of disabled children and young people and their participation is embedded in the work of our Health and Wellbeing Board
4. We set **clear strategic outcomes** for our partners to meet in relation to disabled children, young people and their families, monitor progress towards achieving them and hold each other to account
5. We **promote early intervention** and support for smooth transitions between children and adult services for disabled children and young people
6. We work with key partners to **strengthen integration** between health, social care and education services, and with services provided by wider partners
7. We provide **cohesive governance** and leadership across the disabled children and young people's agenda by linking effectively with key partners

Signed by ..... **Date** .....
Position: Chair of Health and Wellbeing Board.

For guidance on meeting these commitments, please read the accompanying document: Why sign the Charter?

every disabled child matters

Every Disabled Child Matters (EDCM) is the campaign to get rights and justice for every disabled child. It has been set up by four leading organisations working with disabled children and their families – Contact a Family, the Council for Disabled Children, Mencap and the Special Educational Consortium. EDCM is hosted by the National Children's Bureau, Charity registration number: 258825.

The Children's Trust, Tadworth is a national charity providing specialist services to disabled children and young people across the UK. These services include rehabilitation and support for children with acquired brain injury, expert nursing care for children with complex health needs, and residential education for pupils with profound and multiple learning difficulties at The School for Profound Education. Charity registration number: 288018. Find out more about the work of The Children's Trust, Tadworth at www.thechildrenstrust.org.uk

The Children's Trust Tadworth
For children with multiple disabilities

Appendix 4

Joint Integrated Community children and young people Health Care Programme

Scoping – groups of children and conditions and pathways

This is a joint NHS Nottingham City and NHS Nottinghamshire County programme for children and young people with acute or additional health needs including disability and complex needs.

These include the following four groups:

1. Children and young people with acute and short term conditions
2. Children and young people with long term conditions
3. Children and young people with disabilities and complex conditions including those requiring continuing care and neonates
4. Children and young people with life limiting and life threatening conditions and illness, including those requiring palliative and end of life care

These groups are not mutually exclusive. During their development and/or the progression of their condition or illness individual children and young people may and often do move between and overlap these groups.

The tables below show:

Table 1 - Need/list of conditions in each of the four groups above
Table 2 – Local pathways, where known, with CYP group they relate to.
Table 3 – National pathways

Table 1 - CYP Group number (see page 1) and conditions

Group 1

Trauma

- Trauma accidental injuries
- Head injuries
- Fractures
- Lacerations
- Burns
- Poisoning

Medical admissions

- Diarrhoea and Vomiting
- Constipation
- Failure to thrive
- Administration of intravenous antibiotics
- Respiratory Infections e.g., Bronchiolitis

Surgical Admissions

- Orthopaedics
- ENT
- Plastic surgery,
- Renal
- General surgery

Exacerbation of long term conditions

- e.g., Diabetes etc.
- See conditions listed

Group 2

Common conditions

- Epilepsy
- Diabetes
- Asthma
- Renal Conditions

Less common conditions

- Scoliosis
- Sickle Cell Anaemia
- Cystic Fibrosis (CF)
- Arthritis
- Ulcerative Colitis
- Crohn's Disease

Group 3

- Guillain Barré
- Ehlers-Danlos Syndrome
- Aphasia
- Hearing Impairment (HI)
- Hypotonia
- Meares – Irlen Syndrome Syndrome/Scotopic Sensitivity
- Landau Kleffner Syndrome
- Prader-Willi Syndrome
- Angelman Syndrome
- Heller's Syndrome
- Cerebral Palsy / Worster-Drought Syndrome (WDS)
- Developmental Delay
- Global Developmental Delay
- Cerebellar Ataxia
- Cerebral Palsy (CP)
- Apraxia
- Auditory Processing Disorder
- Multi-Sensory Impairment (MSI)
- Sensory Integration Disorder (SID)
- Speech and Language
- Non-Verbal Learning Difficulties (NLD)
- Anxiety Disorders
- Mood Disorder
- Conduct Disorder
- Emotional & Behavioural Difficulties (EBD)
- ADHD
- Obsessive Compulsive Disorder (OCD)
- Oppositional Defiant Disorder (ODD)
- Pathological Demand Avoidance (PDA)
- Pervasive Developmental Disorder (PDD)
- Selective Mutism
- Semantic Pragmatic Disorder
- Severe Learning Difficulties (SLD)
- Down's Syndrome
- Mowat-Wilson Syndrome
- Muscular Dystrophy
- Neurofibromatosis
- Noonan Syndrome
- Osteogenesis

Group 4

- Cancers
- Complex and multiple needs
- Rare genetic conditions
- See conditions listed in groups 1, 2 & 3

Table 1 - CYP Group number (see page 1) and conditions			
Group 1	**Group 2**	**Group 3**	**Group 4**
in group 2		Disorder • Spina Bifida • Tactile Defensiveness • Hydrocephalus • Agenesis of the Corpus Callosum (ACC) • Graphomotor Skills • Dysarthria • Dyscalculia • Dysgraphia • Dyslexia • Dysnomia • Dyspraxia • Fragile X Syndrome • Asperger's Syndrome • Hyperlexia • Autism (ASD) • Atypical Autism • Echolalia Imperfecta (OI) (Brittle Bone Disease) • Physical Disability (PD) • Profound and Multiple Learning Difficulties (PMLD) • Proprioception • Rett Syndrome • Social Skills • Tourettes Syndrome • Visual Impairment • Waardenburg Syndrome • Williams Syndrome Emotional Literacy • Learning Disabilities • Moderate Learning Difficulties (MLD)	

Table 2 - Local Pathways and CYP groups			
1. Integrated care pathways for children with life-threatening or life limiting conditions – diagnosis and recognition (Group 4)	2. Pathway of Care for an Unborn Child or Neonate Diagnosed with Condition that is Life Shortening or Life Threatening. NOTTINGHAM. (Group 4)	3. Integrated care pathway tool for disabled children and young people 0-19 yrs (Group 3)	4. Childrens Continuing Care referral process (Nottingham City - draft) (Groups 3 / 4)
5. Continuing Care transition from child to adult services (Nottingham City)	6. Phases of the continuing care pathway – from Children's Continuing Care and Case Management Service Specification – Nottingham City (Groups 3 / 4)	7. Early support pathway / timeline for children born with severe neurological / multiple problems leading to lifelong profound disability (Nottingham City – draft 5) (Groups3 / 4)	8. Referral pathway for CDC short breaks (Groups 3 / 4)
9. Physiotherapy / OT pathway for pre-school child with cerebral palsy (Group 3)	10. Speech and language therapy core pathway (All groups)	11. Integrated pathway for assessment and support of children with complex needs (Nottingham City and South Shire) (Group 3)	12. Personal Health Budget Flow Chart Children's Continuing Care (Nottingham City) (Groups 3 / 4)

Table 3 - National Pathways:	
ACT / Together for Short Lives palliative care pathways (Group 4)	Neonatal Pathway for Babies with Palliative Care Needs http://www.togetherforshortlives.org.uk/assets/0000/1086/A_Neonatal_Pathway_DIAGRAM_ONLY.pdf
	Care Pathway for children with life limiting and life threatening conditions http://www.togetherforshortlives.org.uk/assets/0000/1087/Core_Care_Pathway_DIAGRAM_ONLY.pdf http://www.togetherforshortlives.org.uk/assets/0000/4121/TfSL_A_Core_Care_Pathway__ONLINE_.pdf
	Transition care pathway for children with life threatening or life limiting conditions http://www.togetherforshortlives.org.uk/assets/0000/1088/Transition_Care_Pathway_DIAGRAM_ONLY.pdf http://www.togetherforshortlives.org.uk/professionals/resources/2432_the_transition_care_pathway_2007
	A Care Pathway to Support Extubation within a Children's Palliative Care Framework http://www.togetherforshortlives.org.uk/assets/0000/1059/Extubation_Care_Pathway.pdf

Appendix 5

The children and young people's health outcomes forum

General recommendations

There are of course, examples of outstanding health care resulting in good health outcomes for children and young people. It is upon these examples that we have built our evidence for change, from which our recommendations come. They are set out under the key themes that need addressing:

Putting children, young people and their families at the heart of what happens.

- Where health outcomes are better it is because children, young people and their families are involved in decisions about their care, having received relevant and age-appropriate information, and that care is provided in environments appropriate for their age.
- All health organisations must demonstrate how they have listened to the voice of children and young people, and how this will improve their health outcomes.
- The revised NHS Constitution is drafted in such a way as to be applicable to all children, young people and their families.
- The Department of Health (DH) should bring together all relevant partners to co-produce a children's health charter based on the principles of the UN Convention on the Rights of the Child, and aligned with the NHS Constitution. The application of these principles should be audited through the regulators.
- *Healthwatch* England gives appropriate consideration to the importance of all children and young people's voices to inform its work programme, and is able to demonstrate this through its annual report. Local *Healthwatch* includes children and young people's voices as core to their work and demonstrates this through their reporting mechanisms.

Acting early and intervening at the right time

- All organisations in the new health system should take a life-course approach, coherently addressing the different stages in life and the key transitions instead of tackling individual risk factors in isolation.
- Directors of Public Health and their local clinical commissioning groups (CCGs) should work together with maternity and child health services to identify and meet the needs of their local population.

Integration and partnership

- The NHS Number should be used as the unique identifier to bring together health, education and social care data for all children and young people.
- The NHS CB and Monitor should prioritise and promote the issue of integrated care provision in their regulatory and performance roles within the NHS, and work with the *Care Quality Commission* (CQC) and *Ofsted* in developing a framework across non-health providers.
- DH should work with other government departments and partners to achieve better integration of health with education, social care and other local authority led services.
- DH and partners should select some sentinel conditions and pathways which reflect needs along the life course in order to monitor significant risk of gaps in services, including prevention, and provide focus on improving integration of care.

Safe and sustainable services

CCGs need to develop local networks and partnerships with providers to address and deliver the sustainable provision of local acute, surgical, mental health and community children's services and to ensure both care closer to home and no gaps in provision.

Workforce, education and training

- The Royal College of General Practitioners proposal to extend GP training to allow for adequate training in paediatrics and physical and mental child health is supported.
- All GPs who care for children and young people should have appropriately validated CPD reflecting the proportion of their time spent with children and young people.

Knowledge and evidence

See also the Making data and information work for children and young people

- Collecting information and turning it into knowledge and evidence, and pursing that alongside research is central to the drive for better health outcomes.
- The NHS CB, with support from Health and Social Care Information Centre (HSCIC), should establish electronic child health records, accessible for both patients and professionals and improve the quality of routinely collected data, collecting them once and using them for multiple purposes, as well as making secondary uses data readily available to and useable by clinical professionals. This data set should also include care and outcomes for children with disabilities and complex conditions

Leadership, accountability and assurance

- Local commissioners, including CCGs and local authorities, should identify a senior clinical lead for children and young people.
- NICE should be commissioned to develop a Quality Standard for safeguarding children.

Incentives

- The NHS CB and CCGs must be mindful of the potential consequences to providers of general and specialist services and consider how they will adopt a risk sharing approach between different provider organisations in developing their commissioning plans for delivering care closer to home.

Public Health recommendations

- The Chief Medical Officer consider how an intelligence network for children and young people's healthcare, which crosses all settings, can be established by 2013, to drive up standards and effective use of data, information and intelligence in decision making, in order to support the Forum's recommendation on a research strategy.
- PH to work in partnership with HEE to assess at the earliest opportunity the workforce required to support Directors of Public Health in ensuring the needs of children and young people are met locally and create a public health workforce development programme with maternity, children and young people at its heart.
- As statutory members of HWBs, demonstrate that they have comprehensive data for all children and young people within their JSNA including those requiring tailored provision, such as those who are looked after, those with disabilities and long-term conditions and those in contact with the criminal justice system

NB: Families with CYP with additional health needs are a targeted population group for PH interventions.

Group 1: Acutely ill consultation recommendations
During the consultation period, interested parties were invited to comment on the Forum's website. Examples of the themes which were recorded are captured in the concept ...'right team, right place, right time and with least risk 'and show the need for integrated care across the acute and community settings, and with partner agencies when required.

- Caring for children and particularly teenagers in the right place;
- Better partnership working and integrated pathways between medical and social care;
- The increase in paediatric admissions due to a lack of confidence in primary care settings, or poor access, creating an overwhelming burden in acute hospitals
- Acutely ill children and young people need access to specialist knowledge, rapid assessment of treatment, admission avoidance, shorter length of stay, with community children's nursing teams managing acutely ill children
- Acute care (especially out of hours) built round the needs of patients and keeping them at home wherever possible;
- Too little continuity between acute and community services;
- Lack of joined up commissioning – NHS direct, groups, walk in centres, A&E Departments
- More collaborative services via networks;
- Improved access to children's nurses in emergency/admission units and to community children's nurses (there are too few of them)
- Improved transition to adult services
- Patient and parents reported outcomes measures need to be developed for children
- Poor knowledge base of parents/professional group to manage the acutely ill child. Some groups have adequate training and experience to assess and manage decisions about the seriously ill or unwell child
- Access point to acute care for a child with special needs e.g. autism or asperger's syndrome – staff need to be experienced to ensure children and young people and their families receive the right access, communication and management plans – this applies to all health care settings
- Key outcomes must include death rates
- Parental education on all aspects of life pathway, particularly when discharged from neonatal units
- Parents/children and young people have a right to access good experienced health advice
- Communication strategies to be clear
- The importance of the role of therapists in care of children and young people
- More thought to children and young people in the NHS cascades down to all of their relationships and their future independence.

Group 2, 3 & 4: Long term conditions disability and palliative care subgroup

Nationally,
Asthma: 17% among boys and 12% among girls. Current asthma, denied as symptoms in the last 12 months or symptoms controlled by medication for asthma in the last 12 months, was reported by 11% of boys and 8% of girls. Both lifetime and current asthma prevalence increased with age for both sexes. (2010 Health Survey for England)
Diabetes: 23,000 children and young people with diabetes in England, around 209 per 100,000 children aged 0-17 (RCPCH. (2009). Growing up with Diabetes: children and young people with diabetes
Children with Disabilities: the estimated number of children in England with a core disability is estimated to be 700,000. (Hansard Column 358W 28 June 2012)
Palliative Care: approximately 39,000 children under 19 in England are living with a life limiting condition that may require palliative care (Leeds Study: Fraser LK, Parslow RC, McKinney PA, Miller M, Aldridge JM, Hain R, Norman P 2012 Life Limiting and Life Threatening Conditions in children and young people in the United Kingdom: Final Report for Together for Short Lives)).

This group encompasses a very wide range of conditions that will follow varying courses including:

- Lifelong (e.g. Deafness);
- Slowly deteriorating (e.g. muscular dystrophy);
- Potentially curable (e.g. cancer); and
- Variable course (e.g. cystic fibrosis).

There is no consistent relationship between a single diagnosis and impairment, functional need or disability. In addition, for many children with one diagnosis, multiple coexisting conditions—also referred to as co-morbidities- will be the rule rather than the exception. For example, a young person with cerebral palsy that affects all four limbs is likely to have speech, eating, chest and gastrointestinal problems as well as being more likely to have intellectual disability, visual impairment and require equipment support for mobility and to enable them to achieve their academic potential.

The healthcare outcomes for this group of children and young people need to focus not only on the condition and the broader determinants of health (including secondary prevention) but just as importantly on the child's, young person's and family's individual experience and their priorities for care. The single disease model, with its focus on diagnosis and guidelines for care, can mean that symptoms that are impairing and co-morbidities that impact on multiple functions are overlooked. However, it is these that will have a major impact on a child or young person's quality of life and should drive the priorities of need and therefore for care.

Recommendations
The main issues that families address are:

- **There are challenges in the identification of CYP and their families with long term conditions and disability:** the recommendation for the addition of identifiers into the pupil database and child health information systems so that they allow subdivision of information by children with long term conditions

and long term mental health problems, disability, complex special educational needs and looked after children.

- **Getting into the health, education and social care system and getting a quality integrated assessment:** Difficulty accessing the services they need, including obtaining diagnosis and accessing expert assessment
- **Getting a quality service:** Inconsistency in the quality and quantity of services, fragmentation of services and particularly, a lack of 'join up' between health, social service and education services;
- Delays in provision of services, therapy and equipment;
- Boundary disputes over which organisation is responsible for provision of services
- **Managing Transition and Family functioning:** The patchiness of good practice, such as the provision of a key worker approach to help with coordination and navigation of the health, education and social care.
- There should be some measure of family functioning, family stress or parental mental health in order to gauge whether an integrated package of care is improving the quality of life for whole families. The stress that is frequently placed on siblings and recommend that siblings of a child or young person with a long term condition or disability should be identifiable via school databases to assess outcomes for them compared with the wider population.

Also,

- Improve the currently poor arrangements for transition
- Better integration of services needed – across health, education and social care, but also community and acute care
- Need for coordinator of care for complex conditions
- Better/quicker access to services needed
- Ongoing support for family needed
- Importance of whole family approach
- Need to emphasise the importance of peer support (ie, from other families)
- Better training needed for doctors and GPs
- Poor provision of therapy services
- HWBs need to be able to hold CCGs to account
- Outcomes frameworks need to help ensure that 'services are delivered in a way that helps disabled
- children in the context of their family and ordinary lives'
- Waiting and treatment rooms need to be more child/family friendly
- Variability of provision – postcode lottery
- Need to look at the child holistically – focus on what they can do
- Delays/problems in getting a diagnosis
- Treatment of children with a learning difficulty – inappropriate placements, need for access to a learning difficulties nurse on request, professionals don't understand the needs of children
- Support for child centred health plan and personal health budget
- Focus should be on primary care with support from specialist services – not the other way around
- Importance of better management of long term conditions (eg. asthma for school age children)
- Children and young people should be represented on CCGs
- Need for a cultural shift in the way practitioners work with children, young people and families – needs to be more inclusive
- Commissioning/funding arrangement prevent a holistic approach

- Frequent organisational change prevents continuity and forward planning
- Concerns about GP commissioning
- Emotional consequences of LTC/disability
- Need for children to get the right start – better focus on maternity
- Better workforce planning and education
- Better equipment needed
- Problems accessing nursery care – 'child's right to play should be protected'
- Need for improved access to mental health services for children with autism
- Health services not child friendly (eg. eye clinic doesn't understand the needs of a child with Downs Syndrome)
- Support focus on outcomes but some measure of processes needed (eg. safeguarding)
- Need for wellbeing/happiness measure at key developmental points

The UN Convention on the Rights of the Child (UNCRC): Article 23: Every child with a disability has the right to live a full and decent life, to be helped to achieve to their potential, and to be offered services that adjust to what the child needs, not the other way round.

Appendix 6

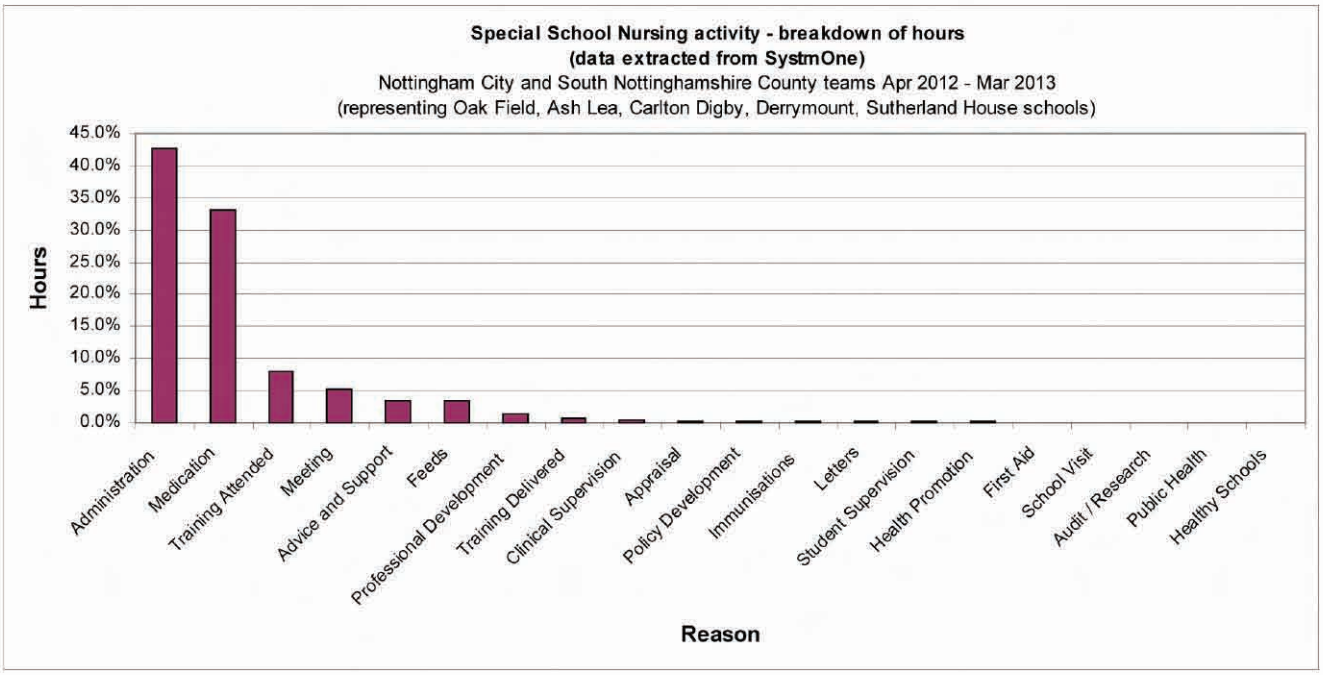
CYP specialist sevice mapping			
Service	**Current Provider**	**Service spec status**	**Geographic coverage**
CCN's (NUH) including Children's Community Matron with a lead for palliative care	NUH	spec in place	City / County exc Bassetlaw CYP with a consultant at NUH – mainly City & South but some coverage in rest of the county. Some coverage in Derbys. For oncology
C.A.R.I.N 4 Families (C4F)	NUH	no spec, part of block contract - there is a spec for the continuing care element of the service only the respite service falls within the block contract	City / County exc Bassetlaw
CCN's (CHP)	CHP	spec in place Spec for early supprt	City / South County exc Bassetlaw
Short Breaks – CDC	CHP	spec in place, needs updating	City & South (some north CYP – should be countywide ?)
CDC children's clinic	CHP	Spec in place (2010) needs updating	City / County exc Bassetlaw
Special School Nurses	CHP	spec in place, needs updating	City / County exc Bassetlaw
HCA/TA's (health funded in schools)	Various	no spec	no specs - part funded by health employed by LA/education
CCN's (SFH)	SFHT	spec in place	County (M&A Newark & Sherwood)
Coordinated Training Service	NUH	spec in place	City / County exc Bassetlaw
Training Service into Crocus Fields/Home from Home	CHP	spec in place	Nottingham City
Nursing Support into Caudwell House	CHP	spec in place, needs updating	County / Bassetlaw. Caudwell CYP only
Specialist Nurses (NUH)	NUH	no spec	City / County & other
Specialist Nurses (SFH)	SFHT	no spec	?
Children's continuing care & case management service - Pilot	NUH	spec in place for pilot - launched Jan 2013	Nottingham City
Paediatric Liaison Specialist Health Visiting Service	CHP	spec in place	City / County, extending to where required
Community Physio Therapy with RRP	NUH	spec in place for pilot	City / County exc Bassetlaw
Paediatric Community Physiotherapy	CHP	spec in place	City / County exc Bassetlaw
Community Occupational Therapy (north & south) & therapeutic support team	CHP	part of overall service spec	City / County exc Bassetlaw
Paediatric Comuunity SLT	CHP	County specification under review. Separate City spec in place from 2013/14.	City / County exc Bassetlaw
COUNTY Occupational Therapy (Social Care)	Nottinghamshire County Council	no spec with Health	County wide delivery, NCC funded
CITY Occupational Therapy (Social Care)	Nottingham City Council	No spec required employess of the city council and undertaking a statutory LA function,	City Wide
COUNTY TA support in Nottinghamshire County schools	Nottinghamshire County Council	No specification - employed by NCC	County wide but not including Nottm City

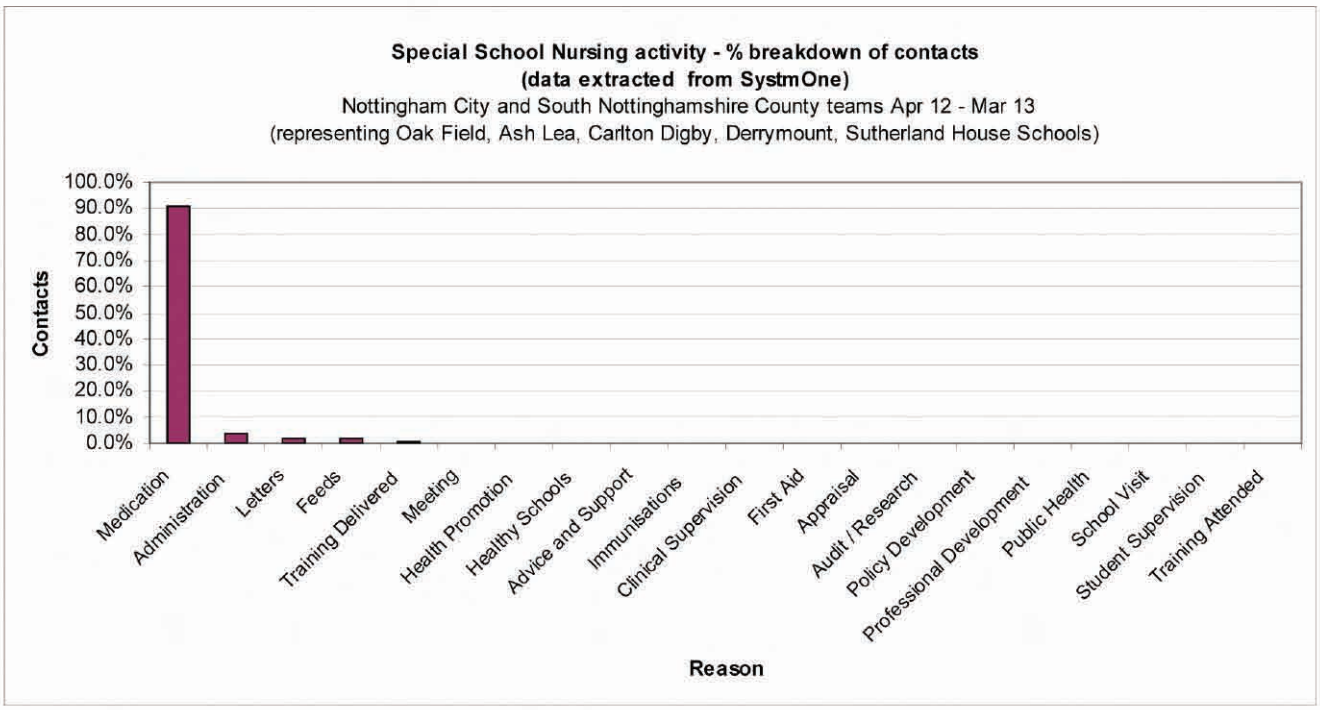
CYP specialist sevice mapping			
Service	**Base**	**Age range**	**Referral routes**
CCN's (NUH) including Children's Community Matron with a lead for palliative care	Nottingham Children's Hospital	0-18yrs 6mths	
C.A.R.I.N 4 Families (C4F)	Nottingham Children's Hospital	0-18yrs 6mths	Health, social care, education & social care professionals Self referral supported by professional
CCN's (CHP)	CDC Hucknall Rd	up to age 19 while in full time education, early support for 0-5	via community Paediatricians based at CDC
Short Breaks – CDC	CDC Hucknall Rd	U19	Interagency panel + via CAF/team around the child meeting for day care provision
CDC children's clinic	CDC Hucknall Rd	0-19yrs	Any child/young person referred with suspected congenital/genetic condition or developmental delay for an opinion of a Specialist Community Paediatrician, or other NUH clinician
Special School Nurses	Special schools: Yoeman Parlk, Ashlea, Fountaindale, Carlton Digby, Oak Field	U19 school age	Via school intake
HCA/TA's (health funded in schools)	Within schools?	U19 school age	Via school intake
CCN's (SFH)	SFHs	birth - transition	Acute services, primary care
Coordinated Training Service	Nottingham Children's Hospital	delivered to staff caring for CYP	via single point of access to training service
Training Service into Crocus Fields/Home from Home	CDC?	8-19 Crocus Fields 0-19 home from home scheme	All CYP identified to receive Crocus Fields short break are assessed & carers trained
Nursing Support into Caudwell House	Caudwell house	5-19yrs	All CYP identified to receive service from Cauldwell House
Specialist Nurses (NUH)	NUH	0-19	Primary, Secondary, and Tertiary - primarily consultant referrals
Specialist Nurses (SFH)	SFHT	birth - 16	acute services, primary care, HV's and SN's (via GP)
Children's continuing care & case management service - Pilot	Nottingham Children's Hospital	U18 (or up to 19 in some cases)	Healthcare professionals, GPs, specialist nurses, CCNs, Sch nuses, SENCOs, social workers etc via single point of access
Paediatric Liaison Specialist Health Visiting Service	QMC KMH	0-16yrs + targetted provision up to 19yrs	Written or verbal referrals + dedicated telephone answering service. Referrals from hospital, community & other agencies
Community Physio Therapy with RRP	Nottingham Children's Hospital	Up to 19yrs	Referral by consultants. Currently. Develping GP referral
Paediatric Community Physiotherapy	CDC, CTC	Up to 19yrs	Written referral from consultant or staff grade doctor or health professional Therapists from within team & other locations. Single point of access. Re-referral - open access for newly identified issues
Community Occupational Therapy (north & south) & therapeutic support team	All staff are based from the Children's Centre, City Hospital, Nottingham	0-18yrs (19yrs in special schools)	Referral by paediatricians, paediatric physios, SLTs SENCOs (noth area only) via referral letter to single point of access
Paediatric Comuunity SLT	Mans Community Hosp (North) Stapleford care Centre (South and City)	0-16 yrs (16 - 19 yrs in FT education) depending on condition and area of residence (North / City & South different service models) Adults 18-90 (stammering service only)	Direct referral by professionals, agencies & parents via open referral system & referral forms, followed by triage
COUNTY Occupational Therapy (Social Care)	Meadow House	U19 school age	Via public and professionals
CITY Occupational Therapy (Social Care)	Mary Potter Centre & Clifton Cornerstone	U19 - school age	?
COUNTY TA support in Nottinghamshire County schools	Individual schools	3-19yrs	From schools to panel/s for individual pupils requiring support during the school day

Appendix 7

Special Schools Nursing
Breakdown of hours and activity recorded on SystmOne 2012/13

Note: this data is subject to variation because the activity codes are so 'loose' that staff input the same activity under different headings due to different interpretation.





Appendix 8

Integrating Community Services Nursing Documentation case study

When a child or young person is accepted onto the case load of the following services: Short breaks, Special School Nursing, or the Children's community nursing team it is necessary for that service to undertake a Health Needs Assessment (HNA) to obtain relevant information about both the child/young person and the family. Following this assessment these services produce care plans based around the identified needs of the child/young person. All services access in the majority, the same case load pool and many of the children/young people are known to any combination of these services at any time.

Short Breaks

- Children's Development Centre (CDC) – Health Needs assessment (HNA) and care plans completed using template on 'systmone'
- Crocus Fields – HNA and care plans are hand written and stored on a 'G' Drive
- Cauldwell House - HNA and care plans are hand written and stored on a 'G' Drive

Nursing Services

- Community Nurses – HNA and care plans are undertaken in paper format and then scanned onto 'systmone'.
- Special School Nursing – Use a different HNA and care plan template which is completed in paper format and then transcribed onto the templates on the 'G' drive.

Information gathered through the HNA has many generic strands for all four services however the information gathered is not shared and the storage method prevents other services from accessing the information. Each service also has specific questions that are not relevant to the other services and this has further facilitated the developmental of service specific HNA tools. This can also be seen in care planning where a care plan is written for a child that is service specific rather than generic.

In summary, each service has its own HNA tool and care planning template which are stored in various locations electronically and on paper.

Issues for Service Users

Parents/carers are asked to relate the same information each time their child/young person is referred to these services and requires a HNA. This can become frustrating for parents/carers who may potentially receive visits from several different teams requiring the same information over the course of a relatively short time frame. Not only is this frustrating for parents/carers due to the repetition of information but it requires a commitment in time from them to be available to meet with teams. Parents/carers also have the potential to receive a mixed message around the care their child receives. When constructing care plans the actions around an identified need e.g. seizure management are written to meet the need of that specific service/location.

Each care plan is correct in the context of their locality and service constraints or practice but not shared across services leading to confusion for parents/carers where practice may differ.

Issues for Service Providers

Different service providers are utilising staff time both clinical and administrative and incurring travel and stationary costs in obtaining the same data and producing HNA's and Care Plans that contain the same gathered data.

Making convenient appointments with parents/carers to undertake the HNA can be problematic leading to potential delay in identifying need.

Solutions

- The use of a generic HNA tool that is stored in a central location ('systmone') and is accessible to all the services identified.
- This generic form should contain core information and also options for specific information to be inputted and viewed that may be of a more service specific nature.
- This assessment would need to be accepted by all services even when it was not undertaken by the specific service the child/young person has been referred to. This would need to be time limited.
- Utilising 'systmone' would allow a schedule to be applied allowing the user to be prompted to undertake agreed regular HNA reviews.
- Care plans should follow a generic template and where possible be applicable and accessible across all services and stored on 'systmone'.
- Where a generic care plan is not feasible clear guidelines should identify how duplicate care plans are written and stored.

Benefits

- Utilising a coordinated approach will reduce the burden on parents/carers to repeat information and the time they are required to be available.
- It will also allow a consistent approach to the care of their child/young person through a single agreed care plan.
- Services should see a reduction in travel costs, stationary costs and an increase in available staff time for service delivery.
- Greater sharing of information at the point of assessment will increase coordinated care and increased awareness of safeguarding concerns.
- It will allow data that is recorded to be current and relevant.

Barriers to Success

- Tools will need developing on 'systmone' that encompass the needs of all the services identified.
- All the services identified currently sit within individual units on 'systmone' consideration needs to be given as to the way forward around sharing the data. The issue is not can we share but how.
- There needs to be acceptance from staff that a HNA undertaken by the CDC for example is valid and reliable and will be accepted by another service.
- That care plans are written holistically and not around the health need whilst in a particular setting.

Simon Jenkinson, Professional Lead for Special School Nursing. CHP

Appendix 9

County Health Partnerships paediatric therapy and children's community nursing activity data – Nottingham City and Nottinghamshire County (excluding Bassetlaw)

Key findings

The table below gives a summary of analysis of activity data (contacts and referrals) for paediatric therapy services provided by County Health Partnerships (CHP) to the population of Nottingham City and Nottinghamshire County (Speech and language therapy, SLT, occupational therapy, OT, physiotherapy, PT and children's community nursing, CCN, services).

Limited data was available from the following sources:

- CHP service data (Q1 – Q4 2012/13) for under 25 yrs, from the NHIS Data Warehouse, supplied by Nottingham City Public Health for Nottingham City and Nottinghamshire County.
- Data from Nottingham City Q4 performance report (Apr 2012 to Mar 2013) supplied by CHP for Nottingham City only.
-

County Health Partnerships activity data summary		
Question	**Nottingham City**	**Nottinghamshire County**
1. Has there been an increase in demand, year on year? **Data:** Indicators of demand (not a specific measure) - increase in referrals and contacts; 3 year trends **Nottingham City** 3 year referral trend data available from CHP performance report only. Full year total contacts only for 2011/12, not available by quarter. Otherwise one year only 2012/13 **Notts County** Only one year 2012/13 referrals and contacts available.	Increased activity data suggests an overall increase in demand for therapy services – varies from service to service: 2012/13 compared to 2011/12 (full year) • Referrals increased by 23% overall. • OT contacts increased by 42%, referrals by 23%. • SLT contacts increased by 14%, referrals by 13%. • No change in PT referrals or contacts. • CDC contacts decreased by 43%, however this does not reflect nature or complexity of contact. 3 year trend (referrals) • OT – increased from November 2011. • SLT – increased from September 2012.	No year on year comparable data available, however therapy service activity appears to have increased during 2012/13 – varies from service to service: 2012/13 • Contacts with OT and SLT appear to be increasing quarter by quarter • Slight increase in referrals • Insufficient data to establish or confirm trends. • Average therapy referrals 272 per month. 68% of these are to SLT.

County Health Partnerships activity data summary		
Question	**Nottingham City**	**Nottinghamshire County**
	2011/12 to 2012/13 • Average therapy referrals increased by 12% from 127 per month to 142 per month. 75% of these are to SLT.	
2: Are there any patterns by age range? **Data:** 2012/13 contacts and referrals by age range.	• Children under 5 years account for 41% contacts with all services and 63% referrals (therapies only, CDC small numbers). • There is little activity around transition with 3% contacts in 16-18 yrs age band. • Contacts - CDC sees the highest proportion of children under 5 years (60%).	• Children under 5 years account for 40% contacts with all services and 64% referrals (therapies only, CDC small numbers). • There is little activity around transition with 5% contacts in 16-18 yrs age band. • Contacts - CDC sees the highest proportion of children under 5 years (68%).
3: Has any potential for increased efficiency / productivity in the system been identified from the data? **Data:** 2012/13 Multiple referrals of individual children.	• SLT has the highest number of multiple referrals to therapy services of individual children during 2012/13 with 18% of children being referred more than once. • Less than 5% of referrals come from GPs. The majority of referrals to OT, PT or CDC nursing come from paediatricians and other consultants. SLT receives referrals from a much wider spread of referrers.	• SLT has the highest number of multiple referrals to therapy services of individual children during 2012/13 with 20% of children being referred more than once. • Less than 5% of referrals come from GPs. The majority of referrals to OT, PT or CDC nursing come from paediatricians and other consultants. SLT receives referrals from a much wider spread of referrers.
	• The issue of multiple referrals of the same child requires further examination to determine the underlying reasons, including client choice, source and quality of referrals.	
4. What information about population needs does the data provide? **Data:** Referral rates are indicative of population needs.	Paediatric therapy referral rates / 1000 population 0-24 yrs: • Nottingham City CCG 12.5 including university practice populations; 17.9 excluding university practice populations.	Paediatric therapy referral rates / 1000 population 0-24 yrs show the highest need in Mansfield and Ashfield CCG, lowest in Nottingham West: • Mansfield & Ashfield 20.50; • Newark & Sherwood 17.08; • Nottingham North & East 17.45; • Nottingham West 13.19; • Rushcliffe 14.49

County Health Partnerships activity data summary		
Question	**Nottingham City**	**Nottinghamshire County**
5: What proportion of cases have complex needs? **Data:** Indicators of complexity 2012/13 number and proportion of children seen by all 3 therapy services (and CDC nursing).	• Total of 2567 individual children seen in 2012/13 across therapies and CDC nursing. Of these 5.3% (137) were seen by all three therapy services and accounted for 24.7% of contacts with them, as such are likely to be more complex cases. • A further indication of this is that approx 25% of the 137 were also seen by CDC nursing. The other 75% of the 137 children accounted for 44% OT, 10% SLT and 14% PT contacts. • In addition many children with complex needs from are likely to have contact with Special School Nursing Services. • See also question 6 below	• Total of 4528 individual children seen in 2012/13 across therapies and CDC nursing. Of these 6.2% (280) were seen by all three therapy services and accounted for 33.2% of contacts with them, as such are likely to be more complex cases. • A further indication of this is that approx 9% of the 280 were also seen by CDC nursing. The other 91% of the 280 children accounted for 43% OT, 12.5% SLT and 42% PT contact • In addition many children with complex needs from are likely to have contact with Special School Nursing Services. • See also question 6 below
6: How does the data support a case for integration? **Data:** Proportion of children seen by more than one service supports a case for integration including shared records to reduce duplication for CYP and families and improve resource utilisation and communication and support effective safeguarding.	• During the 12 months of 2012/13 15% of children were seen by more than one service. This may increase over a longer period.	• During the 12 months of 2012/13 18% of children were seen by more than one service. This may increase over a longer period.
	• The above data is only for the CHP services. The proportion of these children seeing more than one service is likely to be higher if other health services and social care services were included. In addition many children with complex needs from are likely to have contact with Special School Nursing Services. • See also question 5 above.	

Appendix 10

Children's Community Nursing (CCN) Audit

Key findings

A comprehensive audit of daily activity was undertaken during November 2012 to January 2013 by the children's community nursing teams based at the Children's Development Centre (CDC) Nottingham, Children's Hospital Nottingham (NUH) and Sherwood Forest Hospitals NHS foundation Trust (SFH).

A brief snapshot from the initial findings from the data analysis of client-based activity (face to face and non-face to face) is shown in the table below. Non face to face activity analysis currently unavailable:

Summary of Children's Community Nursing Team Audit data			
Question	**CDC team**	**NUH team**	**SFH team**
1. Staff caseload	• CDC have four members of staff • One Healthcare Worker • Three nurses (band 6)* **The team saw 102 clients** over three months. • Around 50% of clients were seen by just one member of staff. • The majority of remaining clients were seen by at least one other member of staff. • Some clients were seen by more than four members of staff, suggesting they were seen by another team.	• NUH have 12 members of staff, the highest across the three teams. • All nurses • Mostly Band 6 with one Band 5 and one Band 7* total WTE 11.8 (1.0 WTE band 7, 9.8 WTE band 6, 1.0 WTE band 5 • **The team saw 157 clients** over the three months. • Staff/client contact: high variation • The majority of clients were seen by at least two members of staff • Some clients seen by at least 5 different members of staff.	• SFH have two members of staff, the lowest number across the three teams. • Both nurses, • One Band 6 and one Band 7, both 0.8 WTE **The team saw 69 clients** over three months. • Around 50% of clients were seen by just one member of staff. • Some clients were seen by more than two members of staff, suggesting they were seen by another team.
2. Client Demographics	**Client gender:** No striking difference in number of male and female clients. **Client age:** 56% 0-4 yrs (11% aged <1 yr). **Client ethnicity:** • Predominantly White (70%+) • 15% recorded as Asian, 6% as Black, remaining [ethnicity not entered] and	**Client gender:** No striking difference in number of male and female clients. **Client age:** 58% 0-4yrs (22% aged <1 yr). **Client ethnicity:** • Predominantly white (75%+) • 10% recorded as Asian, 8% as Mixed, remaining Black or [Ethnicity not	**Client gender:** No striking difference in number of male and female clients **Client age:** 48% 0-4 yrs (19% aged <1 yr). **Client ethnicity:** • Predominantly White (95%+) **Client CCG registration**: Dominantly Mansfield and Ashfield (68%), with Nottingham North and East

Appendix 10 V3 CCN audit data key findings (27.08.13)[1]

Summary of Children's Community Nursing Team Audit data			
Question	**CDC team**	**NUH team**	**SFH team**
	Mixed • **Client CCG registration:** poor data quality. Over 83% CCG not entered	entered]. • **Client CCG registration:** Dominantly Nottingham City (35%). Additionally out-of-county (Derby) practices (15%)., Nottingham North and East (13%).and Rushcliffe (13%) form an appreciable proportion (all combined account for 76% of clients)	(12%) and Newark and Sherwood (13%) with noticeable contributions (all combined account for 93% of clients).
3. Client based Activity	• **Over 490 client based events** (28% of over 1,780 events seen across all teams) • Activity seen mainly by the band 6 nurses • Activity mostly non face-to-face (69% of events) **Face-to-face** activity: top activity Assessment/Review/Discharge] (27% of events) • Including [Gastrostomy cares] and [Supplies] accounts for over 50% of activity **Non face-to-face** activity: Top activity [Support] (43% of events) • Including [Administration] , [No activity entered] and [Supplies] accounts for 91% of events	• **Over 940 client based events** (53% of over 1,780 events seen across all teams) • Activity seen mainly by band 6 nurses (90%+ of events) • Activity mainly face-to-face (80%) **Face-to-face** activity: top activity [Oncology bloods taking] (42% of activity events) • Including [Training/competency assessment accounts for over 50% of activity. **Non face-to-face** activity: top activity is [Administration] (49% of events) • Including [no activity entered], [Support], [Supplies] and [Assessment/review/discharge] accounts for 90% of activity events.	• **Over 340 client based events** (19% of over 1,780 events seen across all teams) • Activity spread evenly between the Band 6 and the Band 7 nurses • Activity dominantly (95%+) face-to-face (across all teams less than 70%) **Face-to-face activity**: • [Oxygen reviews] account for 19% of activity • Including [PORT/CVL flushes], [Support] and [Gastrostomy cares] accounts for over 50% of activity **Non face-to-face** activity is low for SFH (as noted earlier). Of data collected it is mostly [no activity entered] or [Administration].
4. Visits by place of visit (face to face activity)	**Dominantly at [Home (Residence)]** (42% of relevant activity events) • Including [CDC City], [School] and [Hospital] accounts for 90% of activity events	**Dominantly at [Home (Residence)]** (75% of related activity) • Including [School], [place of visit not entered] and [Hospital] accounts for 98% of activity events	**Dominantly at [Home (Residence)]** (71% of related activity) • Including [Hospital] and [School] account for 98% of activity events.
5. How does the data support a case for	Staff within each team don't know if the client has been seen by other teams. The CCN audit allows a view across teams and it appears that some clients are seen by staff from different teams: A small number of clients (<20) seen by staff from two different teams - NUH and either SFH or CDC. No client seen by staff from all		

Appendix 10 V3 CCN audit data key findings (27.08.13)[1]

Summary of Children's Community Nursing Team Audit data			
Question	**CDC team**	**NUH team**	**SFH team**
integration?	three teams Per client: • Activity a mix of face-to-face and non face-to-face. • Between 4 events and 35 events generated. • Seen by between 2 and 8 different members of staff. As well as a small number of children being seen by more than one community nursing team a number of children with complex needs are likely to also receive care from Special School Nursing Services in special school settings. In addition children seen by CCN teams will have contact with a range of other health services (e.g. therapies, paediatricians) and social care and education services. This supports a case for integration including shared records and care plans to reduce duplication for CYP and families and improve resource utilisation and communication and support effective safeguarding.		

*WTE not provided

Appendix 11

Personal Budgets and Direct Payments

Social Care Personal Budgets

Instead of services some families may be offered **personal or individual budgets** by their local authority. The aim is to give carers and disabled people control of how they arrange and buy services to meet their own needs. The budget can be allocated for equipment and adaptations as well as for meeting social care needs. Not to be confused with direct payments, it is important to understand that a personal or individual budget is an amount allocated by the council but not paid to the carer or the disabled person needing services. Whereas direct payments are paid in order to meet a specific assessed need.

Local Authorities can give payments, instead of services, to allow disabled people and carers to buy in the social care services they've been assessed as needing. Any payments they receive must only be used to pay for these services.

Direct payments are there to promote the Independence of parents and disabled children who would like to manage their own social care needs. If a child is under 16 years of age, direct payments will usually be made to their parent. When a child turns 16 they can receive payments in their own right, to allow them to buy in the services they've been assessed as needing. In the past a person couldn't insist on direct payments. But now a request should only be refused in very limited circumstances.

The amount an individual receives should be enough to allow them to meet all the costs involved in arranging services that social services have agreed to help with. This should include any tax and national insurance they might have to pay if they employ someone, as well as the cost of a criminal records check. Social services will usually deduct an amount from the payments, equivalent to what would have been charged if they had arranged the services. Or they may make the payments in full and ask the individual to reimburse them any assessed charge.

Personal Health Budgets

A **personal health budget** is an amount of money that is allocated to an individual to allow them to meet their health and wellbeing needs in a way that best suits them. At the heart of a personal health budget is a care plan.

The money in a personal health budget can be managed in three different ways:

- A notional budget
- A third party arrangement: an organisation legally independent of the individual and the NHS holds the money on the individual's behalf, and buys or provides the goods and services the person has chosen.
- A **direct payment** for healthcare: the money is transferred to the individual, and the individual buys the goods and services the person has chosen. Some direct payments
  support organisations will act as an agent and help the individual manage the direct payment.

Before money is released the support plan, which details how the person would like to spend their budget, must go through an approval process. This should involve their lead clinician.

Sources:
Disabled Children's services in England, Information for Families. Contact a Family October 2012
www.cafamily.org.uk/
Personal health budgets and NHS Continuing Healthcare (2012)
http://www.personalhealthbudgets.england.nhs.uk/_library/Resources/Personalhealthbudgets/2012/Personal_health_budgets_and_CHC_discussion_paper_updated.pdf

Appendix 12

Nottinghamshire County Council

NHS

Integrated Commissioning Hub for Children and Young People

The vision..... *We want Nottinghamshire to be a place where children are safe, healthy and happy, where everyone enjoys a good quality of life and where everyone can achieve their potential. Through integrated commissioning, we will work together with children, young people and their families and use a whole systems approach to improve the planning and commissioning of services for children, young people and their families.*

From fragmentation...

Following the Health and Social Care Act, from 1st April 2013, health services for children in Nottinghamshire will be commissioned by an increased number of organisations including:

- Six Clinical Commissioning Groups (CCGs)
- Local Public Health Department
- Local Authority
- Nottinghamshire Derbyshire Area Team
- South Yorkshire and Bassetlaw Area Team
- Leicestershire and Lincolnshire Area Team
- Public Health England.

There is a serious risk of fragmentation of service provision for children.

Principles

Children, young people and their families at the centre

Safeguarding	Improving Outcomes	Evidenced Based	Efficient
Participation	Prevention	Equity	Equality
Transparency	Early Intervention	Quality	Value for Money

Proposed Model from September 2013

- A single point of accountability/co-ordination for children's health and well-being related integrated commissioning, on behalf of: Nottinghamshire CCGs, NHS England Area Teams and Nottinghamshire County Council, including Public Health.
- A small team, hosted in the County Council's Children, Families and Cultural Services Department. A number of existing posts currently within the Public Health Directorate will be incorporated into the team.
- Non recurrent funding from all six Nottinghamshire CCGs has transferred to NCC to cover the pay and non-pay costs of the Integrated Commissioning Function.
- Based on the alignment and pooling of commissioning resources from the County Council, CCGs and the NHS England Area Teams, in some cases via Section 75 arrangements.
- Operation at different commissioning levels depending on the service/topic area Opportunity for consistency across services in relation to safeguarding, Pathway to Provision and young people friendly services
- Accountable to the Health and Wellbeing Board through the Nottinghamshire Children's Trust Board (membership includes CCGs, CFCS, NHS England, PH). In addition it may be appropriate to establish formal direct links with CCGs if agreed.

.....to Integration

- Whole system approach to planning and commissioning
- Maximise the quality of services for children and their families
- Focus on outcomes
- Reduce silo working and duplication
- Clear processes for engaging with children and families to inform commissioning
- Opportunity to integrate approaches to prevention
- Added value, greater savings, best use of available resources
- Clearer accountability
- Clearer links with recommendations from the JSNA and other in depth needs assessments to inform commissioning decisions
- In line with the Government's focus on better health outcomes for children.

Scope for Commissioning from September 2013.....

- Public health services for children aged 0-5
- Elements of community paediatrics
- Teenage pregnancy
- Substance use services for young people
- Emotional Health & Well-being Services (CAMHS Tier 1/2/3)
- Public health services for children aged 5-19 (school nursing)
- Children with disabilities and SEN (community services)
- Health services for young offenders in the community
- Health needs of Looked after Children's (CAMHS/nursing/medical)
- Oral Health Promotion & Fluoridation

Scope to be considered.....

- General paediatrics (unplanned & planned care)
- Continuing Care
- Maternity
- FNP & Health Visiting from 2015
- Lead on commissioning on NCC services e.g. All of children's disability services

integration

