



SES LIP

South East Sector Led
Improvement Programme

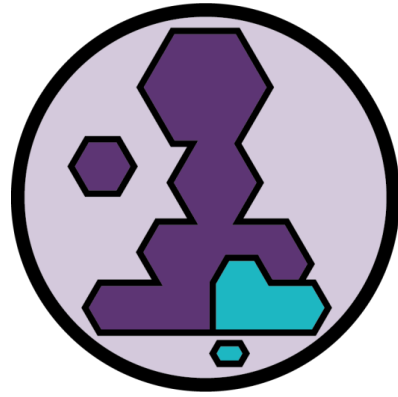
Children's Continuing Care Network Meeting

Friday 6th March 2026

Agenda

Time	Topic	Lead
9:30am	Arrival, coffee and networking <i>Kingham Room</i>	
10:00am	Welcome and introduction	Liam Doherty, Continuing Healthcare Specialist, RBWM Sue Kocaman, SESLIP Consultant
10:20am	Project update, including table discussions <ul style="list-style-type: none"> • FOI request • Questionnaire results 	Sue Kocaman, SESLIP Consultant
10:55am	What are we doing in RBWM? The Health Consultation Journey	Suki Hayes-Lapham, Specialist Services Manager, CYPDS
11:10am	Refreshment break	
11:30am	What works well between Portsmouth City Council and ICB when it comes to CCC and why?	Tracy Fisher, Head of SEND ICB, HIOW
12noon	<ul style="list-style-type: none"> • FOI Insights • Case for Change • Spotlight on lived experience 	Amanda Elliott, Strategic Health Lead, Contact Helen and Paul Brown, Parents
12:30pm	Lunch <i>The Bank</i>	
1:15pm	Legal context and legal review	Liam Doherty, Continuing Healthcare Specialist, RBWM
1:45pm	Activity, discussion and feedback	Liam Doherty, Continuing Healthcare Specialist, RBWM
2:45pm	Final remarks, evaluation and close	Liam Doherty, Continuing Healthcare Specialist, RBWM Sue Kocaman, SESLIP Consultant





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Welcome and introductions

Liam Doherty, Continuing Healthcare Specialist, RBWM
Sue Kocaman, SESLIP Consultant



Icebreaker activity

A truth and a lie

How it works: Each team member shares one true anecdote from their professional experience and one fake scenario. The group guesses which is the lie.





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Project update, including table discussions

- FOI request
- Questionnaire results
- All age Continuing Care dataset

Sue Kocaman, SESLIP Consultant



Freedom of Information requests

7 freedom of information requests were made to ICB's

Kent and Medway ICB responded by saying that they were unable to supply any information within the allowed limits.

The remaining 6 ICB's responded with some caveats:

- Beds/Luton/MK ICB (only MK is within SE region) was only able to supply data for one LA area for years 2020/21 and 2021/22 but for all 3 LAs for other years.
- Surrey Heartlands was only able to provide data for 2023/25 for the questions it responded to.

No ICB was able to provide all the data due to it not currently being collated and the length of time it would take to extract the data.

Extracts from the responses show some of the similarities and differences in data and therefore in the application of the CYCCC framework.



Comparison between Contact FOI and SESLIP FOI-children receiving continuing care packages funded by the ICB as at 31 March 2024

ICB	CONTACT FOI	SESLIP FOI
Bucks/Oxon/Berks (west)	132	132
Frimley	152	30
Hants and IoW	152	165
Surrey Heartlands	30	34
Beds/Luton/MK	51	53
Sussexes	142	145
Kent and Medway	97	n/k



FOI request data

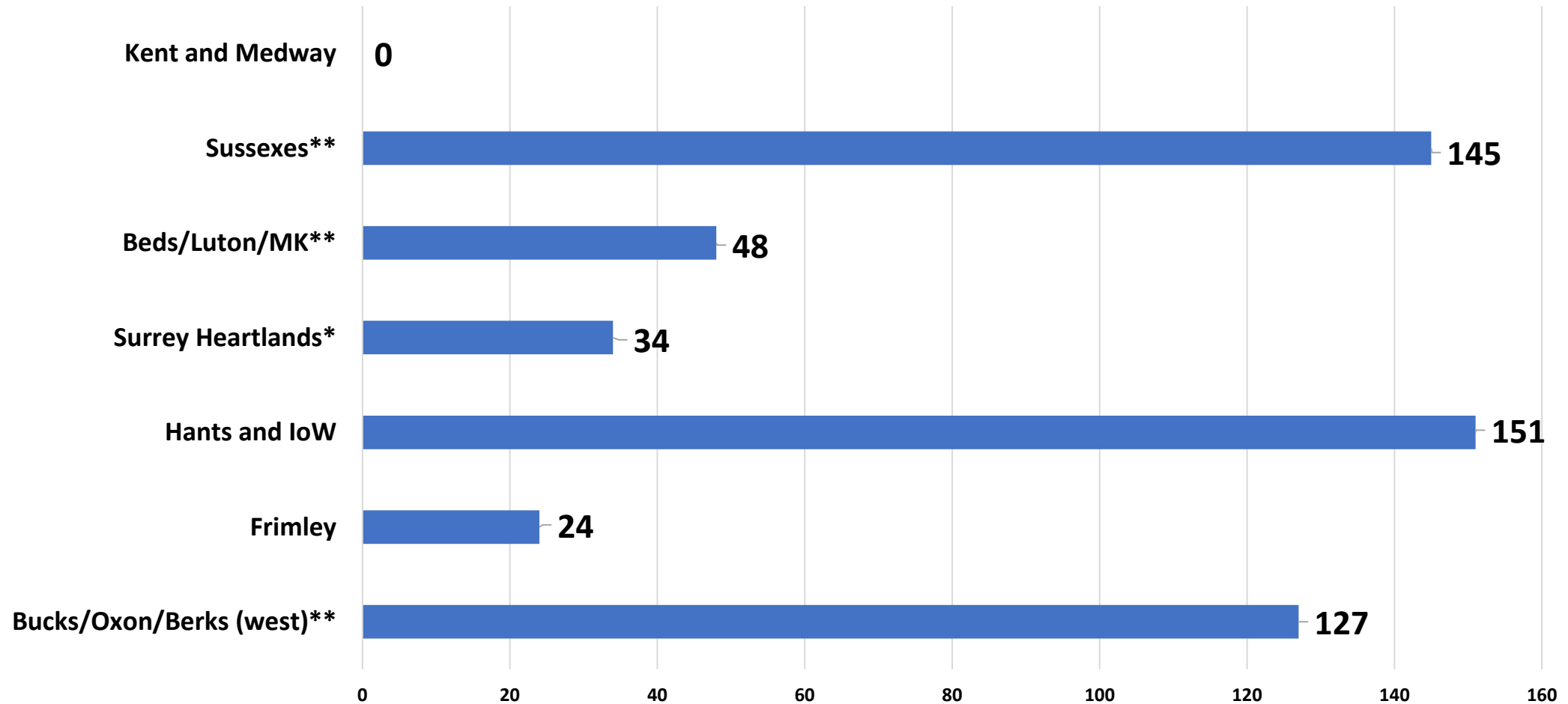
The following figures are from the SESLIP FOI request.

Data was requested for 5 years for some questions and for 3 years for other questions.

Full responses will be sent out after today's meeting, on request. Please contact Sonia Dayal on sonia.dayal@sdsa.net



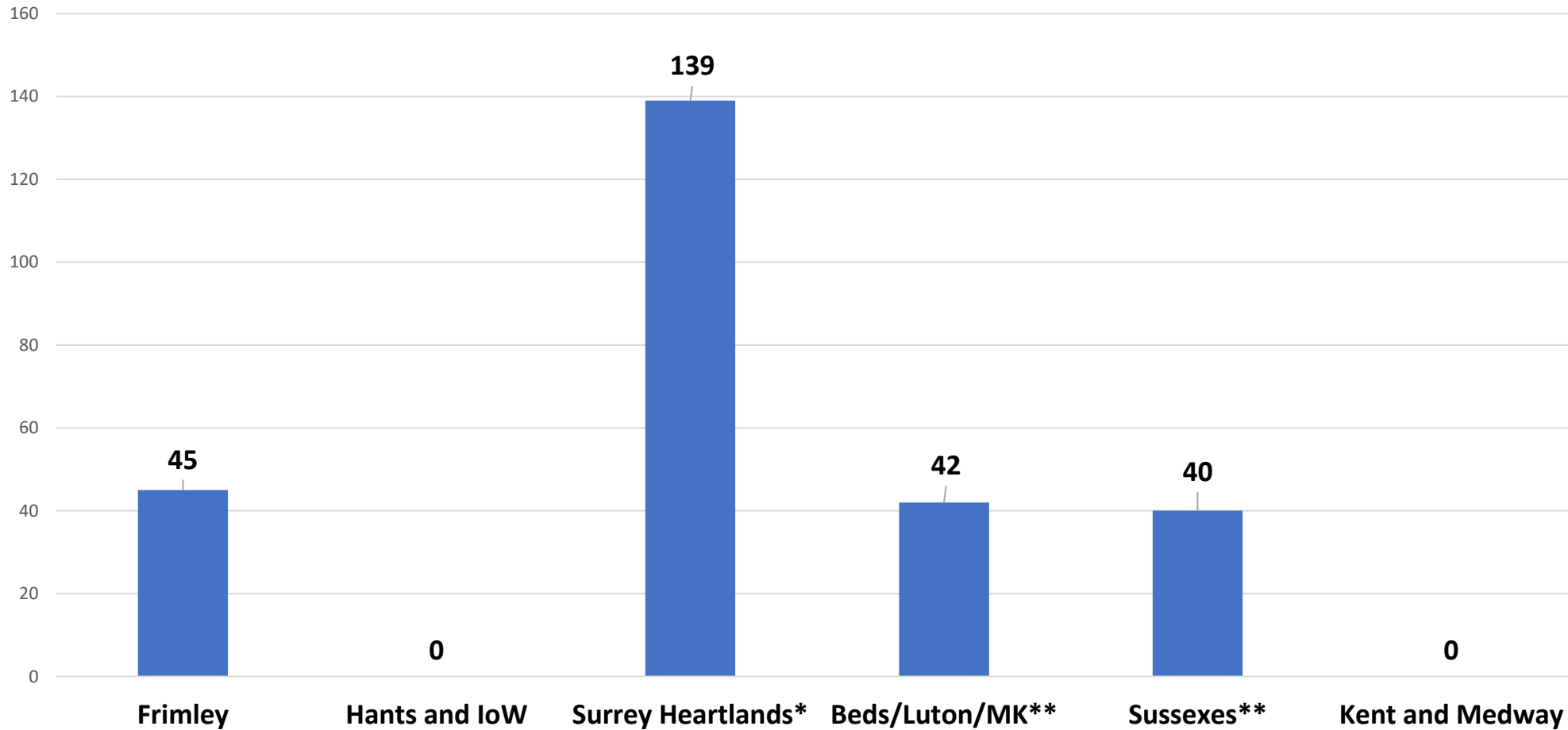
Average number of children eligible for CYPCC funding between 2020 and 2025 per ICB



**Data for 2022-25 only * Data for 2023-25 only



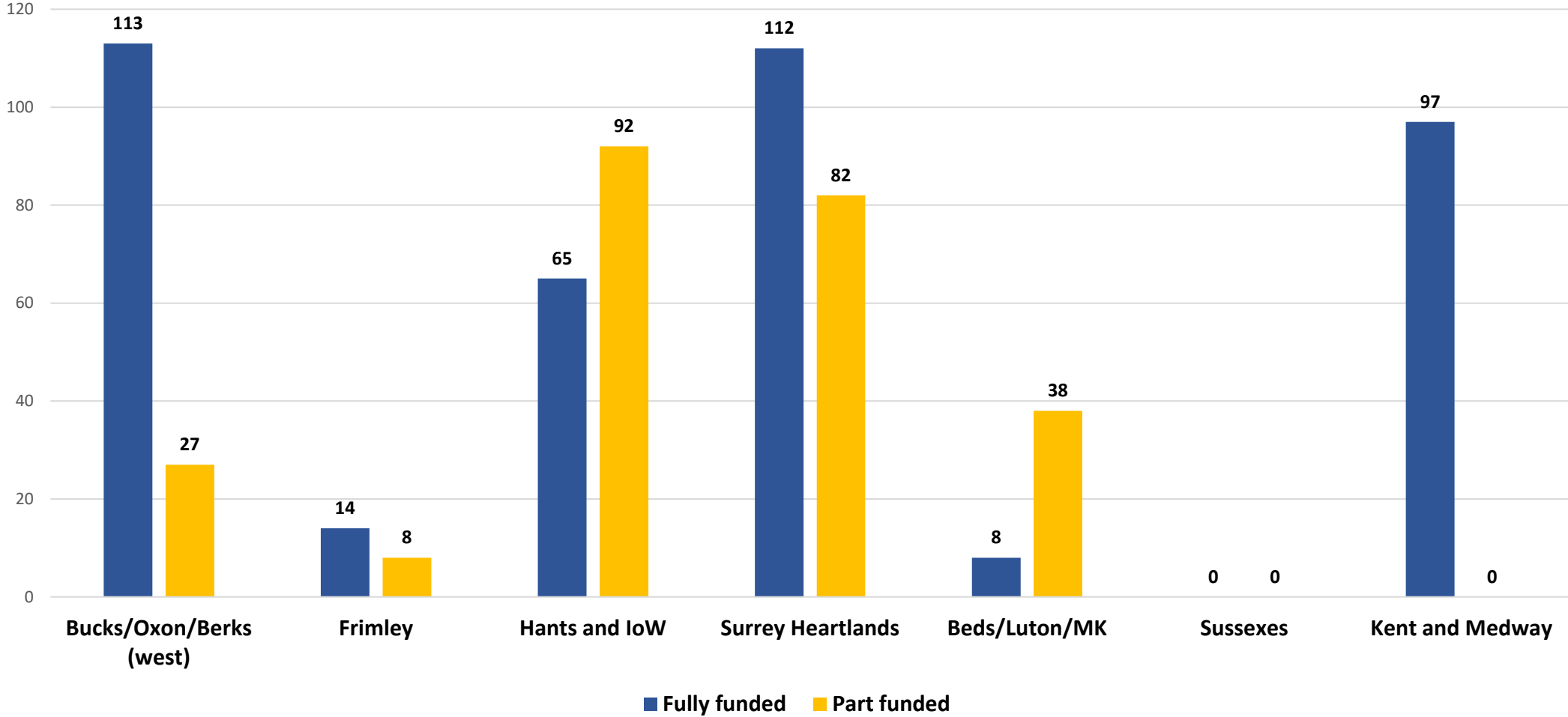
Average length of time in 2024/25 between the child being referred for assessment and the assessment being completed



**Data for 2022-25 only * Data for 2023-25 only



Number of children in 2024/25 fully funded by the ICB v those partly funded with the LA



Number of children in 2024/25 fully funded by ICB, by placement type or setting

ICB	Fully funded	Living with family	Living in foster care	Living in an Ofsted registered Children's Home	Living in an unregistered setting
Bucks/Oxon/Berks (west)	113	n/k	n/k	n/k	n/k
Frimley	14	19	0	Fewer than 6	Fewer than 6
Hants and IoW	65	64	0	Fewer than 5	0
Surrey Heartlands	112	n/k	n/k	n/k	n/k
Beds/Luton/MK	8	44	1	1	0
Sussexes	n/k	n/k	n/k	n/k	n/k
Kent and Medway	n/k	n/k	n/k	n/k	n/k



Number of children in 2024/25 in receipt of CYPCC by 'presenting need'

ICB	MH/Trauma/challenging behaviour	Physical need
Bucks/Oxon/Berks (west)	n/k	n/k
Frimley	0	0
Hants and IoW	22	135
Surrey Heartlands	n/k	n/k
Beds/Luton/MK	0	No reply
Sussexes	n/k	n/k
Kent and Medway	n/k	n/k



Number of children in 2024/25 in receipt of CYPCC funding

- turned 18
- were assessed under adult CHC
- were deemed eligible under adult CHC
- were deemed not to be eligible under adult CHC

ICB	Turned 18	Assessed	Eligible	Not eligible
Bucks/Oxon/Berks (west)	121	106	46	60
Frimley	Fewer than 6	Fewer than 6	Fewer than 6	0
Hants and IoW	10	10	10	0
Surrey Heartlands	6	6	6	0
Beds/Luton/MK	2	2	2	0
Sussexes	n/k	n/k	n/k	n/k
Kent and Medway	n/k	n/k	n/k	n/k



Number of children in 2024/25, not in receipt of CYPCC funding, had a transition to adulthood DST and became eligible for CHC for their 18th birthday

ICB	Number
Bucks/Oxon/Berks (west)**	n/k
Frimley	Fewer than 6
Hants and IoW	Fewer than 5
Surrey Heartlands*	3
Beds/Luton/MK**	0
Sussexes**	n/k
Kent and Medway	n/k

**Data for 2022-25 only * Data for 2023-25 only



Please explain what the quality assurance arrangements are, for ensuring that the numbers of children who are deemed to meet the CCC criteria in your ICB area, are in line with other ICB's, and are likely to be fair and appropriate

Bucks/Oxon/Berks (west) - No response

Frimley - The ICB has robust quality assurance arrangements in place to ensure Children's Continuing Care (CCC) eligibility decisions are fair, consistent, and aligned with national guidance. Decisions are made using the national CCC Framework, subject to clinical oversight (Clinical Review Group), moderation, and audit. The ICB also benchmarks CCC activity and prevalence against peer ICBs and reviews any variation through senior clinical governance processes to ensure equitable and appropriate decision-making.

Hants and IoW - Internal governance policies, SOP'S and processes are in place to access to services are fair and appropriate. This includes CYP Choice and Equity Policy (Aligned to Adult CHC Choice and Equity Policy), clinical decision making panels with multidisciplinary and multiagency representation, use of a number of sophisticated resource allocation tools to support alignment of care hours based on clinical, social and educational needs, and regular collaboration with partners in regional ICB'S to support peer review and challenge for learning and individual cases.



Please explain what the quality assurance arrangements are, for ensuring that the numbers of children who are deemed to meet the CCC criteria in your ICB area, are in line with other ICB's, and are likely to be fair and appropriate

Surrey Heartlands - Whilst there is no active quality assurance process, as you describe, in place at this time in Children's continuing care in Surrey, as there is with adults continuing care, NHS England have recently started to collect data on this from ICBs across the country via the AACCCDS monthly return. This will in turn allow ICBs to understand any local variation as we are able to do with adults continuing care.

Beds/Luton/MK - Community of Practice for East of England facilitated by NHSE and attended by all East of England ICB's. Open channels of communication outside of this forum to discuss individual cases anonymously with neighbouring ICB's.

Sussexes - We periodically arrange peer reviews via other ICB teams as part of our dispute resolution process. This may highlight quality issues or provide assurance in relation to fairness and equity.

Kent and Medway - No response



Please explain what steps are taken and by whom, if your ICB appears to be an 'outlier' (in respect of numbers of children referred/timescales for assessment completion/ numbers of children who meet the criteria, or funding splits)

Bucks/Oxon/Berks (west) - No response

Frimley - If the ICB is identified as an outlier, senior clinical and commissioning leads undertake a data-led review to understand the cause, benchmark against peer ICBs, and assess compliance with the national CCC Framework. Actions such as audit, clinical moderation, staff training, and pathway review are implemented as required and monitored through established governance arrangements.

Hants and IoW - NHS Hampshire and Isle of Wight do not demonstrate data that represents them as an outlier, in either timescales for assessment or number of CYP who meet criteria per head of CYP population. Data evidence's an increase in line with population data for complex CYP.

Surrey Heartlands - Not applicable

Beds/Luton/MK - We are not considered an 'outlier' by NHSE.

Sussexes - There are no nationally published activity data for CYPCC, so we are unable to benchmark.

Kent and Medway - No response



Results from questionnaire

We are pleased to announce that all 19 local authorities responded to the questionnaire, which means we have a good picture across the South East local authorities and the ICB's.

The responses are summarised as follows:



Do you have a Children's Continuing Care operational policy developed and agreed jointly with your partner ICB(s)?

6 of the 19 LA's have policies in place, including a problem resolution process.

- 4 of the 6 were co-produced
- 2 of the 6 were produced solely by the ICB

Does it contain a problem resolution process and is it effective?

The following LA's described their policies as effective, although the problem resolution processes had not all be tested:

- Buckinghamshire
- Hampshire
- Kent
- Medway
- Portsmouth



Can you share your policy?

The following LA's are prepared to share their policies:

- Buckinghamshire
- Hampshire
- Isle of Wight
- Medway
- Portsmouth

Of those who responded that there is no current written policy in place, further comments indicated that work was underway/in progress/workshops and or discussions had taken place or were underway to develop such a policy.



Do you have a policy developed and agreed jointly with your partner ICB(s) to agree joint funding where a child/young person has a health need but is deemed not to meet the criteria for Continuing Care?

The following 4 LA's responded positively to this:

- Brighton and Hove
- Buckinghamshire
- Medway
- Surrey

They were described as effective including the problem resolution process.

It seems that arrangements are also in place in other LAs, but unclear as to whether any of these arrangements/policies were in writing.



Do you have arrangements with your ICB that work effectively to agree LA and ICB funding contributions to a child's care package – either formal or informal

Examples could include S117, CYPCC, Complex Care, EHCP

13 LA's responded positively.

The following LA's do not have such an arrangement in place:

- Bracknell Forst
- East Sussex
- Kent
- Milton Keynes
- Surrey
- Royal Borough Windsor and Maidenhead



Do you use any form of joint funding tool? If yes, can you share it?

LA's using a formal funding tool are:

- Hampshire
- Isle of Wight
- Portsmouth
- Reading
- West Berkshire
- Wokingham

13 LA's do not have a formal funding tool and have provided, in some cases, further clarification:

- work is in progress to develop such a tool
- funding arrangements /formulae were in place and effective, without there being a formal funding tool



Where packages are jointly funded, do you have arrangements for these to be jointly commissioned?

The following LA's have arrangements to be jointly commissioned:

- Brighton and Hove
- Hampshire
- Isle of Wight
- Portsmouth
- Royal Borough Windsor and Maidenhead
- West Sussex
- Wokingham

There was a lot of additional information in response to this questions, both from the LA's who had responded positively, and those who had responded negatively:

- both the LA and the ICB will at times take the lead in commissioning on behalf of the other
- this happens on a case by case basis
- funding is made available from each agency via other means such as direct payments.
- joint funding is common but not joint commissioning.
- arrangements are in development



Do you have CYPCC training in your area?

9 LA's responded 'yes' with 8 of these being single agency and Kent being joint training.

Do you have a process to collate CYPCC data specific to your authority, e.g. number of applications, outcomes, disputes?

11 LA's said 'yes', but both those who had responded yes and those who responded no, clarified, in most cases, that data was recorded on a spreadsheet by one or other (or both) agencies, or in the form of minutes from panels or other decision-making meetings.

What works well between your LA and the corresponding ICB in respect of CYPCC?

The most common responses were about individual commitments to **achieving good outcomes for children** and a determination to **improve those outcomes**

The most common **key factor to making this work**, was 'relationships'



Please identify any concerns in relation to CYPCC in your area.

A variety of different responses were received, including:

- lack of policies
- written procedures
- a feeling that numbers did not reflect need
- outcomes being dependent on individual working relationships
- staff changes/turnover and absences (specifically in ICBs) resulting in delayed decision making Inconsistent decision making.



Overall observations.

- Thank you to everyone who helped us achieved getting responses from all the 19 LA's.
- This helped us with a very comprehensive good start to understanding the experiences across SE as a whole
- Experiences of LAs are very different even within the same ICB area e.g. some people saying no policy-others in the same ICB saying yes lots of written policies-both could be true.
- Individual working relationships and /or joint funded posts identified as a key factor in making things work.
- Biggest risk is staff turnover and losses-even in those LAs who say their policies are effective.



Any questions?





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All age Continuing Care dataset

Sue Kocaman, SESLIP Consultant

New data requests for Children and Young People's Continuing Care – April 25 – March 26

Children and Young People's (CYP) Continuing Care is a package of care that is required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone.



Types of eligibility for CYP include the following:

Children and Young People's Continuing Care: funded by the NHS.

Children and Young People's Continuing Care - Joint with Social Care: joint funded by the NHS and a Local Authority (where the Local Authority funds social care).

Children and Young People's Continuing Care - Joint with Education: funded by the NHS and a Local Authority (where the Local Authority funds education).

Children and Young People's Continuing Care - Tripartite with Social Care and Education: joint funded by the NHS and a Local Authority (where the Local Authority funds both social care and education).



To include:

All new and ongoing activity relating to CYP Continuing Care,

- from receipt of service request (see below for in-scope service request types) to ICB decision whether to refer for assessment,

And for those cases fully assessed,

- MDT recommendation,
- ICB eligibility decision,
- care package details, and
- review (3 month and 12 month) details.



Expected new CYP request types that should be captured are:

- Pre-assessment checklist received (positive, negative, or undefined outcome).
- Direct referral.
- Fast track
- Referral for reassessment following a care package review
- Local Resolution
- Inter-agency Dispute
- Transferred case from another ICB
- CYP transitioning to CHC



Further detailed clarification on:

- What constitutes a joint funded package of care-what is included and excluded
- How to count children and young people transition to adults health and care
- How to count fast track assessments for children, given that different ICBs can process these requests in different ways
- Distinction between a 'service request' and a 'new service' request'



New Service Requests include:

- A new CHC checklist is received, including for a CYP transitioning to CHC,
- A new referral resulting from a care package review
- A new fast track referral is received
- A new request for a previously unassessed period of care is received
- A new CYP pre-assessment checklist is received
- A new request for a joint funded package of health and social care is received



New Service Requests (2)

- A direct referral is received
 - A transferred case is received
 - A re-assessment for existing eligibility is to be made based on a care package review
 - A local resolution request related to an eligibility decision has been raised
 - A formal inter-agency dispute of an eligibility decision has been raised
- this means there can be more than one service request per individual**



Ending or closing a case/cases 'out of scope'

- Assessment decision date
- Eligibility decision communicated to patient

Cases out of scope:

- New and ongoing joint funded packages of care that have not undergone a full CHC assessment with a 'not eligible' decision
- Cases funded under the Mental Health Act (e.g. section 117 aftercare)
- Cases funded on an interim basis 'without prejudice' pending a formal decision being made.



Any questions?



What are we doing in RBWM? The Health Consultation Journey

Suki Hayes-Lapham, Specialist Services Manager, CYPDS



What are we doing in RBWM? The Health Consultation Journey

Suki Hayes, Specialist Services Manager, Children and Young
People's Disability Service



**achieving
for children**

Champions for children and families

What is the Health Consultation Triage?

The Health Consultation Triage is a collaborative, professional discussion between multi agencies to:

- consider what local NHS support can be provided for children and young people 0-18 years (to the ages of 25 years for Care Leavers) with continuing and/or complex health and social care needs
- consider a referral to Integrated Resource Allocation Panel (IRAP)

The triage was set up due to the ICB rejecting CYPCC referrals and saying that health needs were being met/ could be met by existing NHS providers

The triage is not legally required, however RBWM is of the opinion that this supports best practice.

We welcome professional advice, guidance, time and commitment from representatives who are essential in ensuring that we have a wide range of experience represented.

Context:



- At times it is hard for professionals within social care to know what is available to access and without having expert health practitioners within AfC.
- We don't always know the details and implications of a child's health needs, so this triage will enable professionals to consult and make decisions that will enable us to know the best pathway for support
- Whilst the ICB have a Clinical Review Group that screens CYPCC referrals, social care do not attend this, so it can be difficult for us to understand outcomes and what other provisions can be accessed

Role and Function

The Role and Function of the Triage

Role and Function

- considering what local support can be provided, including a referral to further community NHS services
- Recommending further assessment and information gathering
- considering referral to Integrated Resource Allocation Panel (IRAP)* and reviewing IRAP applications before being sent to ICB.
- If the outcome of the pre-IRAP screening by the ICB's Clinical Review Group is not to assess or suggesting signposting, the case is to go back to the Health Consultation Triage for further discussion

Timing: Triage meets monthly on Monday afternoons from 2.00 - 4.00pm

Referral and Papers: A Health Consultation Triage Referral is completed, providing a brief understanding of what the reason(s) for the referral is to ensure we are targeting the right area for desired outcome. Papers to include - recent Assessment, Resource Panel or CYANP Application (Social Care panels), EHCP, school report, clinical letters

Health Consultation Triage Tracker: The tracker captures the discussion for each case with actions and will enable the case to be monitored

- IRAP = the Frimley multi-agency panel that makes CYPCC decisions.

How to decide if a child or young person needs to be discussed at Health Consultation Triage (HCT)

Case Supervision/ Reflective Discussion

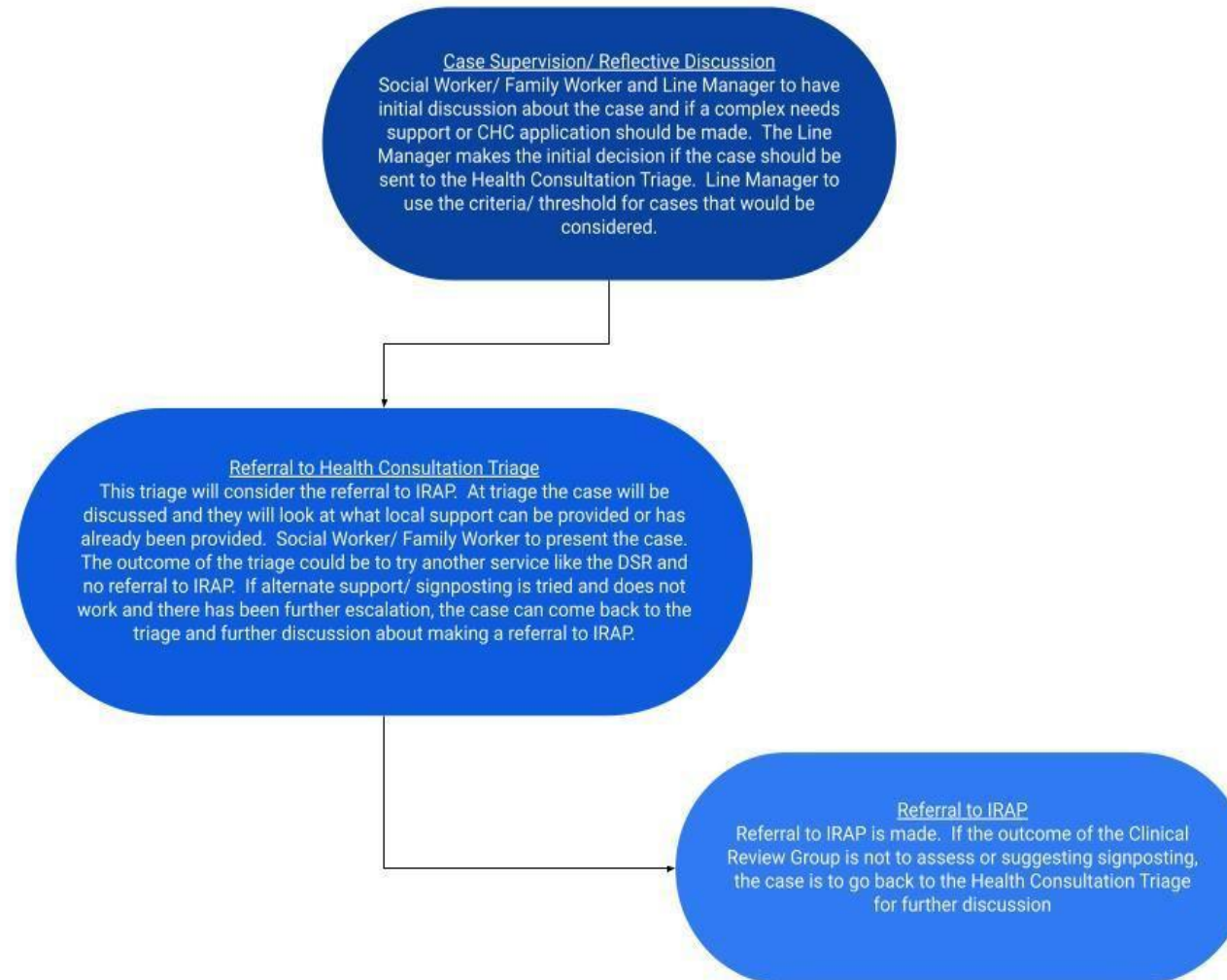
- Social Worker/ Family Worker and Line Manager to have initial discussion reflecting on the child or young person's health needs; continuing care (CCC) or complex needs and the decision to make an application for a joint approach.
- The Line Manager makes the initial decision if the case should be sent to the Health Consultation Triage.
- Line Manager to use the criteria/ threshold for cases that would be considered.

Health Consultation Triage Drop In Session

- Line Manager to refer Social Worker/ Family Worker to meet with Specialist Services Manager on an alternate Thursday HCT Drop In session.
- Drop in session used to discuss cases intended for HCT or IRAP applications already in process
- The session can also be used to discuss the IRAP referral process and understanding how to complete the IRAP referral form

Scope: What is the process

How to make a referral to triage



Membership

Who makes up the triage membership?

- Continuing Healthcare Specialist -RBWM (Co-Chair)
- Specialist Services Manager -AfC (Co-Chair)
- Associate Director for Corporate Parenting - AfC
- CYPDS Social Care Team Manager - AfC
- CYPDS Social Care Assistant Team Manager - AfC
- Acting Head of Service for Quality Assurance & Principal Social Worker- AfC
- Children in Care Team & Leaving Care Team Team Manager - AfC
- Interim Targeted Intervention Manager - AfC
- Preparing for Adulthood (PfA) Project Manager - AfC
- Clinical Lead Specialist and Team Manager Clinical Psychologist CAMHS CiC
- Children and Young People's Complex Needs Liaison Nurse for Frimley ICB
- Advanced Mental Health Practitioner x 2 - CAMHS
- Senior Consultant Psychotherapist - AfC
- NHS Frimley - Learning Disability and Autism Transformation Manager
- BHFT Community Children's Nursing Deputy Team Leader- Designated Lead in Children's Palliative Care
- Specialist Nurse for Children in Care BHFT
- Specialist Nurse for Children and Young People in Care BHFT
- Children Safeguarding Lead Nurse Frimley Health NHS Trust
- Head of The Link - Operational and Wellbeing Safeguarding Lead
- SEND Service Manager - AfC
- Assistant Headteacher AfC Virtual School (RBWM) - AfC
- Strategic Lead - Placements Commissioning - AfC

Data - Since HCT started in November 2024

41 cases have been referred to HCT and discussed since inception.

Below is a breakdown:

- 3 IRAP applications made and awaiting outcome
- 2 completed IRAP applications - split funding agreed
- 6 IRAP applications in process of being written for submission
- 2 cases in process of being referred to DSR
- 2 cases in process of IRAP PBS application
- 1 case in process of referral to LINK CAMHS
- 21 cases required no further action after discussion
- 2 cases required no further action but referred to DSR
- 2 cases no progress as waiting Social Care Assessment

Objectives

- The **core aim** of the Health Consultation Triage is for multi professionals to promptly identify and utilise local support/ resources to ensure children and young people with continuing and/or complex health and social care needs are receiving the right care, from the right person, in the right place.
- The **strategic approach** is to address, encourage and facilitate joined-up thinking and working across education, social care and health services to provide better coordinated support to children and young people with multiple and/or complex needs.

Key Findings

Wins

- Overall feedback is that the triage is working well and enables a comprehensive, child-centered approach
- By bringing together multi professionals these meetings have facilitated the sharing of knowledge, leading to more sign posting and resource sharing
- By sharing expertise, teams have reduced the duplication of efforts and are using resources more efficiently

Issues

- Lack of accountability for actions when monthly updates required
- Delays in gathering evidence together, delays getting social workers to do the applications
- Training needs identified
- the moving target that as these are children with complex needs a number have placement breakdowns and move, and we have to start again.

Aspirations

- The triage receives less referrals due to professionals having a wider knowledge of services available
- Better overall understanding by social care professionals of the different health pathways and application processes

Refreshment break



What works well between Portsmouth City Council and ICB when it comes to CCC and why?

Tracy Fisher, Head of SEND ICB, HIOW





Hampshire and Isle of Wight

Driving Better Outcomes Through System Partnership: The ICB-LA CYPCC Experience in Portsmouth

Tracy Fisher- Head of SEND HIOW ICB

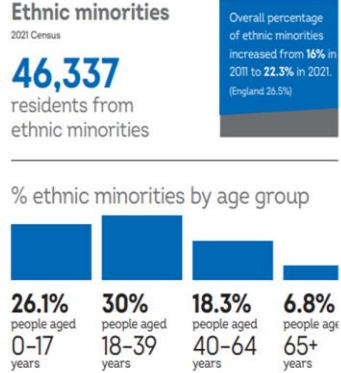
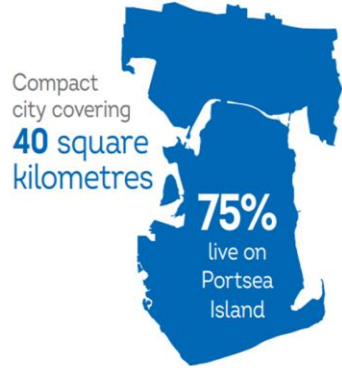
Feb 2026

1. Our City

About Portsmouth

Population
214,300

Second most densely populated local authority outside London



1. Our City

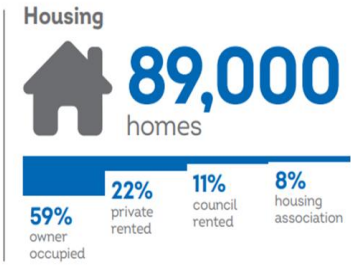
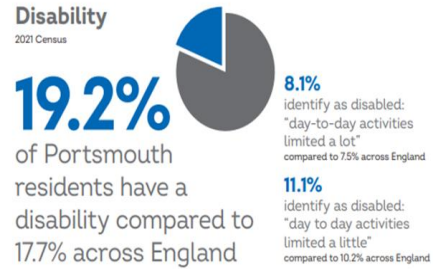
About Portsmouth



18,544 Portsmouth residents (9.2%) did not identify English as their main language

The most common main languages, other than English, were:

Romanian	Bengali
1.25%	0.81%
Polish	Portuguese
1.14%	0.48%



Almost **50% built before 1919**, and **63% terraced**, more than twice England average

Health Services and Joint NHS-Local Authority Services

Hants and IoW Healthcare NHS Trust

- Health Visiting
- School Nursing
- Family Nurse Partnership
- Integrated Therapies Services
- Specialist School Nursing
- ELSEC Team
- Community Paediatrics
- CAMHS

Integrated ICB/LA Commissioning Team

- Mental health commissioning
- Complex Care oversight
- Designated Clinical Officer
- Partnership commissioning with Public Health

Integrated NHS-LA Delivery Teams

- Integrated Early Help Service (including public health nursing) – currently being transformed into 'Family Help' under Social Care Reforms
- Family Hubs
- Neuro-Diversity Multi-Disciplinary Team

CONTEXTUAL INFORMATION

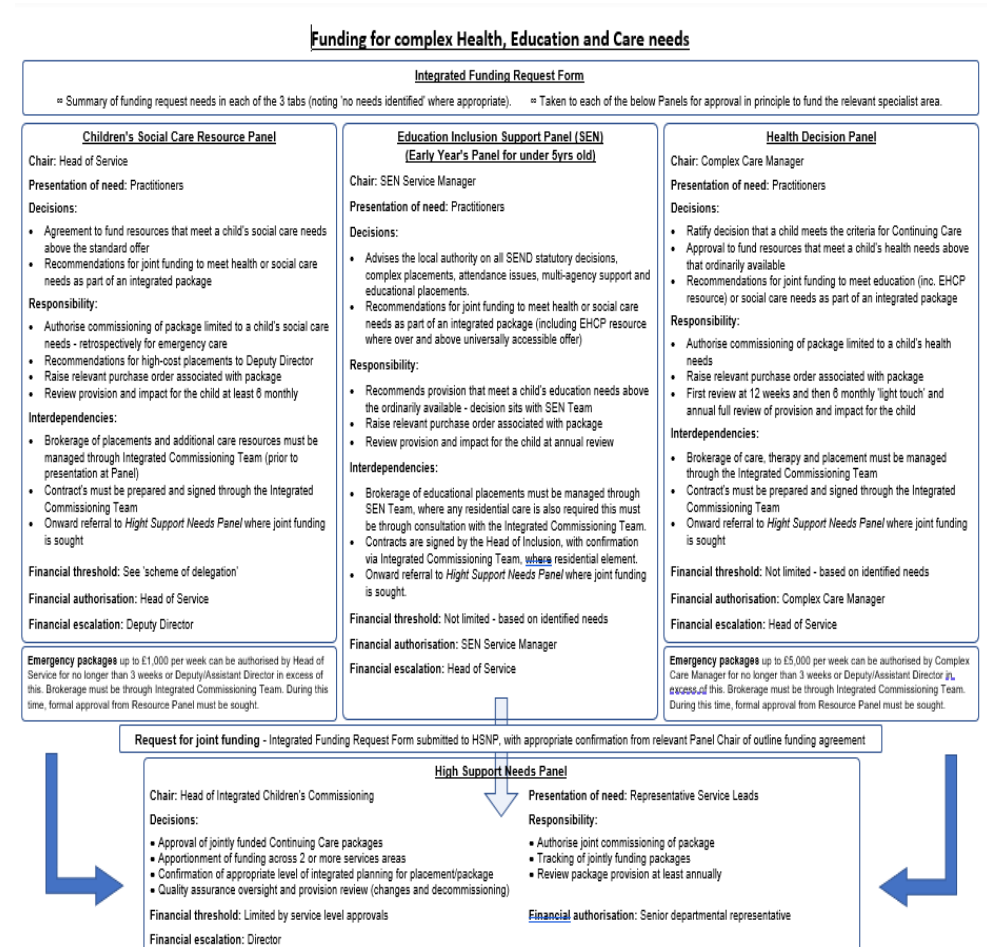
Health and Care Services

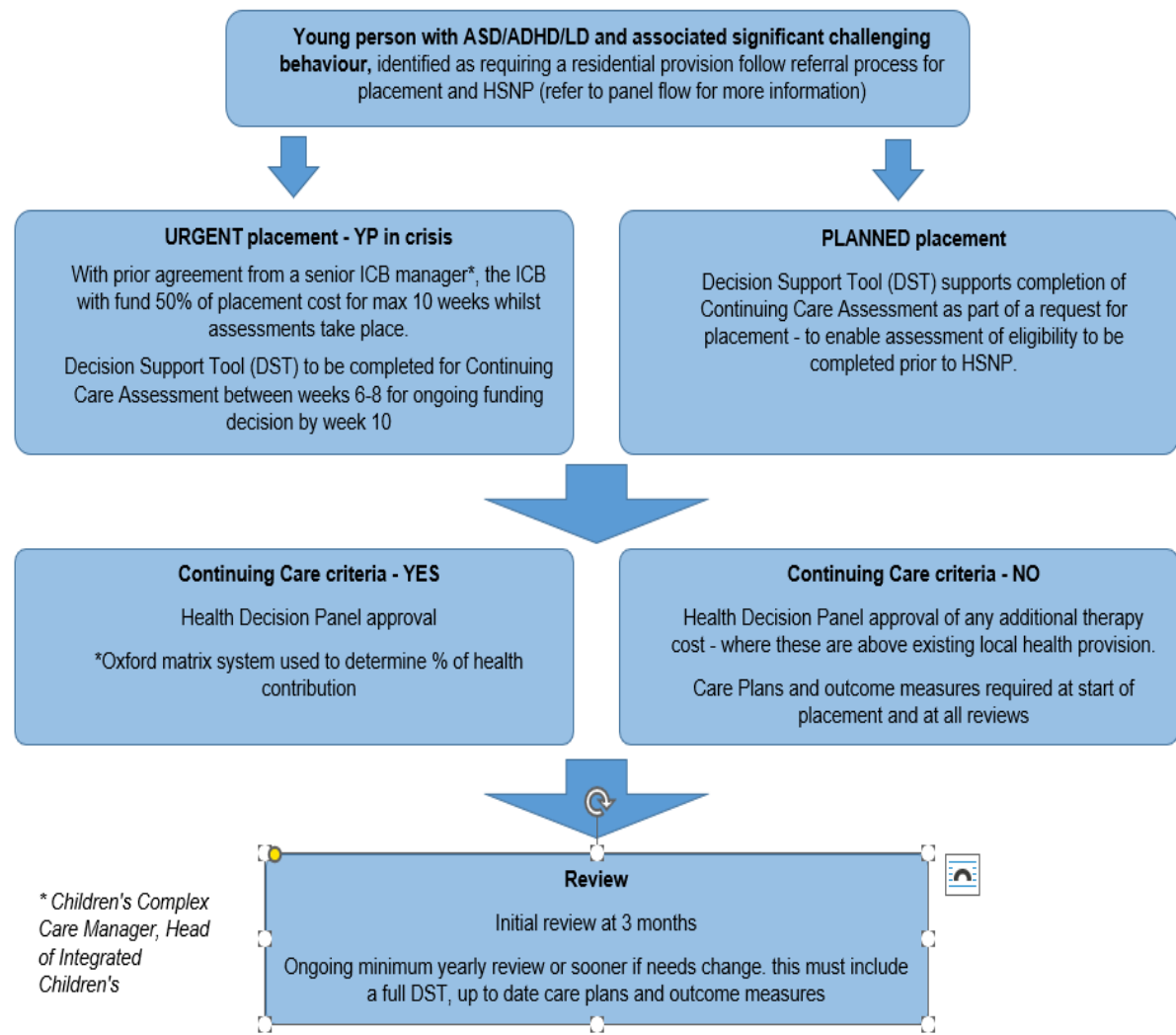
- 1,119 children open to CAMHS
- 1,685 children open to NHS Therapy services
- 210 children receiving support from Specialist Health Visiting service (TEDs)
- 19 children with continuing healthcare needs that meet criteria
- 10 children on the DSR
- 0 children in a Tier 4 CAMHS bed or in paediatric ward as a 'place of safety'
- 97 children open to Children with Disabilities Social Work team
- 209 children open to Children with Disabilities Early Help team

High support needs panel

Overview

- The purpose of the High Support Needs (HSN) Panel is to ensure there is joint planning and joint commissioning of placements and packages of education, health and care support where there is a need for funding by more than one agency. It also oversees decisions relating to provision that falls outside of normal commissioning arrangements.
- Cases are referred to HSN Panel to request joint funding for placements and packages of support from two or more agencies. Referrals must have an 'in-principle' decision from each agency prior to discussion at HSN Panel. All cases, once joint funding arrangements have been agreed, will be reviewed by HSN Panel at least annually, with input from all agencies. There are 3 panels that feed into HSNP as required- Resource panel for children's social care/ multiagency health panel and relevant education panels





* Children's Complex Care Manager, Head of Integrated Children's

CYP domiciliary care framework/preferred provider list

The framework is an integrated quality service model for commissioning and care management of health and care, which is underpinned by personalisation and offers optimum benefits to all parties in terms of value for both the user and taxpayer. · Improve the quality of care and outcomes for CYP eligible for continuing care through the development of jointly commissioned place-based models of care.

It is recognised that there are several high-quality providers working hard to meet the needs of CYP and their families/carers, in a market environment that is challenging in terms of sufficiency and sustainability of provider business models. The solutions to this issue are not limited to stimulating new entrants to the market, it is important that we build on the high-quality provision currently commissioned. This means building opportunities that encourage providers to diversify their offer, developing new and innovative delivery models and facilitating joint working between organisations

- Prioritise work with partners that seek to create a sustainable, high-quality offers.
- Develop an operating environment which is permissive of change and innovation.
- jointly commission care packages between statutory organisations to improve pathways for families/carers.
- Further develop co-production of service commissioning.
- Work to reduce the administrative and reporting burden on the market.

Learnings, what worked well

- **Multi-Agency Governance**

Clear governance enables decisive budget decisions across education, health, and social care agencies with minimal delays.

- **Shared Funding Framework**

Funding protocols like joint funding agreements ensure transparency and reduce disputes over contributions and responsibilities.

- **Delegated Authority for Urgent Decisions**

Delegated authority for senior leaders supports swift approval of emergency placements, improving system responsiveness.

- **Structured Collaboration and Accountability**

Governance frameworks guide pre-panel planning, case preparation, and ensure joint accountability for high-cost placements.

Holistic Integrated Assessments

Integrated assessments combine education, health, and social care insights for a comprehensive understanding of needs.

- **Timely Information Sharing**

Advance sharing of complete case information enables informed, efficient panel decisions and strategic planning.

- **Equity and Proactive Management**

Robust systems reduce risks and support equity, inclusion, and proactive complex case management.

Thank you



FOI Insights

Case for Change

Spotlight on lived experience

Amanda Elliott, Strategic Health Lead, Contact
Helen and Paul Brown, Parents



FOI insights, the case for change, and a spotlight on lived experience

Children and young people's continuing care

Amanda Elliot, health lead for Contact

Helen Brown, parent carer of two children with continuing care needs



Method and response

FOI requests comprising 5 questions sent to 42 ICBs in February 2025 seeking data for 2021-2, 2022-3 and 2023-4:

- Referrals, assessments and new care packages
- Total number of care packages (snapshot) ICB
- % of jointly funded with the local authority
- Total spend at end of year
- Number of care packages lasting > 12 months

Response rate

- 15 ICBs provided complete responses
- A further 18 ICBs provided partial data enabling some analysis
- 9 ICBs provided insufficient data (incl. *NHS BOBW*)



Headline findings

- 4,400 children were in receipt of CCC funding - a fraction of 99,000 CYP living with a life limiting or life-threatening condition*
- Half (52%) of CYP referred for CC assessment in 2023-24 were turned down for support.
- Overall spending on children's CC fell by £2.9m, despite high inflation (2023-24). 60% of ICBs decreased spend.
- Post code lottery of care – big variation in CCC spend per care package and per head of child population between ICBs
- Patchy joint commissioning of children's and young people's care packages

** Making Every Child Count, 2020*



Post code lottery of care

- NHS Birmingham and Solihull funded 434 care packages/child population (335,179 child pop.) v NHS Hertfordshire and West Essex (337,682 child pop.) that funded 10.
- NHS Dorset spent £61.37 on CCC funding per head of its child population - **76 times more** than NHS Hertfordshire and West Essex which spent £0.80.
- NHS Gloucestershire spent an average of £159,434 per care package , **10 times more** than Birmingham and Solihull which spent £15,156.



Joint funding

Responses showed wide variations in ICB joint commissioning with LAs to support children with complex health needs

- % of joint funded care packages ranged from as little as 8% to 100%.
- Under 30% of care packages were jointly funded in 7 ICBs
- 15 ICBs were unable provide data on % of joint funded care packages.
- On average, 57% of continuing care packages were joint funded in 2023-4, down on the previous year.



FOI data – SE region

ICB	CCC packages total (snapshot) 31 March 2024	Child population (ONS)	Total CCC spend 2023-4	% joint funded care packages , 31 March 2024
NHS Buckinghamshire, Oxfordshire and Berkshire West	130	386,893	No data	No data
NHS Hampshire and Isle of Wight	139	361,259	£17.64m	66%
NHS Sussex	136	327,314	£13.3m	No data
NHS Kent and Medway	98	407,813	£12.8m	20%
NHS Frimley	193	176,451	£6.7m	35%
NHS Surrey Heartlands	32	231,280	£2.5m	100%



Mia

Two of Leanne's children were diagnosed with the rare genetic condition PCH Type 6. Cory who sadly died last year, received continuing care in the last two months of his life. Sister Mia, 16, has the same progressive condition and relies on oxygen overnight for her respiratory problems. Mia has multiple seizures a day, has to be moved with a hoist and is tube fed. Her mum provides 24-hour medical and personal care. Mia has been repeatedly screened out for continuing care at the initial assessment stage. Social care provides 36 hours support but cannot provide Mia's medical support needs. Since the local respite centre closed, the family now gets very occasional sporadic overnight respite from a local hospice.



Keir

Six-year-old Keir has a rare genetic, life-limiting condition GABRB3. He is visually impaired and requires round-the-clock care. Mum Becky spent three years battling to get him continuing care support. The LA provides 4 hours short breaks a week. Keir is under palliative, gastroenterology and neurology consultants at Birmingham Children's Hospital. Keir has 3-4 seizures a night, is peg fed and needs suctioning, nebulisers and is dependent on a range of medication including morphine to manage pain. Becky sleeps downstairs every night with Keir to manage his seizures and administer his pain medication.

Becky: "I'm totally exhausted. It's not sustainable."



Case for change

- No parent should have to fight for care their child desperately needs.
- Post code lottery of care for the most vulnerable children with complex health needs – unequal access and support across England
- Children let down by a weak legal framework/poor accountability and transparency – compared to adult's CHC legal rights
- Exhausted families are providing round the clock care for their children who needs are too complex for social care support
- Families of children **with** CCC support living in constant fear support will be removed or reduced at review
- Shortage of trained workforce/inadequate PHB funding
- Lack of transparency and accountability – no-one scrutinising how children with the most complex needs are supported at home
- Children with complex medical needs not mentioned in the NHS Plan



Contact's campaign asks

- **Strengthened Legal framework** Children with the most complex health need deserve the same rights as adults who require CHC.
- **ICB accountability and transparency** – a requirement to publish data on children's continuing care. Too many ICBs failed to provide data
- **Independent advocacy and robust routes of redress**
Guarantee families access to independent advocacy and fair appeals.

Activities: Petition; national media coverage of families; engaging MPs to write to ministers and submit; PQs, pressing for parliamentary debate on CCC delays and inequalities, possible NHS roundtable with regional leads/stakeholders

Opportunities: SEND White Paper; Law Commission reform; NHS Plan



Thank you!

amanda.elliott@contact.org.uk



Lunch



Legal context and legal review

Liam Doherty, Continuing Healthcare Specialist, RBWM



Children & Young People's Continuing Care

Legal context & legal review

Liam Doherty
CHC Lead
RBWM

Context: national trend of increasing needs

- *Independent Investigation of the National Health Service In England*, September 2024 (aka the Darzi report)
- p40 – 43 – Children and Young People
- C&YP are 24% of the population, account for 11% of NHS spending
- Increasing prevalence of mental and physical health needs in C&YP.
- "Since 2019/20, for example, there has been an 82 per cent increase in hospital admissions for eating disorders"
- 250% increase in prevalence of life-limiting and life-threatening conditions in C&YP between 2001 and 2018
- Number of children with eight or more chronic conditions nearly doubled from 7.6% in 2012-13 to 14% in 2018-19
- Number of children receiving long-term ventilation more than doubled between 2013 and 2020

Context: reduction in Tier 4 NHS services

- [Improving the outcomes of looked after children and young people in complex situations with multiple needs, at risk or subject to a Deprivation of Liberty](#), DFE, Sept 2025
- Key themes: escalating use of Deprivation of Liberty Orders; insufficient early help and fragmented services; increasing complexity of needs and experience of trauma; varied placement quality and value for money.
- **“Mental health inpatient provision...** Reductions in children and young people’s mental health inpatient bed numbers over the last 10 years have occurred alongside plans to develop inpatient services and community alternatives to Tier 4 beds. .. the pace and scale of these developments has not filled the gap generated by bed closures and the increased demand for mental health treatment for children and young people. This deficit contributes to the situation in which children’s social care services are required to find and fund provision for children who might otherwise have been in mental health facilities (Ofsted, 2024b).”
- The Ofsted report referenced is: [How local authorities and children’s homes can achieve stability and permanence for children with complex needs - GOV.UK](#) Ofsted, January 2024
- “Local authorities in our project reported difficulty in finding suitable homes for children who fall just below the tier 4 mental health threshold (the threshold for sectioning under the Mental Health Act), or for those children who have just been discharged from a tier 4 hospital placement. These are children whose self-harm can cause serious injuries, or children who express suicidal thoughts and behaviours. This issue has been exacerbated by the reduction in mental health inpatient beds: a decrease of 23% since 2010–11. Children’s social care services are now finding and funding provision for children who might otherwise have been in mental health or secure facilities.”

Context: Law Commission report: Disabled children's social care

- The *Consultation Paper* (2024) and *Final Report* (2025) refer to CYPCC eligibility as
 - 1) determined by needs and case law, not DST scores,
 - 2) the same threshold as for adults, based on common case law.
- Consultation Paper:
 - “14.12 ... The Continuing Care Framework states that a child is “likely to have continuing care needs if assessed as having a severe or priority level of need in at least one domain of care, or a high level of need in three domains of care”. However, the Continuing Care Framework makes clear that this is not a firm rule, and that assessors, when presenting recommendations to the decision-making forum, should “consider the level of need identified in all care domains in order to gain the overall picture.”
- Final Report:
 - “14.4 For children, the courts have adopted the same approach that underpinned section 22 of the Care Act 2014
 - “14.21 ...when dealing with children, local authorities and NHS providers are left to consult the case law which, in relation to adults, section 22 codified into statute.”
- Final Report Recommendation 34 is for amendment to the Children Act 1989, to add a statute definition for LA legal limits that emulates s22 of the Care Act 2014
- A revised CYPCC Framework seems inevitable if there is new legislation.
- 16th March = 6 month deadline for initial government response

Relevant legislation

- Statutory LA duties to children, e.g. Children Act 1989, Children & Families Act 2014
- ICBs general target duties under NHS Act 2006 s3.
- Meeting CYPCC needs comes under these general target duties.

- There are more specific statutory ICB duties re Adult CHC, in Standing Rules Part 6.
- No equivalent statutory footing for CYPCC.

Section 3(1) of the 2006 Act:

(1) An integrated care board must arrange for the provision of the following to such extent as it considers necessary to meet the reasonable requirements of the people for whom it has responsibility—...

(b) other accommodation for the purpose of any service provided under this Act,

(c) medical services other than primary medical services

(i) such other services or facilities for the prevention of illness, the care of persons suffering from illness and the after-care of persons who have suffered from illness as the board considers are appropriate as part of the health service, and

(j) such other services or facilities as are required for the diagnosis and treatment of illness.

(s275, Interpretation: “illness” includes any disorder or disability of the mind and any injury or disability requiring medical or dental treatment or nursing,)

Eligibility threshold for CYPCC?

- No statute law definition for the legal limits of what children’s social services can provide.
- Care Act 2014 gives statute law definition for adults
- In the absence of specific statute law, public bodies follow relevant case law and national guidance.
- What funding duties follow from CYPCC eligibility is also unclear, given the NF sets an expectation of shared funding:
 - “16. Unless there is a good reason for this not to happen, continuing care should be part of a wider package of care, agreed and delivered by collaboration between health, education and social care.
- With no guidance on how funding should be split, there is significant local variation.

Framework guidance on referral threshold?

- No clear guidance in the CYPCC Framework on the threshold for a referral to be accepted by an ICB, to progress to CYPCC assessment.
- The closest it gets:
 - “55. The continuing care process begins when there is recognition that a child or young person may have needs that require additional health services.”
 - “63. A decision on whether or not a child should proceed to a formal assessment has to be made quickly, and must be robust, fully documented and where necessary, agreed with the responsible executive in the CCG”
- i.e. the Framework here lists qualitative factors of the decision (quick, robust, fully documented), but not the criteria to be used in making the decision.
- In the absence of explicit criteria, it is difficult to see how the decision could be robust.

Framework guidance on eligibility threshold?

- “26. In line with the Haringey judgement (see Annex C), there are clear limits to what care should be funded by the local authority, which should not be a substitute for additional NHS care for children. In this case, the High Court determined that the duty under section 17 of the Children Act 1989 did not extent to meeting essential medical needs”
 - The threshold for eligibility for CYPCC is the upper limit of what a local authority can legally fund.
- “144. ... assessors should consider how different but inter-related needs across more than one domain can complicate the child or young person’s overall care needs and result in sufficient complexity, intensity or risk to demonstrate continuing care needs.”
 - The factors of complexity, intensity and risk are effectively key considerations from the Haringey judgement.
- “148. A child is likely to have continuing care needs if assessed as having a severe or priority level of need in at least one domain of care, or a high level of need in three domains of care.”
 - Is this the same as:
 - At least 1 x Severe = Eligible
 - At least 1 x Priority = Eligible
 - 3 or more High = Eligible
- This is NOT the same as ‘No Severe, no Priority, and less than 3 Highs = Cannot be CYPCC eligible’

No Severe, no Priority, less than 3 Highs = cannot be eligible?

- The phrasing is indicative (“A child is likely”) rather than definitive or proscriptive.
- Even clearer in the parallel paragraph in the guidance notes to the CYPCC DST:
- “19. As a rule of thumb, a child is likely to have continuing care needs if assessed as having a severe or priority level of need in at least one domain of care, or a high level of need in at least three domains of care. “
- There is no legal basis for moving from “likely” and “rule of thumb” to ‘less than 3 Highs is never eligible’.
- There is no basis in the CYPCC Framework for a pre-assessment that rules a child out from full CYPCC assessment on the grounds that they are unlikely to score a Severe, a Priority, or 3 or more Highs.
- There is no basis in the CYPCC Framework for determining eligibility based solely on the scores in the DST.
- Remember the Law Commission summary: “...the Continuing Care Framework makes clear that this is not a firm rule, and that assessors, when presenting recommendations to the decision-making forum, should “consider the level of need identified in all care domains in order to gain the overall picture.”

Case law: Haringey case 2005

<https://www.bailii.org/ew/cases/EWHC/Admin/2005/2235.html>

- Summarised in Annex C of the CYPCC Framework
- The case concerned funding responsibilities for a care package for D, a 3-yr old with a tracheostomy.
- “6. The management and safety of her tracheostomy was and remains D’s key care need.”
- Justice Ouseley drew out as key factors:
 - The nature and purpose of care: “65. ... It is spoken of as respite care for the mother... But its nature and purpose is to provide medical care for D”
 - The gravity of consequences of a failure in care: “this is care... to avoid very significant risks of a life threatening nature”
 - The duration of the care need: “required her carer always to be present lest something had to be dealt with rapidly”

Case law: Haringey takes us to Coughlan

- Is the Coughlan case relevant? It's a case about an adult, not a child.
- It is relevant.
 - In the Haringey case Justice Ouseley discusses the Coughlan case.
 - He considered that the Coughlan criteria, used as the threshold for adult Continuing Healthcare, applied equally to children.
- “53. It was accepted by all parties to this case that... there was nonetheless a divide which had to be respected between health provision and social care provision. The distinction was relevant to an understanding of the true scope of the Children Act provisions. In this context all parties found assistance in the discussion in *R v North and East Devon Health Authority ex p Coughlan* [2001] QB 213, decided in 1999.”
- “61. I accept, first, that there is a broad distinction to be drawn between health and social care provision... The discussion in Coughlan is helpful as to the indicators relevant here:... Children Act nursing care provision is only that which properly falls outside scope of the NHS.”
- “62. The scale and type of nursing care is particularly important as is the question of whether its provision is incidental or ancillary to the provision of some other service which the social services authority is lawfully providing, and whether it is of a nature which such authority can be expected to provide.”

Case law: Coughlan criteria

<https://www.bailii.org/ew/cases/EWCA/Civ/1999/1871.html>

“CONCLUSIONS

a) “...The provisions of the Health Act and the Care Act do not, therefore, make it necessarily unlawful for the Health Authority to decide to transfer responsibility for the general nursing care of Miss Coughlan to the local authority’s social services. Whether it was unlawful depends, generally, on whether the nursing services are merely

- i. incidental or ancillary to the provision of the accommodation which a local authority is under a duty to provide and
- ii. of a nature which it can be expected that an authority whose primary responsibility is to provide social services can be expected to provide.

Miss Coughlan needed services of a wholly different category.”

- The Care Act 2014 s22 places the above threshold into statute law for adults.
- Remember the Law Commission summary: “14.21 ...when dealing with children, local authorities and NHS providers are left to consult the case law which, in relation to adults, section 22 codified into statute.”

Case law: EHCPs and LA limits – *East Sussex CC v KS 2017*

<https://knyvet.bailii.org/uk/cases/UKUT/AAC/2017/273.html>

- East Sussex had agreed to pay the education fees for a residential school, as part of an EHCP. The relevant CCG refused funding for the ‘clinical fees’.
- Parents challenged the EHCP, wanting East Sussex to pay the clinical fees.
- The Upper Tribunal agreed with ESCC that the LA had no duty to fund the clinical fees.
- Even though the medical care was needed for the child to engage in education, this did not make the medical care an education need.
 - “65... The Haringey case... illustrates how the scope of other powers, in that case those under the Children Act, should not be expanded so as to exonerate the institutions of the National Health Service from discharging the functions with which they are tasked.”
 - “91 ...It [the LA] is under no duty nor has any power to pay for health care provision.”

Case law: R (JP) v NHS Croydon CCG (2020)

<https://www.bailii.org/ew/cases/EWHC/Admin/2020/1470.html>

- JP was a child with a brain tumour and range of health needs. He required a tracheostomy and overnight ventilation.
- He was initially found eligible for CYPCC and provided a care package including waking night care.
- Croyden CCG re-assessed and decided JP was no longer eligible for CYPCC. Parents brought Judicial Review.
- The judge agreed with parents, and criticised the CCG.
- Mostyn J did not interpret the Framework as stating ‘No Severe, No Priority, and less than 3 Highs = Cannot be eligible’:
 - “11. If a child scores one severe mark or three high marks he or she will be designated as “eligible” for continuing care. But such a designation does not answer the question of how much continuing care. Conversely, a failure to score one severe mark or three high marks does not shut out a child from all care, continuing or otherwise.”
 - NB: Mostyn J did not directly rule on whether Croydon CCG had misapplied the CYPCC framework in its decision that with 1x High JP was not eligible for continuing care, as he had already determined that the CCG’s decision be set aside due to the CCG’s “hopelessly flawed” decision-making process.
- Mostyn J rejected the “adventurous” argument from the CCG that section 1 of the Localism Act 2011, a general power of competence for Local Authorities to do anything that individuals generally may do, gives Local Authorities the power to provide medical care.

Summary: thresholds for referral and eligibility

~~Decision to progress to CYPCC assessment:~~

- ~~• Unlikely to score a Severe, Priority, or 3 Highs = No need to do CYPCC assessment~~

~~CYPCC eligibility decision:~~

- ~~• No Severe, no Priority, and less than 3 Highs = Cannot be eligible.~~

Decision to progress to CYPCC assessment should be based on:

- When there is recognition that a child or young person may have needs that require additional health services (CYPCC NF para 55)

CYPCC eligibility decision should be based on:

- If there are health needs that cannot be met by existing universal or specialist NHS services (CYPCC NF Introduction, para 2)
- Whether the care is above the limits to what care should be funded by the local authority (CYPCC NF para 26)
- Sufficient complexity, intensity or risk to demonstrate continuing care needs (CYPCC NF para 144)
- The nature and purpose of care (Haringey)
- The gravity of the consequences of a failure in care (Haringey)
- The duration of the care need (Haringey)
- Whether the health care is incidental or ancillary to the provision of some other service which the social services authority is lawfully providing (Coughlan, endorsed in Haringey)
- Whether the care is of a nature which a local authority can be expected to provide (Coughlan, endorsed in Haringey)

New case law?

RBKC v NWL ICB (2025), 'the BL case' (1)

<https://www.bailii.org/ew/cases/EWHC/Admin/2025/889.html>

- BL is a child with diagnoses of anxiety, ASD, ADHD. She has episodes of self-harm, suicidal ideation, emotional dysregulation, and disordered eating.
- BL was admitted to hospital from June 2023 – September 2023, with her mother unable to return to caring for her, and a placement required.
- In September 2023, BL was placed by RBKC at a specialist children's home, with 2:1 supervision and waking night care due to concerns about her mental health needs.
- RBKC requested NWL ICB fund 33.3% of the placement, with 66.6% funded by RBKC. NWL ICB declined to fund any contribution to BL's care.
- RBKC sought judicial review of NWL ICB's decision not to contribute to the placement cost.
- Paragraph 50 of the judgement sets out RBKC's 7 grounds of challenge, including that NWL ICB's definition of 'health needs' was irrational and/or unreasonable, that NWL ICB's approach was contradictory to that taken in parallel cases, and that NWL ICB had disregarded Adult CHC guidance.
- The High Court rejected all grounds of RBKC's claim.
- The judge determined that the ICB decision was not unreasonable or irrational, and that the ICB had discretion to decide whether the care provided to BL was appropriate to be funded as part of the health service.

New case law?

RBKC v NWL ICB (2025), 'the BL case' (2)

- Is this a problem for CYPCC cases?
- Strictly – no.
- NWL ICB appear to have kept the decision making for BL outside of the CYPCC Framework; and no grounds of challenge by RBKC were linked to the CYPCC Framework.
- Does highlight the risk of LAs agreeing with ICBs to develop 'Complex Care' or 'Shared Care' funding streams, for joint funding for children deemed to not meet the eligibility criteria for CYPCC, but who have unmet health needs.
- ICBs' belief that 'Complex Care' streams are needed is usually due to a narrow scores-based eligibility threshold for CYPCC.
- If CYPCC eligibility is recognised as being based on LA legal limits, there is not a clear basis for extra-CYPCC funding streams.
- Note also that under Ground 4, RBKC advanced the argument that NWL ICB had taken a contradictory approach in BL's case when compared to parallel cases.
- In response to this the Judge stated that each case is based on its own facts, and that it would be difficult to draw comparison between cases.
- This appears in turn to act as a limit to ICBs claiming that any parallels can be drawn between another case and the BL case.

Update re Legal Review

- Legal review was one of the 3 project goals agreed by SESLIP (along with setting up a network, and gathering data)
- ***Proposal 2: commission legal review of CYPCC Framework***
- *Recommend SE ADCS commission legal review of CYPCC Framework, either through existing resources or external counsel's opinion.*
- *Instructions to counsel to include current concerns, for further exploration.*
- *Goal to use this:*
 - 1) to set out regional position and guidance on CYPCC*
 - 2) to lobby for a revised Framework, with full input to development from LAs and ADCS.*
- **Update:**
- Hampshire Legal services will support with constructing a brief and sourcing a barrister to undertake the review
- 1st meeting booked with HCC, Liam and Sue for 13th March.

Breakout group exercise

- Each of the 4 tables has a different element of the CYPCC process:
 - Referral
 - Assessment
 - Decision making – panels, funding splits, commissioning
 - Ongoing – care management, care reviews and reassessments
- At each table please discuss and write down your views for that element:
 - What works well
 - What works less well
 - Proposals for change:
 - In the short term (6 -12 months)
 - In the long term (12+ months)
 - At local level, at South East region level, at national level?
- 10 minutes at each table, then rotate on to the next one.

Activity, discussion and feedback

Liam Doherty, Continuing Healthcare Specialist, RBWM



Legal activity, discussion and feedback

Breakout group exercise

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10 minutes at each table, then rotate on to the next one.



Final remarks, evaluation and close

Liam Doherty, Continuing Healthcare Specialist, RBWM
Sue Kocaman, SESLIP Consultant



CCC Network Meeting - 6th March
2026



**Thank you and have a
safe journey home**

