Continuing Healthcare workshop

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Material adapted and expanded from NHSE CHC Train the Trainer

Aims of the workshop

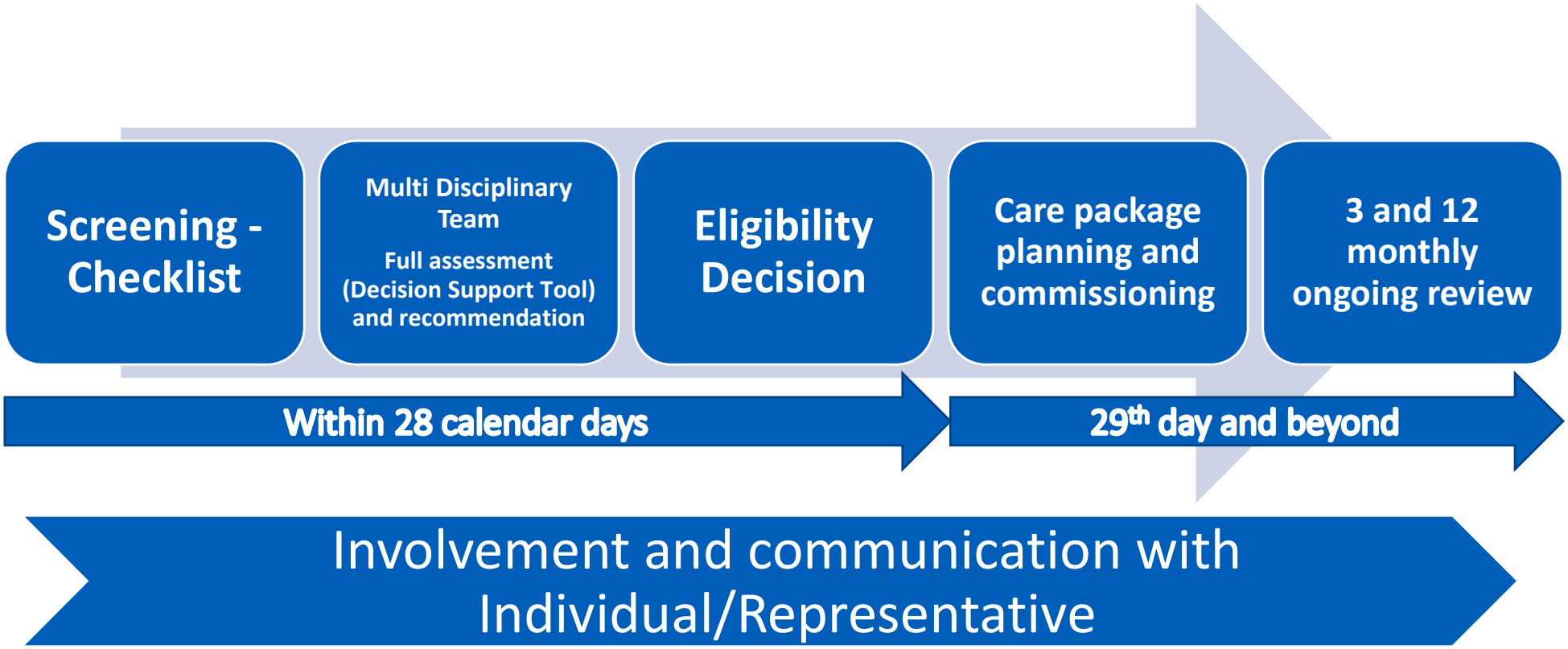
By the end of the training, participants should be able to:

- Construct Checklists appropriately
- Gather evidence and construct an evidence-based Decision Support Tool (DST);
- Understand what constitutes a Primary Health Need (PHN);
- Recognise some key CHC myths and misunderstandings
- Use the four key characteristics to explain an eligibility recommendation.

The Basics – Who and What

- What is NHS Continuing Healthcare?
- Who is eligible for NHS Continuing Healthcare?
- What are the Core Values?
- What is NHS Funded Nursing Care (FNC)?
- Who provides ongoing care for individuals who do not have a Primary Health Need (PHN)?
- What about children?

NHS CHC Overview



Is there a clear threshold?

- National variation
- NHSE measure the rate per 50k of population
- Sizeable variation between areas: Q2 2022/23

- England – 53.31 per 50k
- Lowest – West Berkshire ICB - 13.82 per 50k
- Highest – Staffordshire and Stoke-on-Trent ICB - 140.04 per 50k

- NHSE London region - 37.86 per 50k
- North Central London ICB: 35.43 per 50k

Consent, Capacity, Advocacy and Advice

- Seek consent, provide the Patient Information leaflet
- Progress through Capacity assessment and Best Interests decision if person is unable to consent
- The person/family can choose to have an advocate/other support through the CHC process.
- Beacon
  Funded by NHS England to provide free consultations of up to 90 minutes
  Separate casework service, for a fee.
  www.beaconchc.co.uk
- Check with your local advocacy service

Before you start the Checklist…

- Fail to prepare… prepare to fail…
- Risk of social care records failing to record health needs or recording in overly-positive way
- Does the care provider's paperwork reflect the person's needs?
  - Care plans
  - Risk assessments
  - Positive Behaviour Support plans
  - Daily records
  - Incident recording
- Are further health assessments/reports required?
  - Medical referrals and medication review
  - Psychology/behaviour specialist
  - Physio, OT, SALT, dietician, etc
- Get everything in order before starting work on the Checklist.

Screening and Checklist Tool (1)

- For each domain:
  - Brief statement of need
  - Reference to supporting evidence
  - Select the appropriate level (A, B or C)

- Rationale:
  - Enough detail to explain decision

- Next Steps:
  - Copy to the CCG
  - Copy to individual and/or their representative
  - Information re: process to challenge the decision

Screening and Checklist Tool (2)

A full DST for CHC is required if there are:

2 or more domains selected in column A

or

1 domain selected in column A and 4 in B

or

5 or more domains selected in column B

or

1 asterisk domain selected in column A

Name of individual		**Date of completion**	
	C	B	A
Breathing*	Normal breathing, no issues with shortness of breath. **OR** Shortness of breath or a condition, which may require the use of inhalers or a nebuliser and has no impact on daily living activities. **OR** Episodes of breathlessness that readily respond to management and have no impact on daily living activities.	Shortness of breath or a condition, which may require the use of inhalers or a nebuliser and limit some daily living activities. **OR** Episodes of breathlessness that do not consistently respond to management and limit some daily activities. **OR** Requires any of the following: - low level oxygen therapy (24%); - room air ventilators via a facial or nasal mask; - other therapeutic appliances to maintain airflow where individual can still spontaneously breathe e.g. CPAP (Continuous Positive Airways Pressure) to manage obstructive apnoea during sleep.	Is able to breathe independently through a tracheotomy that they can manage themselves, or with the support of carers or care workers. **OR** Breathlessness due to a condition which is not responding to therapeutic treatment and limits all daily living activities. **OR** A condition that requires management by a non-invasive device to both stimulate and maintain breathing (non-invasive positive airway pressure, or non-invasive ventilation)
Brief description of need and source of evidence to support the chosen level	Mrs X is independent with breathing. No recent chest infections, No diagnosed conditions or prescribed treatments. See GP records, Nursing Home A care plan.		Write A, B or C below: C

Getting ready for the DST

- What happens after the Checklist has been completed?
- Screening process by CHC team.
- Evidence gathering by CHC team
- Invites to MDT/attendees by CHC team
- … but if you want something done properly…

Domain scoring

- You are looking for the best fit, not an exact match.

25. “The descriptors in the DST are examples of the types of need that may be present. They should be carefully considered but may not always accurately describe every individual’s circumstances… If there is difficulty in placing the individual's needs in one or other of the levels, the MDT should use professional judgement based on consideration of all the evidence to decide the most appropriate level.

- Moving to the higher domain if the needs are inbetween.

… If, after considering all the relevant evidence, it proves difficult to decide or agree on the level, the MDT should choose the higher of the levels under consideration and record the evidence in relation to both the decision and any significant differences of opinion. The MDT should not record an individual as having needs between levels.”

Key domains for Learning Disability CHC: Communication

- Speech & Language Therapy report?
- Focus on ‘basic needs’ – hunger, thirst, toilet, pain.
- Some people may have verbal abilities (‘chatty’) but be unable to communicate any needs.
- Person’s ability to *initiate* communication? Not whether they can respond to a carer asking about a needs.
- The importance of being specific – quote examples of words or phrases the person uses.
- What assistance do they need to help them communicate?
- Does ability to communicate fluctuate? Details of when and why? What is the risk/impact when communication is worse?
- Communication implies intentional. If it is observable that the person is distressed, but it is not known what specific needs this relates to, this is not communication.
- Scoring should be based on worst-case not best-case.

Psychological and Emotional

- Are there any formal psychiatric diagnoses?
- Describe the needs/episodes. Frequency? Duration? Do care records show this?
- Quantify the impact:
  - How are other CHC domains affected?
  - Sleepless, weight loss, quality of life, physical harm to self or others?
  - What is the worst that has happened or may happen?
- What are the interventions?
  - Medication, regular and/or PRN?
  - Psychological or behavioural?
  - Frequency of professional monitoring required?
  - Are the interventions effective?
- Note the key escalations in risk:
  - Low – there is an impact
  - Moderate – not readily responding to reassurance
  - High – severe impact on wellbeing
- NB: do not confuse non-engagement with care planning/support/activities due to level of cognitive impairment with non-engagement due to mental health needs.

Cognition

- Has Cognitive ability been formally assessed? WAIS? IQ?
- Disorientation in time, place, person? Always, mostly, occasionally?
- Evidence of short and long term memory?
- Basic needs – pain, ill, hungry, thirsty, toilet or pad change?
- Can the person meet any needs for themself? Do they refuse/resist necessary care and treatment?
- Specific examples of what choices the person can make – clothes, food, TV show, activities?
- Do they understand what choices are safe/appropriate to their needs?
- What are the risks if their needs weren't anticipated and met?
- Basic risk awareness – heat sources or other kitchen hazards, bath/shower temperature, eating raw food/non-food, exploitation
- Can the person follow any instructions/prompts, and if so, what?
- Is DOLS required? What specific restrictions are needed to keep the person safe?
- NB – do not be misled. This domain is ultimately about risk. Some individuals may have a number of competencies but be unaware of basic risks.

Behaviour (1) – behaviours and triggers

- Range of behaviours:
- Harm or disturbance towards others? Physical? Verbal? Sexual?
- Active harm towards self? Head banging, hitting/kicking furniture and walls, absconding?
- Passive harm to self - refusing/resisting necessary care and treatment?
- Damage to property?
- Have injuries have been caused to self or others? Specific details.
- Dates and details of most serious incidents?
- Avoid an unwarranted focus on short time frame.
  - ‘historic’ … meaning 2 months ago!
- Potential level of injury to self or others?
- Even if incidents are rare, what are the risks that are still being managed?
  - The NHS don’t discharge from Broadmoor because the incident was more than 6 weeks ago.
- Are there known triggers? Or is behaviour unpredictable?

Behaviour (2) – the interventions

- What proactive and preventative strategies are in place – behaviour support plans and risk assessments?
- Risk that nurse assessors focus on the number of incidents and the reactive strategies, not the hours of preventative support.
- What professional input is needed, and how much – psychiatry, CPN, psychology, behaviour specialist?
- Emergency interventions – police, ambulance, A&E admissions, Mental Health Act Assessments?
- What level of skill do staff need? e.g. SCIP or other Positive Behaviour Support training?
- Do plans include physical intervention (even if it hasn't been needed)?
- Are 1:1 or 2:1 (or higher) levels of support required? When and why?
- Are there any regular or PRN medications to help manage behaviours?
- NB – note that for Severe, interventions outside the planned range is not a necessary feature. The phrase is "skilled response that ***might be*** [emphasis added] outside the range of planned interventions".
- How will you analyse and present the evidence for DST? Tables, charts, X incidents in Y months, etc.

Inter-related Domains

- Focus on the precise wording of the descriptors in the Decision Support Tool to choose the appropriate level of need
- In the **Behaviour domain**: pay particular attention to identifying the extent of the risk to self, others or property; the speed of response needed; and the amount of skill needed to manage the individual's behaviour.
- In the **Cognition domain**, consider the individual's orientation, ability to make choices, and the individual's ability to understand basic risks. Keep in mind that some individuals may have a number of competences but still be unaware of basic risks.
- In the **Psychological & Emotional Needs domain**, focus on the extent of the impact of any needs on the individual's health and/or well-being. There is a lot of undiagnosed depression in older people, and people with learning disabilities. If an individual is prescribed something like Citalopram, consider whether an assessment of Low Need is more appropriate than No Needs, even if the individual is not showing any signs of depression. Don't confuse the normal everyday ups and downs of how human beings experience day-to-day life with "mood swings".

Making the recommendation

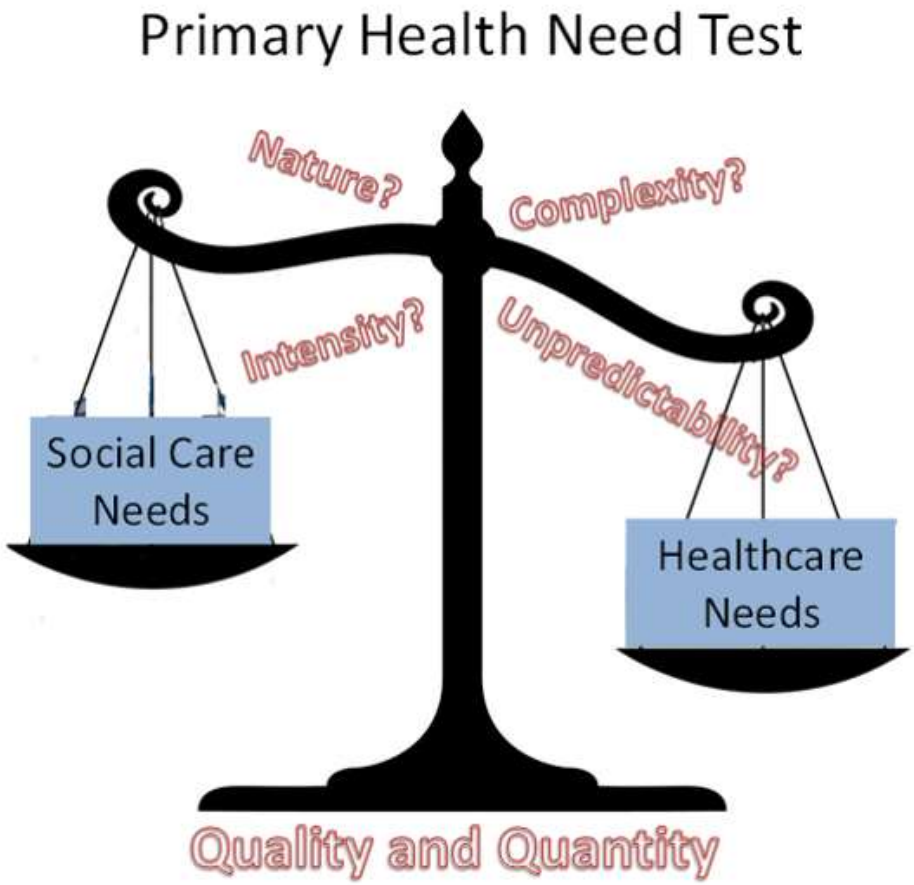
NHS Continuing Healthcare Decision Support Tool

Decision Support Tool for NHS Continuing Healthcare
Section 2 – Care Domains

Please refer to the user notes

Care Domain	P	S	H	M	L	N
Breathing				X		
Nutrition- Food and Drink				X		
Continence					X	
Skin (including tissue viability)				X		
Mobility				X		
Communication				X		
Psychological and Emotional Needs			X			
Cognition		X				
Behaviour			SW	CHC		
Drug Therapies and Medication			SW	CHC		
Altered States of Consciousness			X			
Other significant care needs						X
Totals CHC/SW	0	1	2/4	7/5	1	0

Assessed Levels of Need



Primary Health Need – case law and Care Act

- 1999 Coughlan judgement.
- Pamela Coughlan's needs – spinal injury following RTA. Tetraplegic, wheelchair dependent, no cognitive impairment or challenging behaviour, dependent on others for all personal care and ADL, autonomic dysreflexia.
- Court of appeal judgement. LA can only fund care if nursing services are:
  - no more than incidental or ancillary to provision of accommodation
  - not of a nature beyond which an LA can provide
- Threshold placed in legislation in Care Act 2014:
- "22 (1)A local authority may not meet needs under sections 18 to 20 by providing or arranging for the provision of a service or facility that is required to be provided under the National Health Service Act 2006 unless—

  (a) doing so would be merely incidental or ancillary to doing something else to meet needs under those sections, and

  (b) the service or facility in question would be of a nature that the local authority could be expected to provide."

Primary Health Need - Framework

- The concept of ‘primary health need’ is intended to explain the limit in the Care Act on what local authorities can provide.
- **Para 56 in the 2022 National Framework:** “An individual has a primary health need if, having taken account of all their needs (following completion of the Decision Support Tool), it can be said that the main aspects or majority part of the care they require is focused on addressing and/or preventing health needs.”
- **Para 59 in the 2022 National Framework:**
- “….the ‘primary health need’ test should be applied, so that a decision of ineligibility for NHS CHC is only possible where, taken as a whole, the nursing or other health services required by the individual:
  a) are no more than incidental or ancillary to the provision of accommodation…; and
  b) are not of a nature beyond which a LA, whose primary responsibility is to provide social services, could be expected to provide.
- Four key characteristics are identified to help determine whether the ‘quality’ or ‘quantity’ of care is more than the limits of a local authority’s responsibilities:
  - Nature
  - Intensity
  - Complexity
  - Unpredictability

Primary Health Need Test – DST User Notes

- DST user note 31:

"A clear recommendation (and decision) of eligibility for NHS Continuing Healthcare would be expected in each of the following cases:

  - A level of **priority** needs in any one of the four domains that carry this level.
  - A total of two or more incidences of identified **severe** needs across all care domains.

- DST user note 32:

"Where there is either

  - A severe level need combined with needs in a number of other domains or
  - A number of domains with high and/or moderate needs

This may also… indicate a primary health need and therefore careful consideration needs to be given to the eligibility decision and clear reasons recorded if the decision is that the person does not have a primary health need."

The 4 Key Characteristics - Nature

This is about the characteristics of both the individual's needs and interventions required to meet those needs.

Consider the following:

- How does the practitioner describe the needs (rather than the medical condition leading to them)?
- What adjectives does the practitioner use?
- What is the impact of needs on the overall health and well-being?
- What types of interactions are required to meet the need?
- What would happen if the needs were not met in a timely way?
- Is there particular knowledge/skill/training required to anticipate and address the need?
- Is the individual's condition deteriorating/improving?

The 4 Key Characteristics - Intensity

This characteristic is about the quantity, severity and continuity of needs.

Consider the following:

- How severe is the need?
- How often is each intervention required ?
- How long does each intervention require?
- How many carers/care workers are required at any one time to meet the needs?
- Does the care relate to needs over several domains?

The 4 Key Characteristics - Complexity

Is about the level or skill/knowledge required to address the individual's care need or range of needs and the interface between 2 or more needs.

Consider the following:

- How difficult is it to manage the individual's needs?
- Are the needs interrelated?
- Do needs interact to make the needs more difficult to address?
- How problematic is it to alleviate the needs and the symptoms?
- How much knowledge is required to address the needs?
- How much skill is required to address the needs?
- How does the individual's response to their condition make it more difficult to provide the appropriate support?

The 4 Key Characteristics - Unpredictability

This is about the degree to which care needs fluctuate and thereby create challenges in managing them.

It should be noted that the identification of unpredictable needs does not in itself make the needs predictable (i.e. predictably unpredictable). They should therefore be considered as part of the key indicator.

Consider the following:

- Is the individual or those who support him/her able to anticipate when the need(s) might arise?
- Does the level of need often change?
- What level of monitoring or review is required?
- Does the level of support required need to change at short notice?
- Is the individual's condition stable or unstable?
- What happens if the needs are not addressed when they arise?
- How significant are the consequences?
- To what extent is professional skill/knowledge required to respond spontaneously and appropriately?

DST case study - Charles

- Please read the case study for Charles
- For the 4 key LD domains of Communication, P&E, Cognition and Behaviour:
  - What evidence or further information do you want?
  - What level of need would you give?
- What is your Recommendation in relation to each of the 4 key characteristics?

CHC Myths – Top 10!

CHC Myths (1) - Double Scoring

- There is a common misconception that there is a “no double-scoring rule” - this is not the case.

“**PG 30 Can associated needs be recorded in more than one domain on the DST?**
30.1 Yes, needs associated with a single condition can be reflected in more than one domain. The belief that there is a ‘no double-scoring rule’ is a common misconception.”

Example:

- Cognition: an individual with severe cognitive impairment may also exhibit challenging behaviours associated with this impairment. This challenging behaviour should also be recorded and scored in the Behaviour domain, to give an accurate picture of the needs of the individual.

CHC Myths (2) – Well-Managed Needs part 1

- It's unlikely that the nurse assessor will say 'these needs don't count because they're well-managed'. Watch out for this being the underlying meaning:
  - 'Restraint hasn't been needed'
  - 'There aren't many incidents'
  - 'The provider can meet the needs'
  - 'No unplanned interventions'
  - 'No skill required beyond what is expected in such a specialist establishment'
  - 'All needs are optimally met and therefore no elements that should be met by CHC funding'

- **NF Para 162:** "The decision-making rationale should not marginalise a need just because it is successfully managed: well-managed needs are still needs…"
- **NF Para 163:** "An example… where an individual's support plan includes support/interventions to manage challenging behaviour, which is successful in that there are no recorded incidents which indicate a risk to themselves, others or property…"

CHC Myths (3) – Well-Managed Needs part 2

- The MDT is explicitly directed to consider what would happen if the behaviour support was not in place:
- **DST User Note 31:** "For example, where psychological or similar interventions are successfully addressing behavioural issues, consideration should be given as to the present-day need if that support were withdrawn or no longer available and this should be reflected in the Behaviour domain."

- Two points of caution:

1 – where things were worse when the person was in the wrong setting.

- **NF Para 165:** "Sometimes needs may appear to be exacerbated because the individual is currently in an inappropriate environment rather than because they require a particular type or level of support…" – e.g. how people can present in acute hospital.

2 – distinction between basic care to meet physical needs (medication, personal care) versus ongoing skilled behaviour support.

- **NF Para 166:** "It is not intended that this principle should be applied in such a way that well controlled conditions should be recorded as if medication or other routine care or support was not present". Cf Practice Guidance note 23

CHC Myths (4)

- ***The setting of care matters – 'they're not eligible because they're only in a care home/ they're in their own home/ care is routine/ the provider should be able to manage these needs.***
- 66. …the reasons given for a decision on eligibility should not be based on the: individual's diagnosis; setting of care; ability of the care provider to manage care; use (or not) of NHS-employed staff to provide care; need for/presence of 'specialist staff ' in care delivery; the fact that a need is well-managed; the existence of other NHS-funded care; or any other input-related (rather than needs-related) rationale.

- ***'We can only consider evidence in the 6 weeks/8 weeks/ 12 weeks before the DST'***
- The Framework doesn't directly specify what timeframe to look at.
- "21.1 Assessment in this context is essentially the process of gathering relevant, accurate and up-to-date information about an individual's health and social care needs, and applying professional judgement to decide what this information signifies in relation to those needs."
- Therefore it is a matter of multidisciplinary professional judgement to decide what timeframe matters

CHC Myths (5)

- ***To be eligible, the person has to meet all four characteristics of Nature, Intensity, Complexity and Unpredictability.***
- "Each of these characteristics may, **alone or in combination**, demonstrate a primary health need". (NF 2022, para 61).
- "whilst the recommendation should make reference to all four characteristics of nature, intensity, complexity and unpredictability, any one of these could on their own or in combination with others be sufficient to indicate a primary health need." (DST note 35)

- ***I should only sign the DST if there's an agreed recommendation.***
- You should be signing the *completed* DST to confirm that it is an accurate record of the person's needs and the discussion that has taken place. (You would not sign a blank cheque).
- "If an MDT is unable to reach agreement on the recommendation this should be clearly recorded." (NF 2022, para 171).
- So provided the DST records the disagreements on scoring and recommendation, go ahead and sign.

CHC Myths (6)

- ***The DST has to be completed within 28 days; sometimes 'we have to make a decision today based on the evidence we have'***
- "the overall assessment and eligibility decision-making process should, in most cases, not exceed 28 calendar days" (NF 2022, para 182)
- BUT "When there are valid and unavoidable reasons for the process taking longer, timescales should be clearly communicated… "An example of this might occur where additional work is required to ensure that the DST and supporting evidence submitted to the ICB accurately reflect the full extent of an individual's needs." (NF 2022, para 184)

- ***Only the nurse assessor and social worker count as the MDT and make the recommendation***
- "as a minimum requirement an MDT can comprise two professionals from different healthcare professions, the MDT should usually include both health and social care professionals" (NF 2022, para 141).
- "The MDT… works collectively to make a professional judgement about eligibility" (NF 2022, para 143).

CHC Myths and confusions (7)

- ***Oral evidence doesn't count***, or ***Oral evidence needs to be supported by written evidence***
- Evidence "is to ensure that there is an accurate picture of the individual's needs, not to convince a court of law that those providing the evidence are telling the truth. (NF 2022, Practice Guidance 31)
- "Oral evidence from carers or relevant professionals should be taken into account where it is pertinent to establishing the levels of need". (NF 2022, Practice Guidance 31)

- ***Family must have LPA or Deputyship to take part in the MDT or to appeal***
- The Framework doesn't explicitly cover this at a local/ICB level
- But it does cover it in relation to IRP: "NHS England may receive requests for an independent review [from a] representative who does not have lasting power of attorney (LPA) or deputy status. Where the individual has capacity, the ICB should ask them whether this request is in accordance with their instructions, and where they do not have capacity, a 'best interests' process should be used to consider whether to proceed with the request for an independent review or other challenge." (NF 2022, para 225)
- Therefore expect this at an ICB level to also be a best interests decision.

CHC Myths and confusions (8)

Key principle – please show me where it says that in the Framework?

Fast Track

- Referral completed by a clinician (Doctor or nurse) when the individual has a rapidly deteriorating condition and may be entering a terminal phase.
- No further evidence of eligibility is needed beyond the judgement of the clinician that the person meets the criteria.

Funded Nursing Care

- Person is:
  - Determined as not eligible for CHC
  - Assessed as needing care from a registered nurse.
  - Living in a care home registered to provide nursing care.
- From 01/04/2022, weekly rate of £209.19
- Reviewed within 3 months initially and then yearly.

In summary…

- Involve your CHC lead
- The importance of preparation
  - The right evidence is available
  - The evidence is provided to the CHC service
  - The right professionals are invited and attending
- Have confidence in your professional opinion
- Consider if the CHC Framework is being followed, and state your concern if needed
- Keep your own notes of the MDT meeting

Questions?

NHS Continuing Healthcare – Useful Resources

NHSFuture Platform: Continuing Healthcare Workforce Development: FutureNHS Continuing Healthcare Workforce Development

(where you can find virtual assessment videos that you can download)

Films

- Independent review panel - Private video on Vimeo Password BPNHS2017
- NHS England public information film about CHC- NHS England Continuing Healthcare (CHC) film - YouTube

Websites

- **NHS England NHS CHC e-learning training toolkit:**
  - NHS staff - www.e-lfh.org.uk
  - LA staff - http://nhscontinuinghealthcare.e-lfh.org.uk
  - This website also includes lots else including the important material to be found if you type in improving-mouth-care: a vital ingredient in individuals' health
- **Department of Health National Framework** resources - https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care
- NHS Choices – to establish where a GP is registered www.nhs.uk/Service-Search/GP/LocationSearch/4
- **Beacon** – advice service for the public about NHS CHC funded by NHS England (alongside Beacon's paid advocacy service) www.beaconchc.co.uk
- **Alzheimer's Society**: booklet about evaluating the emotional and psychological needs of people in the later stages of dementia https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2565