Children and young people’s continuing care and meeting the needs of children and young people with complex needs
Agenda for today’s workshop

• Introduction to CCC
• Context: Increasing needs
• CCC process-
• Discussing new approaches
Getting to know each other

Introduce yourself, organisation, and knowledge of or interest in Continuing Care
The NHS and Disabled Children: Why have Continuing Care?

The health system does not have legally defined thresholds, processes or individually owed entitlements for children and young people in the same way as the SEN or local authority social care does.

There are fundamental legal duties that underpin NHS responsibilities for there are enough services for everyone, including disabled children and young people – delivered through this is commissioning.

These services structured in a tiered and children and young people access them through a referral system based on pathways and clinical judgement.
Why was it introduced?

Some children and young people and their families require a lot of support from a wide range of services across universal, secondary and tertiary over a long period of time.

Lack of clarity regarding NHS and local authority responsibilities for providing different elements of this support - i.e. health vs children’s social care vs SEN.

Children Continuing Care Framework response to Case Law - 2005

Haringey Case - Local Authority and PCT in disagreement over provision of overnight nurse.

Judge found that NHS must provide support based on a health need, despite the positive impact it had on family life.
Changing Context of CCC

CCC Framework introduced in 2010 as a guidance for CCG’s to make decisions inline with their statutory duties to provide a comprehensive health system for children and young people with complex needs

Not legal edibility criteria but guidance for making child centred decision

Framework does not define division between local authority social care and CCG health care

Refreshed in 2016 to respond to changing policy framework:
Health and Social Care Act
Children and Families Act
Personal budgets policy

Also pressure of Changing Demographics: increasing numbers of children and young people with complex needs who require significant support from health services
How many disabled children are there with complex needs and life-limiting conditions?

Evidence shows numbers of children with complex needs is increasing significantly.

There are at least **73,000 children of school age with complex needs** (narrowly defined):

- 10,900 children with profound and multiple learning difficulties
- 32,300 children with severe learning difficulties
- 27,500 children with autistic spectrum disorders in special schools
- 2,300 children with multi-sensory impairments.

Using this definition, schools are working with **23,700 more** children with complex needs than in 2004.

- 3,120 more children with PMLD (+40%)
- 270 more children with SLD (+1%)
- 18,860 more children with ASD in special schools (+219%)
- 1,440 more children with MSI (+168%)

School Census data, Jan 2016
Special schools are working with many more children with complex needs than in 2004.

School Census data (N=107,380)
Excludes children in independent schools.
Since 2004, the number of children with profound and multiple learning difficulties (PMLD) has risen in all sectors, to:

- 1,730 in primary schools (+52%)
- 400 in secondary schools (+52%)
- 8,790 in special schools (+38%)

Over the same period, more children with complex needs are being educated in mainstream schools.
Over the same period, more children with complex needs are being educated in mainstream schools

Since 2004, the number of children with a statement/EHC Plan with an autistic spectrum disorder (ASD) has risen in all sectors to:

- 16,310 in primary schools (+54%)
- 13,830 in secondary schools (+182%)
- 27,470 in special schools (+219%)

Growth in children with ASD with higher support needs in schools in England, 2004-2016 (N=57,610)
Lack of evidence about the use of Continuing Care -lack of national data-DH estimate of 5000-6000 assessments a year but unclear evidence. Would equal to 0.05% of CYP
Adult Continuing Healthcare -0.13%
Very significant variation in numbers across country-FOI’s indicate up to tenfold variation
## Transformation programmes with possible impact on CCC

<table>
<thead>
<tr>
<th>IPC Programme</th>
<th>Children and Families Act requirements</th>
<th>Transforming Care</th>
<th>CAMHS Transformation</th>
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<tbody>
<tr>
<td>Proactive coordination of care; focus on early intervention &amp; prevention</td>
<td>- Local Offer&lt;br&gt;- SEN support</td>
<td>- Early Intervention and prevention&lt;br&gt;- Person-centred care and support plan</td>
<td>- Promoting resilience, prevention and early intervention</td>
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<td>Community capacity &amp; peer support</td>
<td>- Local Offer&lt;br&gt;- Parent carer forums&lt;br&gt;- Young person’s voice and parental choice</td>
<td>- Inclusion in activities and support to access mainstream services</td>
<td>- Improving access to effective support - a system without tiers</td>
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<td>Personalised care and support planning</td>
<td>- EHC Plans&lt;br&gt;- Advocacy and information - Independent Support; IASSN&lt;br&gt;- Keyworking</td>
<td>- Outcomes Focused, Person-centred care and support plan&lt;br&gt;- Advocacy and information&lt;br&gt;- Care and support navigator</td>
<td>- Care for the most vulnerable</td>
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<td>Choice and control (over personalised budget)</td>
<td>- Personal Budgets&lt;br&gt;- Young person’s voice and parental choice</td>
<td>- Personal budgets and personal health budgets&lt;br&gt;- Choice of housing and who I live with</td>
<td>- Accountability and transparency</td>
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<td>Personalised commissioning and payment (integrated Commissioning)</td>
<td>- Joint commissioning arrangements&lt;br&gt;- Individualised planning arrangements</td>
<td>- Specialist Multidisciplinary teams integrated with community services&lt;br&gt;- Commissioners understand their population</td>
<td>- Developing the workforce</td>
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Transforming Care data on young people

- At end February 2016, there were 170 in-patients with learning disabilities and/or ASD aged under 18 years and 635 aged 18-25 years.
- Children are more likely to be treated further from home than older inpatients. On average under 18’s were treated 79km from home.
- Young inpatients (<18 years) had on average been in hospital for 285 days or around 9 months, ten times longer than the 28 day limit for ‘section 2’ admissions for assessment and treatment.
- Almost one third stayed for a year or more. Around 10 children were inpatients for 2-5 years.
Impact of current assessment decisions?

Data shows spike in admission/transfers to ATUs between the ages of 18-21

<table>
<thead>
<tr>
<th>Age at admission/transfers</th>
<th>18 - 21</th>
<th>22 - 25</th>
<th>26 - 30</th>
<th>31 - 34</th>
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<tr>
<td>No. of admissions/transfers (Q4 1516)</td>
<td>50</td>
<td>35</td>
<td>45</td>
<td>20</td>
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<tr>
<td>No. of admissions/transfers (Q3 1516)</td>
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<td>45</td>
<td>40</td>
<td>25</td>
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What do we know about these children and young people

- ATU: 165
- Residential Special Schools: 1,129
- LD and Behaviours that challenge: 40,000
Preventing future admissions: Cost of residential care

- **£250,000**
  - ATU

- **£171,176**
  - 52 week residential

- **£99,798**
  - Out of authority boarding place
National Framework for Children and Young People’s Continuing Care

For children with needs that cannot be meet through ordinarily commissioned services

3 stage process - 6 week timescale

1: **Assessment** - carried out by nominated health assessor
   Holistic assessment of need, drawing on existing evidence and using Decision Support Tool and makes recommendation

2: **Decision Making** - multi-agency forum considers the recommendation and decides if the child or young person has a continuing care need.

3: **Arrangement of Provision** - Development and delivery of package of care- any relevant organisations should be notified

Followed by monitoring and review
Identification- Where there are concerns that a child or young person has needs that *may* not be met through available services

This can come from health professionals, but also education and social car- parents?

Stage 1- Pre-assessment- 1-2 days- paper based- discharged by CCG
No specific criteria or guidance for this decision

How well understood is CCC referral route and pre-assessment process understood in your area by families and professionals?

Are there information sharing protocols/processes in place?
**Assessment** - carried out by nominated health assessor- CYP health professional with relevant expertise

Should be holistic assessment of need incorporating 4 areas:

- The preferences of the child or young person and their family
- Holistic assessment of the child or young person
- Reports and risk assessments from the professionals
- Decision Support Tool

Should not be based on existing care package or availability of provision

Family should be provided with clear information throughout process
Decision Support Tool Criteria- 10 domains

Tool to help assessor consider needs in comparison to other cyp their age
Provides 10 domains to build comprehensive picture of overall need

1. breathing
2. eating and drinking
3. mobility
4. continence and elimination
5. skin and tissue viability
6. communication
7. drug therapies and medicines
8. psychological and emotional needs
9. seizures
10. challenging behaviour

Not tick box exercise with yes/no answer
Must consider outcomes
3. **Recommendation**: Assessor makes recommendations to independent professionals

4. **Decision**: should be taken by multiagency panel- CCG and LA representative and clinician
   
   Decision must be needs based not provision led.
   
   Positive Outcomes- package of care developed as quickly as possible- information in assessment can provide relevant information
   
   May require multiagency coordination

How well is this process working
If CYP is eligible for CCC they have a right to a personal health budget

3 options for managing the money

**Notional budget** – the council or the NHS manages the budget and arranges care and support.

**Third party budget** – an organisation independent of the person, the council and the NHS manages the budget and is responsible for ensuring the right care is put in place, working in partnership with the person and their family to ensure the agreed outcomes can be achieved.

**Direct payment** - the budget holder has the money in a bank account or an equivalent account such as a pre-paid card, and takes responsibility for purchasing care and support.
Transition

Sets out a clearer transition timetable
Part of proactive multiagency transition planning
Involve adult services are equal partners

Year 9
age 13/14

Age 16-18

18+

Bring to attention of CCG as likely to need assessment for NHS Continuing Healthcare
years screening for NHS Continuing Healthcare and agreement in principle
full transition to NHS Continuing Healthcare or universal and specialist health services
Children and Families Act placed greater focus on joint commissioning and a multiagency understanding and response to children and young people’s needs.

EHC Plans are multiagency - CCC should be integrated into EHC Planning process - building on existing good practice in many areas.

Significant overlaps between CCC process and EHC Plan
<table>
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<td><strong>6 week process</strong></td>
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<td>The preferences of the child or young person and their family</td>
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<td>Holistic assessment of the child or young person’s needs</td>
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<td>Outcomes</td>
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<td>Personal Budgets</td>
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<td>Arrangement of provision</td>
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<td>NHS Complaints System</td>
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Developing New Approaches: How is this happening in practice

Incorporating CCC into multiagency governance framework, built into pathways

Audit of EHC health provision in EHC Plans above existing contract requirements

Role of Designated Clinical Officer/ Designated Medical Officer as key link

Early identification, shifting resources to prevention

CCC funding used to develop/enhance multiagency jointly funded support packages

Shifting Support below existing CCC criteria- use of IPC resources

Aligning/integrating multi-agency “complex needs panel” that helps to review cases such as those whose support package across EHC and CCC
Questions

• What are the biggest barriers to effective assessment and planning?
• How well is your CCC assessment framework aligned to your EHC assessment and delivery timescale?
• Who pays, and how much? How can agreement be reached?
• How can transition to adulthood be supported?
• Does your current decision making on CCC reflect the needs of the population and best support community based care for children with the most complex needs?