Contact Officer:
Maureen Potter 01352 702322
maureen.potter@flintshire.gov.uk

To: Cllr Hilary McGuill (Chair)

Councillors: Mike Allport, Paul Cunningham, Jean Davies, Rob Davies, Andy Dunbobbin, Carol Ellis, Gladys Healey, Cindy Hinds, Mike Lowe, Dave Mackie, Ian Smith, Martin White, David Williams and David Wisinger

12 July 2019

Dear Councillor

You are invited to attend a meeting of the Social & Health Care Overview & Scrutiny Committee which will be held at 2.00 pm on Thursday, 18th July, 2019 in the Delyn Committee Room, County Hall, Mold CH7 6NA to consider the following items

AGENDA

1 APOLOGIES

Purpose: To receive any apologies.

2 DECLARATIONS OF INTEREST (INCLUDING WHIPPING DECLARATIONS)

Purpose: To receive any Declarations and advise Members accordingly.

3 MINUTES (Pages 3 - 10)

Purpose: To confirm as a correct record the minutes of the meeting held on 6 June 2019.

4 FORWARD WORK PROGRAMME (SOCIAL & HEALTH CARE) (Pages 11 - 22)

Report of Social and Health Care Overview & Scrutiny Facilitator

Purpose: To consider the Forward Work Programme of the Social & Health Care Overview & Scrutiny Committee and to inform the Committee of progress against actions from previous meetings.

5 INTEGRATED AUTISM SERVICE (Pages 23 - 30)

Report of Chief Officer (Social Services) - Cabinet Member for Social Services

Purpose: To provide members with a progress report of the local implementation of the Integrated Autism Service

6 COMMENTS, COMPLIMENTS AND COMPLAINTS (Pages 31 - 58)

Report of Chief Officer (Social Services) - Cabinet Member for Social Services

Purpose: To report to members the number of complaints received by Social Services during the period 18 – 19 including their broad themes and outcomes and any lessons learned

7 CONTINUING NHS HEALTHCARE (CHC) IN WALES CONSULTATION (Pages 59 - 388)

Report of Chief Officer (Social Services) - Cabinet Member for Social Services

Purpose: To provide Members with information on the Council’s proposed response to the Welsh Government CHC Consultation

8 ROTA VISITS

Purpose: To receive a verbal report from Members of the Committee.

Yours sincerely

Robert Robins
Democratic Services Manager

SOCIAL & HEALTH CARE OVERVIEW & SCRUTINY COMMITTEE
6 JUNE 2019

Minutes of the meeting of the Social & Health Care Overview & Scrutiny Committee of Flintshire County Council held in the Delyn Committee Room, County Hall, Mold on Thursday, 6 June 2019

PRESENT: Councillor Hilary McGuill (Chair)
Councillors: Mike Allport , Jean Davies, Rob Davies Andy Dunbobbin, Gladys Healey, Cindy Hinds, Brian Lloyd, Mike Lowe, Dave Mackie, Ian Smith, Martin White and David Wisinger

SUBSTITUTES: Councillors: Veronica Gay (for Dave Mackie) and David Healey (for Ian Smith)

APOLOGY: Senior Manager, Children and Workforce

CONTRIBUTORS: Councillor Christine Jones, Cabinet Member for Social Services; Chief Officer (Social Services); Senior Manager, Integrated Services, Lead Adults; and Senior Manager, Safeguarding and Commissioning. For minute no. 6: Planning and Development Officers – Social Services

IN ATTENDANCE: Democratic Services Manager and Democratic Services Officer

Prior to the start of the meeting the Chair asked all present to stand in a minute's silence to mark D Day 75 in honour of those men and women who had fought and made sacrifices on 6 June 1944, in France during World War II.

1. APPOINTMENT OF CHAIR

The Democratic Services Manager advised that it had been confirmed at the Annual Meeting of the County Council that the Chair of the Committee should come from the Liberal Democrats Group. As Councillor Hilary McGuill had been appointed to this role by the Group, the Committee was asked to note this.

RESOLVED:

That the committee noted the appointment of Councillor Hilary McGuill be confirmed as the Chair of the Committee.

(From this point, Councillor Hilary McGuill chaired the remainder of the meeting)

2. APPOINTMENT OF VICE-CHAIR

Councillor David Wisinger nominated Councillor Gladys Healey as Vice-Chair of the Committee and this was duly seconded.

Councillor Veronica Gay nominated Councillor Dave Mackie as Vice-Chair of the Committee and this was duly seconded.

On being put to the vote Councillor Gladys Healey was appointed Vice-Chair of the Committee.

Councillor Gladys Healey thanked the Committee for their renewed confidence in her.

RESOLVED:

That Councillor Gladys Healey be appointed Vice-Chair of the Committee.

3. DECLARATIONS OF INTEREST

None.

4. MINUTES

The minutes of the meeting on 28 March 2019 were received.

Matters Arising

Minute number 61: the Chair referred to the closure of the Windmill in Buckley and asked if alternative arrangements had been found for the affected individuals and their families. The Senior Manager, Integrated Services, Lead Adults, explained that two social workers had been appointed to look at the arrangements for the individuals who attended the Windmill and everyone had been found alternative daytime care support and feedback had been positive.

RESOLVED:

That the minutes be approved as a correct record and signed by the Chair.

5. SOCIAL SERVICES ANNUAL REPORT

The Chief Officer (Social Services) introduced a report on the Annual Director's Report for Social Care Services 2018/19. He provided background information and advised that the purpose of the Social Services Annual Report was to set out the improvement journey and evaluate Social Services' performance in providing services to people that promote their wellbeing and support them to achieve their personal outcomes.

The draft Social Service Annual Report 2018/19 was appended to the report and was intended to provide the public, the regulator and wider stakeholders with an honest picture of services in Flintshire and to demonstrate a clear understanding of the strengths and challenges faced. The Chief Officer advised that the report would form an integral part of the Care Inspectorate Wales (CIW) performance evaluation of Flintshire's Social Services. The evaluation also informed the Wales Audit Office's assessment of Flintshire County Council as part of the annual improvement report.

The Chief Officer explained that the Annual Report had been prepared following an in-depth review of current performance by the Social Services Senior Management Team, Service Manager, and Performance Officers. The improvement priorities contained within the report were aligned to the priorities contained within the Portfolio Business Plan, the Council's Improvement Plan, and associated efficiency plans. The Chief Officer reported on the improvement priorities identified for 2019/20 as detailed in the report.

Councillor David Healey thanked the Chief Officer and his team for their work and for a comprehensive report. He commented on the crisis in continuing health care in some areas of the United Kingdom and the risk to provision of care services in the private sector due to lack of funding. He asked if the Authority was also at risk and what support was provided to assist people to remain independent and continue to live in their homes and specifically patients who were discharged from hospital. He suggested that the criteria for eligibility for care at home be looked at to enable more people to receive support from care providers and to have adaptations in their homes. The Chief Officer thanked Councillor Healey for his positive comments and in response to his questions said that the risk to care services provided in the wider sector due to lack of funding was real for the Authority and nationally. He commented on the recent lobbying by the Chief Executive and Members to the Welsh Government to make the case for more funding for key services to local authorities and to state that current funding was unsustainable.

In summary the Chief Officer provided reassurance regarding the provision of social care services in Flintshire. The Senior Manager, Integrated Services, Lead Adults, responded to Councillor Healey's question regarding support to help people maintain their independence and continue to live at home and referred to reablement when people are discharged from hospital, recycling of aids and equipment to assist independence, and disabled facilities grants.

The Chair advised that she had asked that an item on the continuing health care budget be considered at the next meeting of the Committee to be held on 18 July and said that the consultation would be sent to the Committee prior to the meeting for information.

Councillor Martin White spoke on the need for care and support services and the preventative work which could be achieved with adequate funding. He also spoke in support of the excellent care services provided in Flintshire and commented on the high standard of care and facilities experienced by some of his family members.

Councillor David Wisinger asked what support was available for people with mental health problems. The Chief Officer acknowledged the concerns raised by Councillor Wisinger regarding the need for people to seek urgent support outside office hours. He gave an assurance that the Authority was doing all it could to support mental health services and referred to the services and future initiatives which were supported. He said that further discussion could be raised at the North Wales Mental Health Service transformation project. The Senior Manager, Safeguarding and Commissioning. provided further information on the Service and the programme. The Chair asked what links the Authority had with the Samaritans. It was agreed that the Senior Manager, Integrated Services, Lead Adults would make enquiries to determine whether the Authority had any formal links between its mental health services and the Samaritans and whether it provided any funding.

In response to a question raised by Councillor Gladys Healey concerning out of county placements for young people the Chief Officer advised that a new small residential care facility was being developed in the Deeside area and work was in progress with an experienced voluntary organisation. The Chief Officer also referred to the Mockingbird project which provided specialist fostering placements for young people with challenging behaviour. The Chief Officer continued that there were a number of services and initiatives used to support young people collectively. He also referred to the Children and Mental Health Service (CAMHS) and said that although the waiting list for CAMHS had reduced the waiting lists for other services had increased.

Councillor Cindy Hinds commented on the issue of cyber bullying. The Chief Officer said there was an initiative around cyberbullying within the Regional Safeguarding Children’s Board and commented on the work being undertaken with the Health Board and other agencies and local authorities to combat abuse through social media. The Senior Manager, Safeguarding and Commissioning. commented on safeguarding and the need to be aware of early signs and spoke of the further work to be undertaken in this area to protect both young and vulnerable people.

RESOLVED:

That the draft Social Services Annual Report be approved.

6. MARLEYFIELD HOUSE EXPANSION PROGRESS UPDATE

The Chief Officer (Social Services) introduced a report to update on progress in relation to the extension to Marleyfield House Care Home, Buckley. He introduced Michael Jones and Gareth Stapley-Jones, Planning & Development Officers, Social Services, to the meeting.

The Senior Manager, Integrated Services, Lead Adults provided background information and said the development of Marleyfield House would increase existing capacity by an additional 32 beds and provide accommodation to support 64 people in total. Following an initial feasibility study, approval was granted to engage a construction firm to take the project forward. A revised, modern, and innovative design had been proposed which maximised the landscape topography and provided purpose built efficient accommodation for the range of services being delivered. The plans allow increased operations functionality, a closer link with existing facilities, and supported recovery for short term residents and well-being for long-term residents. Investment for the development had been sourced through a Capital Grant as part of Welsh Government's Integrated Care Fund (ICF) with additional investment from the Council's Capita Programme. An application was also being made to the Innovative Housing Programme (IHP) to further support the project.

The Planning and Development Officers presented an artist's impression of the extension, explaining the plans and layout.

Members spoke in support of the project and the innovative approach to supporting individuals in residential settings. During discussion, Officers responded to the questions raised around staffing levels, catchment areas, provision for people with dementia, and day care and respite facilities.

Councillor David Healey asked why solar panels had not been incorporated into the design. It was agreed that further information on the possible use of solar panels would be sought from the Design Commission for Wales.

The Chair expressed concerns that the proposed parking arrangements may not be sufficient and asked whether the provision could be increased without compromising planning requirements. Officers acknowledged the points made and explained that a number of staff had indicated that they wished to cycle to work which would further reduce the number of parking spaces required.

RESOLVED:

That the Committee supports the progress made on the Marleyfield House expansion Project as a strategic priority for Social Services.

7. THIRD SECTOR UPDATE

The Chief Officer (Social Services) introduced a report to provide an annual review of the social care activities undertaken by the third sector in Flintshire. He spoke of the thriving voluntary/third sector which provided invaluable support and services to Flintshire residents and the good working relationship between the Authority and Flintshire Local Voluntary Council (FLVC). The report provided an overview of the range and breadth of services funded by Social Services and detailed the recent activity undertaken to review services commissioned through the third sector to ensure they continued to meet the needs of the people in Flintshire. The report also detailed the approach taken to co-produce new and innovative services and gave an update on learning disability day and work opportunities and the plans for commissioning carers services in 2019/20.

The Senior Manager, Safeguarding and Commissioning, explained that Flintshire had developed a strong working relationship with its third sector partners and continued to invest in the sector by commissioning, where appropriate, to deliver services in the community as they were often best placed to engage and support individuals and their carers. She reported on the main considerations, as detailed in the report, around the work of the FLVC, Carers Services, Disability Services, Adults Advocacy, Children's Advocacy, Action for Children Strategic Partnership, Single Point of Access, and Mental Health.

In response to a query raised by the Chair, further information on the Single Point of Access service was provided.

Councillor Veronica Gay commented on the North East Wales Carers Information Service (NEWCIS). The Senior Manager, Safeguarding and Commissioning, explained that Flintshire Social Services delivered a range of support services for carers both in-house and commissioned through external third sector organisations. She reported on the highly valued work provided by NEWCIS to support carers, individuals, and families, and said that NEWCIS worked in close partnership with the Authority to deliver some of the key services required under the Social Services and Well Being Act.

Councillor Martin White spoke in support of the valuable work provided by the social care third sector for the local population and suggested that the Chair sends a letter of thanks to the FLVC on behalf of the Committee. This was agreed by the Committee.

RESOLVED:

(a) That the Committee supports the social care activities that are being delivered within the third sector in Flintshire; and

(b) That the FLVC be thanked for their role.

8. ROTA VISITS

Councillor Mike Lowe provided feedback on his visit with Councillor Andy Dunbobbin to the North East Wales Community Equipment Services (NEWCES) centre in Hawarden. He said they had been impressed with the high standard of service and the thorough procedures to ensure cleanliness of equipment provided to individuals. He said the Manager of the Centre had given them a presentation and tour of the building which had been very informative.

Councillor Christine Jones thanked Councillor Lowe for his positive comments and said she had invited the Manager of NEWCES to give a presentation on the Service to a future meeting of the Committee.

Councillor Mike Allport reported on his visit to Croes Atti Care Home and said the visit had been positive and he had no concerns to raise. He said he had received a warm welcome and staff were enthusiastic and helpful. He had spoken to individual residents/users who were pleased with the care and services provided.

The Chair provided feedback on her visit to Llys Gwenffrwd Care Home. She said residents were happy and pleased with the services and commented on the improvements to access outside the building which were excellent. She said Llys Gwenffrwd had extended an open invitation to their Summer Fayre to be held on 22 June.

RESOLVED:

That the update be noted.

9. FORWARD WORK PROGRAMME

In presenting the Forward Work Programme, the Democratic Services Manager advised that a report on the Continuing Health Care Crisis would be included on the agenda for the next meeting to be held on 18 July. He said a link to the consultation on Continuing Health Care would be sent to the Committee beforehand.

The Officer referred to the item on Betsi Cadwaladr University Health Board (BCUHB) and Welsh Ambulance Services NHS which was also scheduled for the next meeting and advised that the Chief Officer (Social Services) had suggested that the Committee may wish to invite the Countess of Chester Hospital to attend the meeting. This was agreed by the Committee. Members were asked to forward questions for BCUHB and Countess of Chester to the Social & Health Facilitator in advance of the meeting.

Following a suggestion by Councillor Christine Jones it was agreed that a presentation by the Manager of NEWCES be included on the Forward Work Programme for a future meeting of the Committee.

RESOLVED:

(a) That the draft Forward Work programme as submitted be approved.

(b) That the Facilitator, in consultation with the Chair of the Committee be authorised to vary the forward Work Programme between meetings, as the need arises; and

(c) That the Countess of Chester Hospital be invited to attend the next meeting of the Committee on 18 July 2019.

10. MEMBERS OF THE PUBLIC AND PRESS IN ATTENDANCE

There was one member of the press and no members of the public in attendance.

(The meeting started at 2.30 pm and ended at 4.10pm)

....
Chair

SOCIAL & HEALTH CARE OVERVIEW & SCRUTINY COMMITTEE

Date of Meeting	Thursday 18th July, 2019
Report Subject	Forward Work Programme and Action Tracking
Cabinet Member	Not applicable
Report Author	Social & Health Care Overview & Scrutiny Facilitator
Type of Report	Operational

EXECUTIVE SUMMARY

Overview & Scrutiny presents a unique opportunity for Members to determine the Forward Work programme of the Committee of which they are Members. By reviewing and prioritising the Forward Work Programme Members are able to ensure it is Member-led and includes the right issues. A copy of the Forward Work Programme is attached at Appendix 1 for Members' consideration which has been updated following the last meeting.

The Committee is asked to consider, and amend where necessary, the Forward Work Programme for the Social & Health Care Overview & Scrutiny Committee.

The report also shows actions arising from previous meetings of the Social & Health Care Overview & Scrutiny Committee and the progress made in completing them. Any outstanding actions will be continued to be reported to the Committee as shown in Appendix 2.

RECOMMENDATION	
1	That the Committee considers the draft Forward Work Programme and approve/amend as necessary.
2	That the Facilitator, in consultation with the Chair of the Committee be authorised to vary the Forward Work Programme between meetings, as the need arises.
3	That the Committee notes the progress made in completing the outstanding actions.

REPORT DETAILS

1.00	**EXPLAINING THE FORWARD WORK PROGRAMME AND ACTION TRACKING**
1.01	Items feed into a Committee's Forward Work Programme from a number of sources. Members can suggest topics for review by Overview & Scrutiny Committees, members of the public can suggest topics, items can be referred by the Cabinet for consultation purposes, or by County Council or Chief Officers. Other possible items are identified from the Cabinet Work Programme and the Improvement Plan.
1.02	In identifying topics for future consideration, it is useful for a 'test of significance' to be applied. This can be achieved by asking a range of questions as follows: 1. Will the review contribute to the Council's priorities and/or objectives? 2. Is it an area of major change or risk? 3. Are there issues of concern in performance? 4. Is there new Government guidance of legislation? 5. Is it prompted by the work carried out by Regulators/Internal Audit?
1.03	In previous meetings, requests for information, reports or actions have been made. These have been summarised as action points. Following a meeting of the Corporate Resources Overview & Scrutiny Committee in July 2018, it was recognised that there was a need to formalise such reporting back to Overview & Scrutiny Committees, as 'Matters Arising' was not an item which can feature on an agenda.
1.04	It was suggested that the 'Action tracking' approach be trialled for the Corporate Resources Overview & Scrutiny Committee. Following a successful trial, it was agreed to extend the approach to all Overview & Scrutiny Committees.
1.05	The Action Tracking details including an update on progress is attached at Appendix 2.

2.00	**RESOURCE IMPLICATIONS**
2.01	None as a result of this report.

3.00	**CONSULTATIONS REQUIRED / CARRIED OUT**
3.01	In some cases, action owners have been contacted to provide an update on their actions.

4.00	**RISK MANAGEMENT**
4.01	None as a result of this report.

5.00	**APPENDICES**
5.01	Appendix 1 – Draft Forward Work Programme Appendix 2 – Action Tracking for the Social & Health Care OSC.

6.00	**LIST OF ACCESSIBLE BACKGROUND DOCUMENTS**
6.01	Minutes of previous meetings of the Committee as identified in Appendix 2. **Contact Officer:** Margaret Parry-Jones Overview & Scrutiny Facilitator **Telephone:** 01352 702427 **E-mail:** Margaret.parry-jones@flintshire.gov.uk

7.00	**GLOSSARY OF TERMS**
7.01	**Improvement Plan:** the document which sets out the annual priorities of the Council. It is a requirement of the Local Government (Wales) Measure 2009 to set Improvement Objectives and publish an Improvement Plan.

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SOCIAL & HEALTH CARE OVERVIEW & SCRUTINY FORWARD WORK PROGRAMME APPENDIX 1

CURRENT FWP

Date of meeting	Subject	Purpose of Report	Scrutiny Focus	Responsible / Contact Officer	Submission Deadline
3 October	**Supporting families to access the free childcare Offer**	To receive a progress report	Assurance	Chief Officer – Social Services	
	Arosfa update	To receive a progress report	Assurance	Chief Officer – Social Services	
	Extra care Strategy including update on Holywell.	To receive a progress report.	Assurance	Chief Officer – Social Services	
	Progress for providers update	To receive a progress report.	Assurance	Chief Officer – Social Services	
	2018/19 Year End Reporting **Council Plan Monitoring**	To enable members to fulfil their scrutiny role in relation to performance monitoring	Performance monitoring/assurance	Facilitator	
14 November	**Hospital avoidance**	To receive an update on work being undertaken to avoid hospital admittance	Assurance	Chief Officer – Social Services Chief Officer – Social Services	
	Support building resilient communities by developing social prescriber role within Single Point of Access.	To receive an update	Assurance	Chief Officer – Social Services	

	Engagement and consultation on in-house provision	To consider the draft consultation.	Consultation	Chief Officer – Social Services	
12 December	**Safeguarding**	To provide Members with statistical information in relation to Safeguarding - & Adults & Children.	Performance monitoring/assurance	Chief Officer Social Services	
	North Wales Adoption Service Annual Report	To provide an overview of the performance and quality of the work of North Wales Adoption Service in 2018-19.	Assurance	Chief Officer Social Services	
30 January	**Presentation on equipment store**	To provide members with an update of the work undertaken at the equipment store.	Awareness raising	Chief Officer Social Services	
26 March					
21 May	**Comments, Compliments and Complaints**	To consider the Annual Report	Assurance	Chief Officer Social Services	
16 July					

Regular Items

Month	Item	Purpose of Report	Responsible/Contact Officer
Nov/Dec	**Safeguarding**	To provide Members with statistical information in relation to Safeguarding - & Adults & Children	Chief Officer (Social Services)
May	**Educational Attainment of Looked After Children**	Education officers offered to share the annual educational attainment report with goes to Education & Youth OSC with this Committee.	Chief Officer (Social Services)
May	**Corporate Parenting**	Report to Social & Health Care and Education & Youth Overview & Scrutiny.	Chief Officer (Social Services)
May	**Presentation by Young People**	To inform Joint Social & Health Care and Education and Youth Overview & Scrutiny	Chief Officer (Social services)
May	**Comments, Compliments and Complaints**	To consider the Annual Report	Chief Officer (Social Services)
June	**Betsi Cadwaladr University Health Board Update**	BCUHB are invited to attend on an annual basis – partnership working.	Facilitator

Joint meeting with Education & Youth Overview & Scrutiny on Thursday 25th of July at 2pm.

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Appendix 2

Social & Health Overview & Scrutiny Committee

Action Sheet

6th June 2019

Duration of Meeting: 2.30 – 4.10

Item	**Decision**	**Comments/Action required and by whom**	**Action taken**
6. Annual Director's Report	Report approved, as per recommendation.	MPJ Need to send CHC consultation to Members and put onto the July agenda. Susie Lunt. Need to ascertain whether FCC has any formal links with Samaritans and whether FCC provides any funding.	CHC consultation documents circulated to members of the Committee. (MPJ) Flintshire signposts to Samaritans through Single Point of Access. We have also commissioned training through the Workforce Development Team as and when required. However, we do not commission formal services from Samaritans.
7. Marleyfield house Expansion Progress Update	1. That the ctte supports the progress made on the Marleyfield House expansion Project as a strategic priority for Social Services.	Michael Jones: look into incorporation of solar panels into design. Consider whether proposed parking is adequate or can be increased without compromising planning requirements	Solar Panels have been added to the proposed design for the refurbishment of the existing Marleyfield House building. Solar Panels were considered for the roof of the new building, with guidance sought from Planning Officer and Energy Team advice. The proposed green roof is preferred by all parties at this stage. Additional energy efficient features are under consideration and will be confirmed as part of the Planning application. Planning Officer guidance confirms that the location and layout of the car park will

Item	Decision	Comments/Action required and by whom	Action taken
			provide the most effective car park for this site. Staff and Visitor Travel surveys confirm that proposed capacity will be sufficient, even at staff shift handover periods. Staff will also be encouraged to use public transport, cycles and lift shares as an energy efficient action plan.
8. Social Care Third Sector Services	1. That the ctte supports the social care activities that are being delivered within the third sector in Flintshire.2. That the FLVC be thanked for their role.	MPJ to draft letter to FLVC for Chair.	Completed. Response received from FLVC which has been circulated to members of the Committee via email.
9. Rota Visits	That the Rota Visits updates from the Members who had carried them out be noted.		
10. Forward work programme	1. That the draft Forward work programme as submitted be approved. 2. That the facilitator, in consultation with the Chair of the committee be authorised to vary the forward work Programme between meetings, as the need arises. 3. That the Manager of the Equipment Store be invited to give a presentation to the Committee. 4. Clarify date of Joint meeting.	MPJ: 1. Add CofCH invitation to attend the July meeting: may need to move other items off. Ask members for questions to BCUHB and CofCH in advance. 2. Add Continuing HealthCare Crisis consultation to be added July : please circulate consultation link to Member beforehand. 3. Presentation by the manager of the Equipment store to be added to FWP 4. Clarify the date of the joint meeting. Friday is 26th July.	Being investigated. (RJR) On agenda for July meeting. Consultation documents circulated. MPJ On FWP for Jan 2020 Joint meeting is on Thursday 25 July at 2pm. Email sent on 10 June 2019 (MPJ)

Appendix 2

Item	Decision	Comments/Action required and by whom	Action taken

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Agenda Item 5

Social & Health Care Overview and Scrutiny Committee

Date of Meeting	18th July 2019 Thursday, 18 July 2019
Report Subject	North Wales Integrated Autism Service
Cabinet Member	Cabinet Member for Social Services
Report Author	Chief Officer (Social Services)
Type of Report	Strategic

EXECUTIVE SUMMARY

It is estimated that Autistic Spectrum Disorders (ASD) affect 1 in 100 people.
For Flintshire, this could mean 1,500 people.
It was recognised by Welsh Government that there was a gap in service for this client group and in response the Welsh Government has committed £13 million of Integrated Care Fund (ICF) up to 2021 to develop an Integrated Autism Service (IAS) across Wales.

Welsh Government also fund a small national team to lead this initiative. This team has recently secured funding until 2022, and there are indications that the fund will continue after 2021.

The North Wales region has an annual allocation of £ 615.800

The IAS provides:

- New adult diagnostic services
- Support for autistic adults to meet defined outcomes
- Support for families and carers
- Training, consultation and advice to professionals in other services supporting autistic individuals.

The aim of the service is to ensure that individuals with autism, their family and carers are able to access the advice, support and interventions needed to enable them to reach their full potential where these are otherwise unavailable.

*IAS Supporting Guidance (Welsh Government, 2017)

Flintshire County Council is jointly hosting the North Wales Integrated Autism Service with Betsi Cadwaladr University Health Board (BCUHB) on behalf of the region.

This report will give an overview of the Integrated Autism Service in North Wales and outline the progress made to date.

RECOMMENDATIONS	
1	Note the update on the North Wales Integrated Autism Service.
2	Elected members are assured that progress has been made during the year to meet our duties on behalf of the region.
3	To note the difference this has made to people with Autism.

REPORT DETAILS

1.00	**EXPLAINING THE NORTH WALES INTEGRATED AUTISM SERVICE**
1.01	For North Wales the Integrated Autism Service (IAS) service is jointly hosted by Flintshire County Council and Betsi Cadwaladr University Health Board (BCUHB). The creation of the Integrated Autism Service (IAS) is supported by an IAS Strategic Group, comprising of representatives from across children and adults' health, social care, education, third sector organisations and people with Autism. This Strategic group is supported by an Operational group.
1.02	The IAS Strategic Group reports to the North Wales Leadership Group and to the Regional Partnership Board.
1.03	The North Wales IAS has an annual budget of £615.800 in the main this is made of staffing costs for the service, including social care and health staff. As staff were not in place from April '18, when the budget became available, an under spend has accrued. IAS colleagues are working with the Strategic and Operational groups to build a plan for effective use of this funding in line with the wider aims of the IAS and ICF funding. The underspend options will be approved by the WLGA National Autistic Team and Welsh Government this comes via the Integrated Care Fund (ICF),
1.04	What the IAS does: • Assess people who present with ASD, for example they will assess people who don't have multiple conditions such as a Learning Disability or a known mental health difficulty. • Support for adults with Autism. • Provides Information, advice and support for parents, families, partners and carers of individuals with Autism Spectrum Disorder (ASD) and the professionals who support them. • Provides advice, training and support for agencies linking with people with ASD.
1.05	What the IAS doesn't do: • Social work assessments or Care management type functions, for example they will not commission or provide care packages. • Emergency or crisis intervention • Does not provide Respite care

- Rapid response
- Direct Payments
- The service does not commission services

1.06 The North Wales Integrated Autism Service Launch Conference took place on 27th June 2018. The event was jointly chaired by Neil Ayling Chief Officer, Social Services and Jill Timmins, Director of Operations and Service Delivery at Betsi Cadwaladr University Health Boards' Mental Health.

The Conference was a great success and provided the 255 people attending an opportunity to gain a better insight into the North Wales IAS, as well as how it will interact with other existing services, e.eg those who already work with individuals with autism and their families across North Wales.

1.07 We appointed a Practitioner Manager on 20th August, 2018. The service became operational. The team comprises of the following posts, working across North Wales, along with one support worker per Local Authority area.

Practitioner Manager (Social Worker)	Christine Burns
Administrator	Kathy Cocking
Support Worker * 8	Across NW one per LA
Education Practitioner	Vacant at this time
Occupational Therapist 0.5	Catherine Seals
Speech and Language Therapist 0.5	Tricia King
Psychologist * 2	Freya Spicer –White and Simon
Nurse	Lynda Marl

1.08 BCUHB health staff receive clinical supervision within BCUHB, however, the day to day running of the service sits with the Practitioner Manager. Flintshire County Council is the host authority on behalf of the North Wales region.

1.09 **How the service operates**

Referrals –

- Direct to the IAS or via the Single point of access.
- These are triaged by the IAS Practitioner Manager in line with the guidance from Welsh Government.
- Prioritised dependant on presenting need.
- Allocation to relent worker, e.g. health or social care or both.
- There is no waiting list for social support, there is however a wait list for psychology assessment.
- Following feedback from individuals with Autism and advisors to the service, the referral form has been streamlined and process have been updated.
- All staff are making contact with individuals referred within 48 hours of allocation.
- The busiest areas are Flintshire and Denbighshire.

1.10 The Support Workers are in the process of developing a series of ‘drop-ins’ across the region where individuals with Autism, and their carers can make contact with the IAS in their own localities. Drop in locations include job centres, leisure centres, libraries and other community based venues.

1.11 County Engagement Events are also being scheduled. These will have an autism focus and will include a ‘marketplace’ of services as well as workshops and speakers from the local area. These follow on from Events last October which were held at Ty Pawb and Deeside Leisure Centre.

1.12 The Support Workers across the region are also promoting the resources available online. The ASDInfoWales website. This includes the ‘Can you see me Campaign”.

1.13 IAS staff have raised awareness and trained other staff on the “Can you see me Campaign” in a variety of setting including Connah’s Quay Job Centre, Asda and shops on the Broughton retail Park. The staff working in shops and the job centre are currently completing an Autism Awareness online course and will then complete ‘Can You See Me’ Training.

1.14 Support Workers are mapping resources, partners and facilities available in each county to ensure we are able to provide services close to where people with Autism live.

1.15 The team are current based at Greenfield, however, they are soon to relocated to Ty Dewi Sant, Ewloe.

1.16 Partnership working is key to the IAS, and we have from available slippage money in 2017/18 been able to support Community Voluntary Council’s across the region to develop a number of localised programmes to support individuals, their families and carers. These range from supported volunteering programmes, training and awareness raising, small grant schemes, activities and community and business events.

1.17 The IAS works collaborative with Social Worker’s and other professionals and the consultancy element of the service is strengthening.

1.18 **Performance Data**

	Aug 18- Mar 19
Assessment for Diagnosis	193
Support for adults	179
Support for parents	73
Total Referrals	**445**

2.00 RESOURCE IMPLICATIONS

2.01 The annual budget for the North Wales region is £651.800 up to 2021, however there are indications that the service will likely be funded beyond this point.

2.02 The ICF budget allocation funds the staffing structure along with travel expenses. Due to the regional nature of the service, mileage costs could be a challenge, however the service is monitoring this closely.

2.03	Welsh Government brought forward the funding and made it available for the North Wales region early than expected, as a result the staffing structure was not fully established. The consequence is a current underspend. WG have confirmed that will support a plan for the under spend across the region, so IAS colleagues are working with the Strategic and Operational groups to build a plan for effective use of this funding in line with the wider aims of the IAS and ICF funding. The underspend options will be approved by the WLGA National Autistic Team and Welsh Government.
2.04	The service also benefits from some addition planning and development officer time. Until March 2020.

3.00	**CONSULTATIONS REQUIRED / CARRIED OUT**
3.01	The service continues to be developed with involvement from people with Autism.
3.02	There is a standard Service Specification in development by Welsh Government, this should be available in the autumn.
3.03	The IAS is developing a volunteer programme where autistic individuals will co-present training and support staff at events.
3.04	Spectrum voices will continue to offer advice and guidance and represent users in all aspects of the work undertaken by IAS.

4.00	**RISK MANAGEMENT**
4.01	This is a relatively new service and staff are working hard to ensure everyone has a clear understanding of what the service will provide, that said , on occasion the IAS receives requests for services e.g. a package of care and support , these are re directed during the screening process.
4.02	The team manager continue to have regular and ongoing conversation with colleagues and in particular Community Mental Health Teams with regard to the team remit.
4.03	This service will have a significant role to play in supporting autistic individuals to access services that they may have had difficulty in doing so before, promoting equality and contributing to the anti-poverty agenda.

5.00	**APPENDICES**
5.01	How we have made a difference

6.00	**LIST OF ACCESSIBLE BACKGROUND DOCUMENTS**
6.01	**ASDInfoWales Website** - Here you will find information about Autism Spectrum Disorders (including Autism and Asperger Syndrome), service details, training opportunities and updates on the implementation of the ASD Strategic Action Plan for Wales. You will also find downloadable resources that can be shared with individuals with ASD, their family and carers. This

	site is aimed at those working with children and adults with ASD. https://www.asdinfowales.co.uk/home
6.02	North Wales IAS pages on the above website – This includes drop in information, and information leaflets. https://www.asdinfowales.co.uk/north-wales-integrated-autism-service
6.03	Can you see me?' Campaign - This awareness raising campaign provides individuals with autism with a wristband, card and screensaver for their mobile device so they are able to let you know in a discrete manor, that they have autism. https://www.asdinfowales.co.uk/can-you-see-me
6.04	IAS Facebook Page - https://www.facebook.com/NW-Integrated-Autism-Service-Gwasanaeth-Awtistiaeth-Integredig-GC-1879852932047031/
6.05	IAS Youtube Channel - This resource contains videos made with local autistic individuals and staff. https://www.youtube.com/channel/UCZzMF0IFN7aDpDfXiS7ZmHQ
6.06	**Contact Officer:** Emma Murphy, Planning & Development Officer, Social Services **Telephone:** 01352 701463 **E-mail:** emma.murphy@flintshire.gov.uk

7.00	**GLOSSARY OF TERMS**
7.01	**Autism -** Autism is a 'hidden disability', meaning it is not easy to recognise when someone has the condition. Autistic individuals may experience difficulties in social communication, social imagination and flexibility of thought, social interaction, repetitive patterns of behaviour, activities and interests and unusual sensory responses.
7.02	Autistic Spectrum Disorders – On one end of the spectrum, autistic individuals may have an additional learning disability and be more severely impaired. At the other, individuals may have an above average intellect and may function at a higher level.

Integrated Autism Services - How we have made a difference

Example (a):

Parent/carer called IAS ‘drop-in’ at Jobcentre seeking advice regarding her adult son. Team member gave information on housing and Keyring (voluntary agency) details. Keyring have now agreed to support this young man. Housing being pursued and NEWCIS supporting carer.

The young man wants to work in a paid job. Parents support him.

Went to volunteer course at FLVC and was provided with support to attend placements to gain work experience. They then held a meeting with Job Centre staff who have had ASD training (Can You See Me campaign). They discussed tools available on ASD website to help in employment.

The young man and his mum helped IAS team on a community day as volunteer. Lots of communicating with the public. Very positive day.

Job secured at Morrison’s. Young person thrilled. Success factory is the training Job Centre and employers have had in ASD. Training certificates on walls of Job Centre and workplace show people with ASD that this is a ‘safe environment.

Example (b):

Staff Member received the following thanks: “It has meant that because of the support and service that IAS has given that as a partnership we have been able to give genuine person centred approach”. “I want to thank you for all your invaluable knowledge and how comforting and reassuring it has been to be able to refer participants to your service”. “I have been very grateful for all the advice from yourself, but mostly I have found the assessment process by yourselves most helpful.”

Example (c):

Gentleman with ASD threatened with having his driving licence removed and this is particularly worrying as he cares for his elderly parents.

Because he had a diagnosis of Autism, the District Nurse had reported him to DVLA querying his suitability to drive. The process is that the person is obliged to contact DVLA but in this case, the man wasn’t given the chance.

The IAS support worker accompanied the gentleman to DVLA meeting and was able to explain about ASD and that the gentleman had no reduced or impaired functioning that would prevent him driving.

The judgement which could have had such a negative impact on his life, was made to retain his licence.

The gentleman said “Couldn’t have done it without you. Thanks for being there with me”.

Examples (d):

The service has recently received some very positive feedback from one of the volunteers via the Facebook page:

“There is some very valuable work being done with this service in terms of helping those who have fallen through the gaps in services in the past. Diagnosis is being speeded up, sign posting to support, awareness raising and so on. I have become a volunteer with them and I find the service does all it can to listen to those on the spectrum. They are a lovely approachable group of people.”

SOCIAL AND HEALTH CARE OVERVIEW AND SCRUTINY COMMITTEE

Date of Meeting	18th July 2019
Report Subject	Annual report on the Social Services Complaints and Compliments Procedure 2019-20
Cabinet Member	Cabinet Member for Social Services
Report Author	Chief Officer for Social Services
Type of Report	**Strategic**

EXECUTIVE SUMMARY

The Social Services and Wellbeing Act (Wales) 2014 and Social Services Complaints Procedure Regulations 2014, requires Local Authorities to maintain a representations and complaints procedure for social services functions (referred to as the “procedure” from now on). The Welsh Government expects each Local Authority to report annually on its operation of the procedure.

Complaints made about Adult Social Care are down compared to previous years and there has been a positive increase with the number of complaints responded to within timescale. Of the 3,965 adults who receive care and support during 2018-19 from Adult Social Care, 51 individuals complained about the service they received (1%). This compares to 80 individuals who complained during 2017-18. There was also an increase in the number of compliments received.

Of the 2,188 children and families who received care and support from Children’s Social Services, 55 individuals complained about the service they received (2.5%), compared to 49 individuals complaining during 2017-18. The number of complaints received in Children’s Social Services is comparable year on year.

All complaints are scrutinised and used to improve both services as part of a ‘lessons learned’ process.

RECOMMENDATIONS	
1	That Members scrutinise the effectiveness of the complaints procedure with lessons being learnt to improve service provision.

REPORT DETAILS

1.00	**EXPLAINING THE NUMBER OF COMPLAINTS RECEIVED, THE ISSUES RAISED AND THEIR OUTCOMES**
1.01	Feedback in the form of compliments and complaints from service users, their family or carers can highlight where services are working well or where services need changing. Flintshire County Council wants to learn from this feedback and use the experiences to improve services for everyone who uses them.
1.02	As part of our day to day business staff deal with questions, concerns, problems, dissatisfaction, and general feedback which frequently includes praise. We encourage staff to listen to people, to explain decisions, to clarify where misunderstandings have arisen and to take action to put things right where they can. This approach enables us to provide a responsive and effective service. However, we recognise that there will also be complaints that we need to listen to, address and learn from.
1.03	Our assessment is that Social Services has a robust complaints procedure in place. We welcome complaints and want to ensure service users, carers and families are listened to, their views acted upon, and that receive a timely and open response. Staff and Managers work hard to resolve problems as soon as they arise, and advocacy is actively promoted. As part of our wider approach to quality assurance all complaints are reviewed to bring together information about the overall quality of services, to identify trends, and action required including any lessons learned to avoid similar issues arising again.
1.04	**Overview of complaints: Adult Social Care**
1.05	51 complaints were received in the year, a significant decrease compared to last year’s 80 complaints that were received. This number should also be considered against the context that 3,965 adults who received care and support from the Service during the year. The Act is now firmly embedded in practice and the decrease can partly be attributed to improving our advice and communication with service users and their families, and managing their expectations.
1.06	All complaints received across the Service are scrutinised to see if anything further could have been done to alleviate a complaint being made in the first place: broadly speaking there were no such instances where a complaint could have been avoided. Every effort is made by social work staff and Managers to resolve issues/concerns quickly with service users and families. See Appendix 1 for a summary of complaints grouped into themes.
1.07	This year also saw a decrease in the number of complaints received about both registered residential and domiciliary providers. Complaints about registered providers are shared with the Contracts Monitoring Team who visit on a regular basis to ensure their contractual obligations are being fulfilled. A multi-agency information sharing meeting takes place between the Department, Health and the Care Inspectorate for Wales (C.I.W.)

where complaints information is shared and considered together with other information collated by agencies.

1.08

Service	2018-19	2017-18	2016-17
Older People – Localities	19	21	14
Older People – Provider	2	7	4
Learning Disability Community Team	6	8	10
Learning Disability Provider	2	10	
Mental Health and Substance Misuse	4	7	1
Disability Service inc. Transition	5	4	5
Safeguarding	0	3	3
Other (inc. Business Support etc.)	2	3	5
Registered Residential Provider	6	10	5
Registered Domiciliary Providers	4	7	8
***Integrated Autism Svc.**	1	n/a	n/a
Total number of complaints	**51**	**80**	**55**

** The Integrated Autism Service was formed in July 2018.*

1.09 Broadly speaking the complaint themes are broken down into the following areas with the number received in brackets).

- Dignity (2 complaints)
- Communication (14 complaints)
- Timeliness of our decisions or actions (10 complaints)
- Disagreements with our decisions or actions (10 complaints)
- Quality of care from a home or carer (23 complaints)
- Charges applied or financial issues (4 complaints)
- Hospital discharges (2 complaints)
- Process issues (14 complaints)
- Staff issues (6 complaints)

1.10 A range of methods are used to resolve complaints including:

a. A meeting or conversation with the complainant to discuss their concerns
b. Involving Advocates and self-advocacy groups
c. A written explanation as to the reasons for a decision
d. An apology where appropriate
e. Action taken to review a decision
f. Independent investigation (Stage 2 of the procedure)

1.11 The Regulations place a duty to discuss and resolve any complaint within 10 working days and write formally to the complainant confirming the outcomes. There is a 25 working day timescale for Stage 2 complaints.

Adult Social Care	**2018-19**	**2017-18**	**2016-17**
Within timescale at Stage 1	98%	86%	95%

1.12 In previous years, the Service has seen a consistent and high number of responses to complaints made within the statutory timescale. This year saw a further improvement with only one complaint responded to outside timescale. Even this one late complaint involved Managers meeting with the complainant in a timely manner to ensure the important issues were resolved quickly (it was the overall response that took time to resolve). This is against the backdrop of busy workloads and competing demands.

1.13 Stage 2 (Independent Investigation)

1.14 3 complaints were investigated at Stage 2 of the complaints procedure (Independent Investigation), the same as last year (2017-18) and lower than the 7 complaints investigated independently during 2016-17. All complaints that progress to Stage 2 are scrutinised to see if anything further could have been done to resolve the complaint formally at Stage 1: there was no option but to progress these 3 complaints to Stage 2 due to their nature or complexity. This relatively small number reflects the time and effort that Managers put into reviewing what has happened and effectively responding.

See appendix 3 for a summary of the Stage 2 investigations and their outcomes.

1.15 Ombudsman

1.16 One new complaint opened by the Ombudsman's office this year partly involved the new Integrated Autism Service. The Service agreed to settle the complaint without the need to escalate into a formal Ombudsman investigation and we completed an assessment with the complainant and their children.

1.17 A complaint opened by the Ombudsman during 2017-18 remains open at the time of this report's publication. The Department completed a retrospective review of a safeguarding case that subsequently raised questions about the Ombudsman's own investigation.

1.18 A complaint opened by the Ombudsman during 2016-17 was finally closed this year. The complaint was "upheld to a limited extent" as there had been a failure by Officers to consider the complainant's needs for a reasonable adjustment at a meeting the complainant attended with her husband. The recommendations have been implemented and signed off by the Ombudsman.

1.19 Lessons Learned

1.20 Learning from complaints is important and we use the findings and outcomes to inform policy and practice in delivering services (known as the 'lessons learned' process). Examples of action taken on issues raised as a result of complaints to Adult Social Care include:

- The Service Provider Due Diligence Questionnaire was revised to include whether members of a commissioned organisation's management team required assistance under the Equality Act 2010 when communicating with Local Authority Officers.

- Reviewing and updating the existing recording policy for the Service.

1.22 **Compliments**

1.23 It is pleasing to report that Adult Social Care received 285 compliments during the year, an increase in last year’s number of 204 compliments received. Compliments are received in the form of cards, letters or emails from service users or their families when they recognise staff have done “over and above” what is expected. See Appendix 4 for a summary of some of the compliments received across service areas.

1.24 **Overview of Complaints: Children’s Social Services**

1.25 During 2018-19, 55 complaints were received and 2,188 (2.5%) children and families received care and support from the Service. The number of complaints relating to Children’s Social Services is consistent with previous years. Again, all complaints received are scrutinised to see if anything further could have been done to alleviate a complaint being made in the first place. Every effort is made by social work staff and Managers to resolve issues/concerns quickly with service users and families. See appendix 2 for further details about these complaints.

1.26 7 young people complained during the year. 1 young person was supported by their Advocate, the other 6 were offered but did not want the services of an Advocate.

Service	2018-19	2017-18	2016-17
First Contact, FIT, PACT and TAF	43	39	42
Fostering Service	4	3	7
C.I.D.S. (Children’s Integrated Disability Service)	3	2	3
Safeguarding Unit	1	2	1
Flying Start	1	0	0
Other (including commissioned providers)	3	3	0
Total Number of Complaints	**55**	**49**	**46**

As explained earlier, a range of methods are used to resolve complaints. These include:

a. A meeting or conversation with the complainant to discuss their concerns
b. Involving Advocates and self-advocacy groups
c. A written explanation as to the reasons for a decision
d. An apology where appropriate
e. Action taken to review a decision
f. Independent investigation (Stage 2 of the procedure)

1.27 Of the 55 Stage 1 complaints received, 51 out of the 55 complaints were responded to within timescale (93%). The 4 late complaints were responded shortly outside timescale.

Social Services for Children	**2018-19**	**2017-18**	**2016-17**
Within timescale at Stage 1	93%	80%	91%

1.28 **Stage 2 (Independent Investigation**

1.29 Five complaints proceeded to Stage 2 and independent investigation during the year. This is an increase compared to previous years (1 during 2017-18 and 2 during 2016-17). Close scrutiny of these Stage 2 complaints shows these were complex cases involving difficult family or personal dynamics. A summary of these Stage 2 complaints is described in Appendix 3.

1.30 **Ombudsman**

1.31 1 complaint about failing to properly deal with a request for financial assistance under Special Guardianship Regulations was investigated by the Ombudsman and upheld this year. We apologised for the failings identified in terms of not following process and paid financial redress in recognition of this. The Local Authority settled 2 other complaints without the need for formal investigation.

1.32 **Lessons Learned**

1.33 The lessons learned and discussed at team meetings as ‘practice developments’ including:

- Reminding staff they visit children as part of every Section 47 investigation at their current placement address. This applies to children who may be subject to a private arrangement made between families and must take place whether there is parental engagement or not.
- Reviewing current practice about informing a third party that a P.N.C. check is to be undertaken on them and its outcome recorded on our files.

- Reminding staff of the process to follow in terms of Special Guardianship applications.
- Drawing up an adoption checklist for a casefile which will assist staff if the caseholder is on leave, sickness absence etc.

1.34 **Compliments**

1.35 Children's Social Services recorded x compliments during the year from families, the Courts and other public bodies. They were in the form of cards, emails, texts or letters. See appendix 4 for a summary of some of the messages received.

	2018-19	2017-18	2016-17
Social Services for Children	**75**	**82**	**61**

2.00 RESOURCE IMPLICATIONS

2.01 The Regulations state all Stage 2 complaints involving both Adult and Children's Social Services are commissioned to Independent Investigators (and an Independent Person for Children's Social Services as set out in the Children Act, 1989). The cost for Stage 2 complaints for the period 2018-19 was £11,031.02 (the cost for the previous year amounted to £4,148.75).

3.00 CONSULTATIONS REQUIRED / CARRIED OUT

3.01 None undertaken.

4.00 RISK MANAGEMENT

4.01 No risks identified.

5.00 APPENDICES

5.01 Appendix 1: Summary of complaints categorised into themes (Adult Social Care)

5.02 Appendix 2: Summary of complaints categorised into themes (Children's Social Services)

5.03 Appendix 3: Summary of Stage 2 independent complaint investigations and their outcomes (both Children and Adult Social Services)

5.01	Appendix 4: Summary of compliments received across service areas (both Children and Adult Social Services).

6.00	**LIST OF ACCESSIBLE BACKGROUND DOCUMENTS**
6.01	‘A guide to handling complaints and representations by Local Authority Social Services’, August 2014 (Welsh Government). **Contact Officer:** Ian Maclaren, Complaints Officer for Social Services **Telephone:** 01352 702623 **E-mail:** ian.maclaren@flintshire.gov.uk

7.00	**GLOSSARY OF TERMS**
7.01	Stage 2 complaint: the Regulations stipulate that where a complainant remains dissatisfied with their response from the Council, consideration must be given to progressing the complaint further in the statutory procedure, i.e. to Stage 2. An independent investigation is commissioned using a shared North Wales ‘pool’ of retired social care Officers.

Appendix 1

Adult Social Care

Summary of complaints by theme (2018-19)

Complaints relating to dignity (2 complaints)

1. X complained about the standard of care provided by the home in terms of dignity and how they treated residents there.

The home interviewed carers on duty at the described times and all were shocked at the comments allegedly made. They insisted they were discreet and treat residents with dignity and respect. The home assured staff do engage with residents, do short bursts of activities and these are reflected in diary notes. There were no concerns from ourselves.

2. X complained their partner was not attended to one night despite X pressing the alarm meaning they slept in a wet bed. Staff did not change the bed the following morning and instead placed a blanket over him.

The home apologised for any upset and anxiety caused. They explained a bottle had overflowed and the Nurse went quickly once the alarm bell was pressed. No evidence was provided by the home as to the response time that night, so the timeliness of responding to alarm calls was featured in the next visit by a Contracts Monitoring Officer.

Complaints relating to communication (14 complaints)

3. X complained they had booked time off work to attend a family member’s review meeting but the Officer left earlier than the time agreed.

We apologised for our actions and leaving the venue early without checking to see if a family member was on their way. The Officer had already spoken with staff and met with the individual concerned before the agreed review time which is not acceptable. Officers in future will ensure they have the contact details of those invited so if changes are to be made, invitees can be contacted.

4. X complained we had visited mother without a family member being present or without them being informed so we could assess the safety of bed rails that had been installed by family. Mother becomes anxious with new faces visiting and no family member being present. We removed the bed rails which X believes left mother at risk of falling out of bed.

We apologised for visiting without advising family, but we explained why we had to undertake a prompt visit to check upon the handrails given our understanding that family had left mother to attend a wedding over the weekend. An O.T. will complete another visit and go through in detail our concerns about the handrails and suggest alternative solutions.

5. X complained they had not been informed of their rights in terms of contact with their son, who is sectioned some distance away. X believes we have washed our hands of their son now that he is locked up and we aren't exploring placements nearer to home.

We reminded X their rights were explained to them by the Approved Mental Health Professional and their son's G.P. at the time son was sectioned and placed. We assured X we had not washed our hands of her son but Health were now responsible for their son's care co-ordination, though we had identified a placement closer to the area.

Complaints relating to timeliness of our decisions or actions (10 complaints)

6. Family complained that we were not following the recommendations made by the Multi-Disciplinary Team. We were not enabling X to return home and instead keeping them in hospital and hampering their recovery.

We reassured family it was never our intention to have X stay in hospital and apologised if our communication came across this way. Their care provider is now in a position to able to support her return home and a planning meeting has been convened to facilitate this soon.

7. X complained about our timeliness of agreeing a package of care for their mother who was moving from England to Flintshire.

We explained the cross-border referral process to X and the difficulties we had faced in engaging with the Local Authority of origin. We had also found it difficult to engage with family about the matter. As a package of care cannot be sourced at this time, we offered short term care in a residential setting here.

Complaints relating to disagreements with our decisions or actions (10 complaints)

8. X challenged Panel's decision to reduce their respite care nights. X’s daughter's needs haven't changed and X remains an ‘elderly’ sole carer.

We reviewed our decision and found X’s allocation had been calculated correctly. However, given the impact a 6 night reduction may have upon them we agreed to reduce by 3 nights this year and implement the full 6 night reduction next year.

9. X complained about Panel's decision not to award her a direct payment because of historical mismanagement of funding. Panel instead agreed to a package of care.

We reviewed our decision and agreed a direct payment given X’s circumstances. However, our decision came with a number of caveats for X to adhere to given their previous mismanagement of funds.

10. X complained of our decision to return their mother home, a home that has been empty for 15 months after family emptied its furniture and contents. X believed their mother wouldn't be returning home as she lacked capacity and she would continue living in the residential home where she currently resides.

We explained we had twice completed a mental capacity assessment several months apart, which confirmed X's mother had capacity. The DoLS process was also followed. Family were communicated with during this time. Mother wants to return home and we are respecting her wishes by supporting a phased return home.

Complaints relating to charges applied or financial issues (4 complaints)

11. X complained about Panel's decision not to financially support their mother's move to a privately registered home. X also needed some financial help until their mother's home was sold to fund the placement.

We explained our assessment of mother meant she could be supported at home with a care package but this option was declined by her. Mother decided however that she wanted to go into a home privately which she has every right to do. Family can approach the home and negotiate an arrangement until X's property is sold.

12. X complained about the safeguarding concerns made against them re. alleged financial abuse and on whose authority did we re-direct their son's benefits and set ourselves up as Appointees?

We explained a referral was received earlier this year regarding a lack of funds being provided by X for their son. Requests for funds had previously been requested on many occasions but none were forthcoming causing X's son financial hardship and impacting on his personal and social opportunities etc. We contacted the Department for Work and Pensions who stopped son's benefits to X and we took over their Appointeeship.

13. X complained he had started to receive bills in relation to their friend's residential fees. X's friend had transferred their property to X in the 1980s but has no documentation to evidence this.

We explained we had agreed X's friend for short term care funding support which runs for up to maximum of 8 weeks under Welsh Government rules. X has been offered a bungalow and the plan is for their friend to eventually move in with them. If however the friend remains in a home after the short term care runs out then "Temporary" care applies which means the friend's care charges will change and increase, and be applied to X.

Complaints relating to hospital discharges (2 complaints)

14. X complained about the length of time it was taking to assess their mother so she could be discharged from hospital and moved to supported living accommodation nearer to X.

We apologised for the delay in assessing X's mother though the hospital was not the right setting for a housing and social care assessment to be completed. A Social Worker was allocated to visit mother at home to advise and support her with her wish to move to Cheshire.

15. X complained their partner had been kept in hospital for three and a half months as we couldn't source carers for them to return home.

We explained we assessed X's husband and made a request to Brokerage for a new package of care that day. However, given the demand on care providers, one could not be found and X's partner stayed in hospital for a further two months. An I.C.F. bed was offered after a month but this was declined.

Complaints relating to the quality of care from a home or carer (23 complaints)

16. X complained that planned work to make their father's room safer was not taken forward. Father was found on his bedroom floor one morning soon afterwards and passed away soon after in hospital.

The home advised it was unsafe for father to mobilise without the Zimmer frame and that the use of pressure mats, with advice from O.T., would further increase his risk of trips and falls. We sought to reassure X his father was provided with excellent care and support at a time his overall health was deteriorating.

17. X complained their carer had made an unplanned visit to their home and acted strangely, possibly under the influence of alcohol. The provider themselves gave an unusual response that required a formal follow up.

The provider explained the carer had not long received some distressing news and had misunderstood a telephone message hence why she attended X's home unannounced. She was not under the influence of alcohol.

18. Daughters raised a number of concerns following their late father's stay and their mother's stay in separate homes, but under the same home management. Their concerns included: dental hygiene, inappropriate food, the home's general environment and staff interaction with residents.

We undertook an already planned contract monitoring visit to both homes and made general observations but no concerns were raised. We also read through all residents' reviews held this year in both homes and found no issues against the themes identified.

19. X complained a carer had not checked if their father had taken his medication on one occasion and that staff had been unprofessional with them when they questioned the matter.

The agency reviewed their records for the evening concerned. The evening carer went to give father his medication and noticed the pack had already been opened. Father could not remember taking the medication. Checks were made with earlier carers who both confirmed the medication was there. It is believed father took his own medication. The agency did try and explain this to X but they were continuously rude and abrupt, and X would not listen to the explanation.

20. X complained about the manner with which a home had managed their mother's move from the home to another home. The move was done with a lack of advice, support and empathy/understanding.

The home apologised for the service family received toward the end of mother's placement there and that information was not expressed in a clear manner to them. The former Manager involved in the move no longer works at the home. The home advised family the decision to move their mother was taken in her best interests given her increasing health needs.

21. X complained we were denying their mother some liberties by now dictating visiting times.

We explained mother had been returned as late as 1.30am on occasions which was affecting her health and wellbeing, and her medication. We reminded X it was important to return their mother at an acceptable time so her medication is taken on time. X is not reliable to oversee their mother's medication. Given our concerns about X's own health and wellbeing, and their admittance that their life had no structure or routine, with Legal advice X was instructed not to remove their mother from the home until we fully complete our assessments. X is welcome to visit their mother at the home and leave before the allotted time.

Complaints relating to process issues (14 complaints)

22. X complained about a number of issues with regard to their initial assessment including being recorded as a "known risk to lone workers" and being put under pressure to confirm an appointment or their assessment would be closed.

We acknowledged the "known risk" box should not have been ticked and was done so in error and we apologised for the misinformation recorded in the assessment which we have since put right. We explained the Social Worker had heard nothing from X for four weeks so sent a 14 day letter to clarify if she wished to continue with the referral or not as is our usual procedure.

23. X complained that their partner's C.H.C. funding had ended and they were now self-funding. X couldn't understand why.

We reminded X of the meeting when it was discussed X's partner no longer met the criteria for Continuing Healthcare Funding and the reasons why (which was followed up in writing by Health). The letter we sent was in relation to a means tested financial assessment that indicated X's wife was over the financial threshold to apply for financial assistance.

<u>Complaints relating to staff (6 complaints)</u>

24. X complained their working relationship with her Social Worker had broken down following her request for additional support.

We reminded X of her current package of support including a direct payment which provides a reasonably high level of supervision throughout the day. Many of the concerns X has are health related and we redirected them to Health where we will support their application for Continuing Health Care funding.

25. X complained about the way we had spoken with them about their grandmother.

We acknowledged that tensions have run high and conversations have been emotional for some. However, we sought to work with the family on behalf of grandmother, who has expressed a wish to return home which family members did not agree with.

26. X complained that their Social Worker 'intimidates and demoralises' her.

Although X withdrew their complaint and given the allegations made, we completed a comprehensive investigation that involved Health as well. No evidence was found to uphold X's allegations that her Social Worker was disrespectful or intimidated her.

Appendix 2

Children's Social Services

Summary of complaints by theme (2018-19)

Complaints relating to contact (16 complaints)

1. X complained about the contact arrangements with their children at a time when contact was being increased with their father/ex-partner.

A parenting assessment was being completed at the time the complaint was made. The children are now living with their father permanently. Contact with X remains as usual but there will be no increase in contact.

2. X was unhappy they had to have supervised contact with their children when Court had ordered it could be unsupervised.

We sympathised with X's situation as the Court Order clearly stipulates X is allowed unsupervised contact with their child. Unfortunately there is little we can do to assist as this is a civil matter and X was advised to seek legal advice.

3. X complained they were supposed to have contact with their son. When X arrived for the session, X found her son was away on holiday.

We explained we had twice tried contacting X in the lead up to the weekend of contact as X's son was indeed away on holiday. Although the Social Worker hadn't managed to reach X, the person who arranges contact had managed to and X had already agreed to a change in date.

Complaints relating to communication (19 complaints)

4. X complained about the confusion for a forthcoming Review as paperwork wasn't ready. X had also lost faith in her son's Social Worker due to a lack of communication following incidences involving her son.

We apologised for the confusion in the lead up to X's son's LAC Review (the meeting went ahead as planned with X present). Missing paperwork was sent registered post to X. A new Social Worker has been allocated to her son.

5. A young person X complained about the contact arrangements that were put in place for her over Christmas.

We explained contact arrangements had already been agreed and X was to return to her placement on Boxing Day. X didn't inform us of a visit by their step-sister until very *late on Christmas Eve. X chose to stay over at their mum's anyway and not return when originally agreed. The moment has now passed.*

6. X complained about our lack of communication with her in the lead up to her daughter being adopted.

We found that during the time X’s Social Worker was off sick, we hadn’t realised a meeting between X and her daughter’s prospective adoptive parents hadn’t been arranged as promised. We apologised for the distress and anxiety this must have caused and promised to review our procedures to ensure something similar doesn’t happen again.

Complaints relating to a lack of advice or support (13 complaints)

7. The NHS Concerns Team wrote to a number of agencies involved with a family. Among the issues was an alleged lack of timely support in the lead up to the husband/father passing away.

We made several checks with other agencies at initial referrals and found there was enough support being provided to family. We explained our approach with the children was appropriate and sympathising with their present situation. In terms of contact with the family during a difficult time, we believed sensitivity was required in this case and we were reassured by other agencies more familiar with the family they were indeed being supported.

8. X is pregnant and must move out of her father's home due to issues. X feels we are not giving her enough support and we are not actively pursuing the move on her behalf.

There were issues with X not engaging with us early on but matters now appear to be progressing. A property has been identified close by where she lives.

9. X complained that we had failed her and her family by not providing advice and support

We reminded X of the information, advice and assistance we had provided including completing an assessment, agreeing 8 hours direct payment support, signposting for other support and providing a range of information in terms of family support etc.

Complaints relating to the timeliness of our decisions or actions (6 complaints)

10. X complained she received no follow up checks from her Flying Start Health Visitor after her initial five week visit and she didn't feel supported by them.

We confirmed visits were in accordance with policy. We explained as the designated Health Visitor was off sick, the BCUHB's vacancy caseload policy reduces the usual number of visits to essential contacts, which X received as well as telephone support. X was advised to seek G.P. support until their son started to regain weight. A Flying Start worker also visited. We, however, apologised if X felt let down.

11. X complained that despite the care plan stating his children could return home him, they hadn't. X has co-operated with us but the situation has not moved forward.

We discussed with X concerns school had about their daughters' behaviour and academically going backwards. Adult relationships within both sets of maternal and paternal families also fluctuated which has an impact. X remained unhappy but acknowledged the girls would remain with their grandmother for the foreseeable future. The girls have been referred for advocacy.

12. X complained about the length of time it was taking to progress with a conversion to his family home and the uncertainty about moving matters forward. X and their partner look after a number of sibling children.

We apologised for the length of time it had taken to reach this stage. We explained the need for a formal policy to be drawn up and agreed by Members, and a legal agreement for a 'charge' to be made against the home to recover costs should the placement break down. We gave an undertaking that a conversion was needed and monies from Welsh Government had been identified. Acknowledging some matters may be outside our control (e.g. builders), we gave an undertaking for work to be completed by Christmas.

<u>Complaints relating to disagreements with our decisions or actions (13 complaints)</u>

13. X complained although her daughter isn't 19 until September, daughter can't access advocacy at a time when she is going through options for college etc.

The Advocacy provider explained that given daughter's disability and her communication difficulties, she would be unable to instruct their Advocate. Instead non-instructed advocacy would be used to work with her. The provider would use a Watching Brief Approach and observe daughter in a series of settings. At this point in time, there is nothing for an Advocate to observe, but if alternative options are being considered, support can be reviewed.

14. X complained of our involvement in their daughter's case and our 'heavy-handedness'

We reminded X that she had abducted her daughter and taken her outside the E.U. The Police became involved and her maternal uncle stepped up and agreed at very *short notice to fly out to repatriate her which he did do. Daughter stayed with her uncle. This was all done under the auspices of a Section 47 safeguarding investigation. X was advised to seek legal advice.*

15. X complained we were ending their son's direct payments which they had been in receipt of for several years.

We explained the direct payment was originally made in 2014 after X's son had returned home from hospital extremely poorly so family could have time for themselves. Son's health has greatly improved over the years, he no longer needs social work intervention and he no longer meets the criteria for services as he has no permanent disability. Diana Nurses will continue to be involved however. We agreed to maintain the direct payment over the school summer holidays.

Complaints relating to staff (16 complaints)

16. X complained a Social Worker was unprofessional toward them and they don't believe the Social Worker is impartial.

We apologised if the Social Worker's actions and behaviour were perceived as unprofessional, but a difficult conversation had to take place. We offered a change in Social Worker but X confirmed they wanted to work with us and the Social Worker will continue as planned. We explained our duty to ensure children are seen alone whenever possible.

Complaints relating to our processes (17 complaints)

17. X complained gifts they had purchased for their son's birthday had to be seen by social work staff. We weren't being consistent as we had waived seeing presents X had bought at Christmas time for his children.

We apologised and acknowledged we should have followed the Schedule of Expectations at Christmas time. The sheer number of presents was overwhelming and given the busy period in the lead up to Christmas, we waived seeing the presents. The Schedule will be followed by all parties in future.

18. X shared her negative experience with the kinship care / fostering process and the emotional and financial impact this had upon her. We had approached X to act as a carer but after a period of several months of assessments, we had recommended another set of carers instead of X.

This was a complicated and emotive case. We confirmed we were supportive of X as a carer during a large part of the process. X had a very positive assessment, demonstrated she could work well with the Local Authority and set aside any personal family issues. The final decision was finely balanced and the child's potential life *journey was central to discussions between staff. It was concluded the other set of carers should be the long term carers for the child, with continued involvement through contact from X. This decision was taken in the days leading up to the Court Hearing and a personal home visit was arranged beforehand to explain our decision.*

19. X complained about the number of changes in Social Worker for their autistic son. The worker had been changed again and Court proceedings were due to start in the next three months. It takes time for their son to build trust in people.

We apologised that X's son had experienced a number of changes in Social Worker over the last couple of years. This is down to his Social Workers changing jobs and moving on which is outside our control. However, a Social Worker was always allocated which was our priority. We explained the case is now in the Court arena and it is the Permanency and Court Team's role to manage cases that are in legal proceedings. However, X's son's previous and current Social Worker will work together to ensure an effective handover after the Court Hearing.

<u>Complaints relating to foster placements (4 complaints)</u>

20. Young person X complained their pocket money is not in line with their age and current needs. X's foster carers receive the proper amount on their behalf but they do not give X the full amount as they are concerned what X will spend their money on. This is not a justifiable reason to withhold money.

We reviewed the money X received and increased it to the appropriate level. The money was not backdated as their foster carers had spent money on X in the preceding weeks by way of phone payments and ad-hoc money when X requested it. There were also additional concerns about X accessing additional monies.

21. X complained that a female she doesn't know contacted her via social media with some information about her baby daughter and also disclosed her placement address. The female concerned lived in the same foster placement with X's baby daughter.

From the information we had the foster carers were not the source of any leak. The source was a young person who had been in the same placement as X's daughter. The young person will have overheard discussions about daughter as they were caring for her. However the carers have been spoken with and reminded about ensuring their private conversations are not overheard by others in their home.

22. X receives no reassurances from us or their daughter's placement about being out late at night.

The home reassured X their daughter is never out late at night on the streets or at parties whilst in their care. They have a strict routine for times when daughter is out with friends during the evening.

Appendix 3

Summary of independent investigations and their outcomes at Stage 2

Social Services for Adults

1. X complained about our actions and interference and of being 'pre-judged' whilst he was the main carer for his the partner.
   The complaint was not upheld. The investigation found X was appointed an Advocate and they were involved in meetings to support X and ensure they understood the matters discussed. It was X's ex-partner's choice to have the Power of Attorney revoked. X's partner had the capacity to make this decision and this was respected. We did not interfere. There was no evidence to support his belief that he was 'prejudged' by us.

2. X complained about a wide range of issues following their father's stay including the home not taking appropriate steps following father's fall and their poor communication when he was admitted to hospital. Care Inspectorate Wales requested this matter be looked into independently.

   None of the 13 elements to the complaint were upheld. However, we sought to reassure X that her father received proper and appropriate care during his stay, the home recorded appropriately and sought advice promptly when necessary. The home attempted to contact family in the early hours of the morning X was admitted to hospital.

3. X complained about a range of matters after their father was discharged from hospital and into a new home. It included: confusion as to who was responsible for paying top up fees and a lack of communication from us during this critical time.
   X's complaint was upheld in terms of communication issues for which we apologised for, but the element of the complaint relating to process was not upheld. We reiterated our offer of a visit from a Welfare Benefits Officer to receive sound financial advice.

Social Services for Children

1. X complained we were not adhering to a recent Court Order and we had ignored their concerns over several years during which they had been the subject of domestic abuse. They also complained about our current communication with her.
   We had very different perspectives on the issues raised. Domestic violence referrals were received up to 2014, but no referrals were made since. We believed X was offered appropriate support and we sought to communicate and engage with them in a meaningful way during all this time. The outcome of the Court Hearing was muddled but this was not the fault of Social Services. We agreed to the recommendations made regarding adding X's ex-partner's convictions to X's son's casefile.

2. X complained we had breached her daughter’s confidentiality by informing a family member of her self-harming. We also allegedly told X that their granddaughter did not want to see X (at the time) and we told family members to hang up/block calls made by X.
   The complaint about informing a family member of the self-harm was partially upheld on the basis that X or their daughter should have been informed such a disclosure was to be made as a matter of good practice. We apologised. However, the disclosure was to be made regardless as per child protection procedure. The remaining complaints were not upheld.

3. X complained they were not being listened to, our reports about X were negative and not impartial, and that we were dismissive of their concerns and not taking appropriate action.
   X’s complaints were not upheld. The investigation found she was given opportunities to be listened to and be able to contribute and participate fully in the child protection process. Reports were evidence based and balanced with the focus on X’s child’s welfare. There was sufficient evidence her concerns were taken seriously and acted upon based on the available evidence and facts.

4 Mr X and ex-partner Ms X complained separately about the disclosure of inappropriate and disproportionate information being presented to Court about them both, and our negative approach and dismissive attitude toward Mr X throughout proceedings.
Neither complaints were upheld. We agreed, however, to review our practice in relation to informing a third party that a Police National Computer (P.N.C.) check is to be undertaken on them and recorded on file.

5 X complained we hadn’t made a record of a historical disclosure made, that we offered no help and/or support following the disclosure and X complained about our communication with her.
The complaint was not upheld. The investigation found that events and allegations were recorded, there was nothing to support the complaint that no offers of help/support were made and alternative methods of communication with X had been explored.

Appendix 4

Examples of compliments received

Compliments received are shared with all staff via email and a selection are included in the staff bulletin.

Adult Social Services:

Single Point of Access: "…it was X's manner that impressed me. She was always understanding, explained things calmly, and was sympathetic in a professional manner at, what was, a very upsetting time for me. When talking to my mum, X's manner was everything you would ask for. She was calm, friendly yet professional and not in the least patronising… and showed a gentle sense of humour when appropriate."

Older People Localities: "I wish to place on record they did a first class job in assisting with the transfer of X to a more appropriate nursing home, to cover their ongoing needs and requirements. Their assistance was invaluable. They were extremely helpful, professional, caring, understanding, knowledgable etc. We would have struggled without them."

O.T.: "This has made a huge difference to his confidence and independence. X has also arranged delivery of a wheelchair which now means that we can go for days out and not be concerned about not being able to socialise with friends outside the home."

Older People Provider Service: (Marleyfield) "The girls who looked after X showed exemplary consideration and kindness at all times. During his last day the sensitivity and respect show to X and me was greatly appreciated."

(Llys Raddington): "X had lost all his confidence and life was a major struggle for him. Since his move he is a changed man, he loves life and his new flat and company."

(Llys Gwenffrwd): "Never will I be able to find the words to express my heartfelt thanks for everything you did for dad. I will always have fond memories of each and every one of you."

Homecare: "I just want to say how brilliant you are! I thought I'd have to wait a long time to get care in but you've all been great, the carers are wonderful and I'm so happy you managed to get me home so quickly. I'm doing much better than I was expecting to with their help".

Crisis and Reablement: "All the care staff looked after X in a very caring and personal and professional manner. They were part of the family. They were so caring and would recommend all of them to be sent to anyone's family to assist."

Learning Disability Community Team: "I would just like to say thank you for the support you have given us both over the past year and thank you for keeping me involved in making sure we got X the right care he needed in the right place. X can now show his true potential with a bright and happy future."

Learning Disability Provider Service: "I would like to thank you and your team for all your hard work and support. X in particular was amazing and a great comfort and I'm not sure if we would have been successful if she wasn't there. Please could you pass on our thanks to X for her compassion, kindness and person centred approach which was so important in supporting X through this difficult time."

Transition: "…how totally grateful we are for the compelling support and service that X has provided for my brother. We simply do not know how we would have coped with (brother's) situation without her help. Her professionalism and dedication to her work is simply to be applauded… She has helped (brother) to a personal position whereby he is now probably the happiest he has ever been in his life."

Mental Health and Substance Team: "I could never have contemplated any of this twelve months ago or even six months ago. It has become possible because of the help and support I have been given and the kindness I have been shown by all the people I have met."

P.D.S.I.: "We are so lucky to have you looking after my mum's care! It really does help to have one less reason to stress these days."

Integrated Autism Service: "Thank you so much for inviting X to present at your conference yesterday - he was beaming all the way home. We never realised how much it would take it out of us.

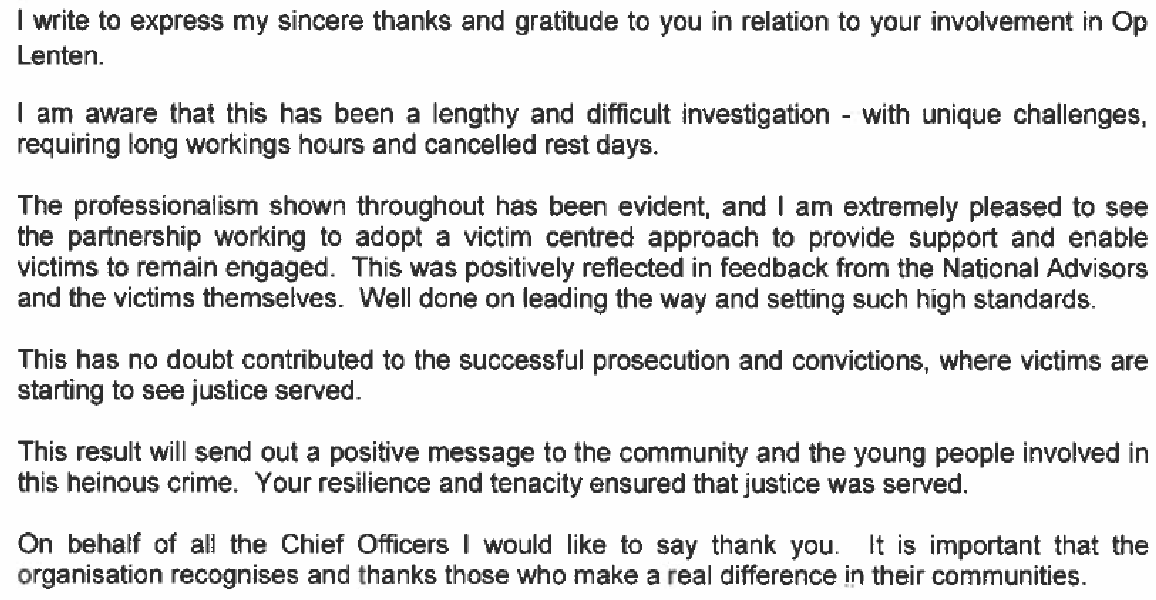
Safeguarding: "I want to say thank you for all your help, support and guidance over the years. It means a great deal to me."

Financial Assessment and Charging Team: "(Daughter) spoke extremely highly of X. She said you had been so helpful to her and fought her corner with regards to finances and care package. She was quite emotional almost with how much you had helped her."

Workforce Development: "Thank you very much for all your patience, guidance and encouragement over the three plus years."

Children’s Social Services:

The Deputy Chief Constable for North Wales Police wrote to the Department in relation to Operation Lenten. He wrote:



I write to express my sincere thanks and gratitude to you in relation to your involvement in Op Lenten.

I am aware that this has been a lengthy and difficult investigation - with unique challenges, requiring long workings hours and cancelled rest days.

The professionalism shown throughout has been evident, and I am extremely pleased to see the partnership working to adopt a victim centred approach to provide support and enable victims to remain engaged. This was positively reflected in feedback from the National Advisors and the victims themselves. Well done on leading the way and setting such high standards.

This has no doubt contributed to the successful prosecution and convictions, where victims are starting to see justice served.

This result will send out a positive message to the community and the young people involved in this heinous crime. Your resilience and tenacity ensured that justice was served.

On behalf of all the Chief Officers I would like to say thank you. It is important that the organisation recognises and thanks those who make a real difference in their communities.

Permanency and Court Team: X was complimented by a family at conference: Mum stated that she has “loved working with X, she has been brilliant”. Mum added that she “wouldn’t have got to this point without X’s support” and that she will really miss her.

Family Intervention Team: A family expressed how supportive X had been and how she had helped them through a difficult time which included a death. It was evident that she had established a rapport with the parents and children which enable the family to bring about change. X also received a card from the young person and their mother that read: “Thank you so much for what you have done. We are going to miss you.”

Targeted Support Team: X was thanked by a Barrister for her input and stating that it was invaluable.

Children’s First Contact Team were complimented by Police colleagues: “…how excellent you and your team have been in assisting us with the abundance of enquiries we have sent your way. Every email and request has been answered promptly and I do feel that both organisations have worked with the best interests of the children at heart. We pass on our thanks to you and your team for the excellent level of services you have provided to our investigation.”

Fostering Service: “We really don’t know what we would have done without all your help. You have been truly amazing. You have always been there for us, no matter what time of day or night. Your help, support and advice has been invaluable and we will never forget that.”

Safeguarding: X and X were both complimented following a meeting they had with a parent: “The meeting went really well and as a person involved with the Social I can honestly say they are two wonderful people… Thank you for your time.”

Family Information Service: “I just wanted to say thank you for the session this morning on the new online Childcare offer system. It was really informative in a relaxed environment, and I found that it was definitely worthwhile attending.”

Flying Start: “A big Thank you to all the members of the Flying Start team who devoted so much time and energy to making the day a success for Holway parents and children. It was really wonderful to witness the family engagement with us and other services and activities which included.”

SOCIAL AND HEALTH CARE OVERVIEW AND SCRUTINY COMMITTEE

Date of Meeting	Thursday 18th July 2019
Report Subject	Continuing NHS Healthcare in Wales - Consultation
Portfolio Holder	Cabinet Member for Social Services
Report Author	Chief Officer for Social Services
Type of Report	Strategic

EXECUTIVE SUMMARY

Welsh Government are seeking views on their proposed new Continuing Healthcare (CHC) Framework which replaces the previous version published in 2014. This new Framework sets out the arrangements for CHC in Wales and how eligibility is determined. It stipulates that Local Health Boards have the lead responsibility for CHC in their local area. They must, however, work with local authorities, other NHS organisations and independent/voluntary sector partners to ensure effective operation of the Framework.

This report is to provide Members with information on the Council's proposed response to the Welsh Government CHC Consultation. Further detail will be presented to Councillors such as case studies and practicalities at the meeting.

RECOMMENDATIONS	
1	Members are aware of the Flintshire position and are adequately informed to respond to the consultation as individuals.
2	Members raise awareness of the consultation with professional and personal networks.

REPORT DETAILS

1.00	**Background**
1.01	Continuing Health Care (CHC) is a package of care and support for people over 18 years of age who have complex care issues which are primarily health based. The NHS in Wales is responsible for the delivery of CHC, though the Local Authority (LA) has a role. The Health Board for North Wales is Betsi Cadwaladr University Health Board (BCUHB)
1.02	Under the Social Services and Well-being (Wales) Act 2014, Social Services will provide/fund care and support for adults who are in need of this. The LA cannot fund or provide care to undertake health tasks and if this is necessary, BCUHB are asked, through CHC, to provide and/or fund services. Some peoples' needs are clearly identified as all social care, or all health and as such, each agency will fund 100% of the package.
1.03	For a number of people, they have both health and social care needs and their package of care is jointly funded by BCUHB and Social Services. This can be commissioned by either agency with financial settlements through invoices from the commissioner to the lead partner agency. Existing arrangements are set out in the National Framework for Continuing NHS Healthcare in Wales (2014).
1.04	Around 5,000 people in Wales are receiving CHC at any point and this accounts for £360m of the annual Wales NHS budget.
1.05	There is a CHC mechanism to support Children and Young People, although there are some differences between how CHC supports adults and how it supports children.
1.06	The framework for both Adults and Children and Young People are currently being reviewed and some amendments to both the framework and the Decision Support Tool (DST), a document which helps to record evidence of an individual's care needs to determine if they qualify for continuing healthcare funding, have been proposed.
1.07	This consultation is currently being carried out by the Welsh Government and will close on the 21st of August for the Adults framework, and the 9th of August for the Children and Young People's Framework.
1.08	**Continuing Healthcare In Flintshire**
1.09	The CHC process is well-established and regularly used by Social Services. The current challenges are as follows: • As people become older, frailer, or their health deteriorates, their health needs increase. The social care package which used to meet their needs now needs to contain some health tasks. It therefore befalls on Social Services to gain engagement from CHC team in BCUHB to contribute to the cost of care packages. This is a challenge for Social Services. • Flintshire and Wrexham have the highest number of CHC packages across North Wales. This is likely due to the population size and that

officers have acted promptly and diligently to pursue CHC claims where appropriate.

- BCUHB employ a team of specialist CHC reviewers and have a management structure to solely undertake this work which affords them resource and capacity. Social Services staff however, undertake this role as part of their work.
- At the time of writing this report, there remains an outstanding amount of £565,668.49 owed to Flintshire. This represents 12 CHC cases where the agreed split of care costs is disputed by Social Services. Under the current framework, as soon as a dispute is initiated, BCU and Social Services must fund the package 50/50 until the matter is resolved.
- The challenges experienced when working with Childrens Health is that the CHC framework is less prescriptive than the current Adult framework. This can make it a challenge to secure consistent decisions on funding. For information, there are very few children who receive 100% CHC funding, and this can be attributed to how the system operates and is not directly linked to the complexity of need. Often when a child supported through CHC becomes an adult, the contribution from Adult Health BCUHB increases.

1.10 **Flintshire's initial response to the Adult CHC Consultation**

1.11 One of the most significant changes to this process is how the domains in the DST have been amended. The 'Severe' category that looks at cognition has been removed and the highest that an individual will score in this domain will be 'high'. The implications of this are that individuals with a severe cognitive impairment from, for example, an acquired brain injury or degenerative neurological condition such as dementia, who would under the current framework be funded through CHC, could no longer be eligible under this criteria.

1.12 Another example is that the domain 'other significant care needs' will no longer be scored and will instead be used as supporting evidence. This implies that an individual currently receiving CHC funding as a result of their needs in the domain, would no longer be eligible.

1.13 These two areas are of concern for Flintshire. An individual whose needs are deemed by the Local Authority to be beyond that which Social Services can support and who are currently supported through CHC funding may, under this new framework, no longer access support through CHC. This could lead to an increase in care costs for the authority.

1.14 Further work also needs to be completed to ensure that there is a practical route for those with a Direct Payment to access CHC in a way that is meaningful for the individual. Under the current framework it is not possible for those receiving a Direct Payment from the Local Authority to use the same care and support arrangements when their care costs move to full or partial CHC funding. The proposed changes do not appear to address this anomaly, thus removing control and choice for the individual and their relatives that their Direct Payment would have provided.

1.15	It would appear that the proposed changes to the CHC Framework and DST will result in fewer appropriate packages of care being funded by CHC in the future.
1.16	**Flintshire’s initial response to the Children and Young People’s CHC Consultation**
1.17	There are concerns that the wording used for the children’s framework is open to interpretation and lacks clarity. This is further complicated by differences between the Children & Young People Framework and the Adult Framework which may result in a person who was not eligible for CHC funding prior to their 18th birthday, becoming eligible as they move to adulthood.
1.18	Other concerns identified relate to gastrostomy feeding (a tube which is inserted through the abdominal wall into the stomach) which is being identified as the responsibility of either the parent carer or a Social Services carer and not a health professional. Despite the training for these individuals needing to be delivered by a health professional.
1.19	It is also noteworthy that a child or young person’s care package will not be able to be funded wholly by CHC (100% CHC is possible under the current and proposed Adult Framework). Whilst Flintshire County Council recognise that Education and Social Services have a substantial role to play in supporting these children, the fact that this arrangement will change on their 18th birthday again leads to an inconsistent approach.
1.20	This is a short summary of some of the Flintshire has identified in relation to these two consultations.

2.00	**RESOURCE IMPLICATIONS**
2.01	Delivering the actions contained within the report are within existing human and financial resources.

3.00	**CONSULTATIONS REQUIRED / CARRIED OUT**
3.01	The closing date for the consultations are : 21/08/2019 : Adults’ Consultation 09/08/2019 : Children and Young People’s Consultation.

4.00	**RISK MANAGEMENT**
4.01	There are no specific risks arising from this report and subsequent actions.

5.00	**APPENDICES**
5.01	Consultation documents (Adults)
5.02	Consultation documents (Children and Young People)
5.03	Continuing Healthcare Framework
5.04	Decision support tool

6.00	**LIST OF ACCESSIBLE BACKGROUND DOCUMENTS**
6.01	National Framework for Continuing NHS Healthcare in Wales (2014) https://gov.wales/sites/default/files/consultations/2019-05/continuing-nhs-healthcare-the-national-framework-for-implementation-in-wales_0.pdf **Contact Officer:** Jane Davies – Senior Manager Safeguarding and Commissioning **Telephone:** 01352 702503 **E-mail:** jane.m.davies@flintshire.gov.uk

7.00	**GLOSSARY OF TERMS**
7.01	**(1) Decision Support Tool**: The purpose of the Decision Support Tool is to support the application of the National Framework for NHS Continuing Healthcare and inform consistent decision making. It should be used in conjunction with the guidance in the National Framework for NHS Continuing Healthcare.

Number: WG35641

Welsh Government

Consultation Document

Continuing NHS Healthcare

The National Framework for Wales

Date of issue: 29 May 2019
Action required: 21 August 2019

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.
This document is also available in Welsh.

CONTENTS

OVERVIEW OF CHANGES

Overview

Continuing NHS Healthcare in Wales (CHC) is a package of care and support for people who have complex care issues which are primarily health based. The NHS in Wales, though local health boards, is responsible for the delivery of CHC, though there are roles for others, including local authorities, in this process. Existing arrangements for the provision of CHC are set out in the National Framework for Continuing NHS Healthcare in Wales which was published in 2014. This consultation seeks your views on amendments to the 2014 Framework.

How to respond

You can respond to this consultation by completing and returning, by midnight on the closing date, the consultation response form at the back of this document. The response should be sent to:

Complex, Unscheduled Care and Disability Branch
Partnership and Cooperation Division
Welsh Government
4th Floor, North
Cathays Park
Cardiff
CF10 3NQ

Further information and related documents

Alternatively the consultation response form is available on our website http://wales.gov.uk/consultations/?lang=en and can be returned to us, by midnight on the closing date, via e-mail to:

(English) CHCFramework.Consultation@gov.wales
(Welsh) FframwaithGIP.Ymgynghoriad@llyw.cymru

Large print, Braille and alternative language versions of this document are available on request.

Contact details

For further information, please contact:

Complex, Unscheduled Care and Disability Branch
Partnership and Cooperation Division
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email:

(English) CHCFramework.Consultation@gov.wales
(Welsh) FframwaithGIP.Ymgynghoriad@llyw.cymru

General Data Protection Regulations

The Welsh Government will be the data controller for any personal data you provide as part of your response to the consultation. Welsh Ministers have statutory powers they will rely on to process this personal data, which will enable them to make informed decisions about how they exercise their public functions. Any response you send us will be seen in full by Welsh Government staff dealing with the issues covered by this consultation. Where the Welsh Government undertakes further analysis of consultation responses then this work may be commissioned from an accredited third party (e.g. a research organisation or a consultancy company). Any such work will only be undertaken under contract. Welsh Government's standard terms and conditions for such contracts set out strict requirements for the processing and safekeeping of personal data.

In order to show that the consultation was carried out properly, the Welsh Government intends to publish a summary of the responses to this document. We may also publish responses in full. Normally, the name and address (or part of the address) of the person or organisation who sent the response are published with the response. If you do not want your name or address published, please tell us this in writing when you send your response. We will then redact them before publishing.

Any respondents to the consultation will need to be aware of the Welsh Government's responsibilities under Freedom of Information legislation. If your details are published as part of the consultation response, these published reports will be retained indefinitely. Any of your data held otherwise by Welsh Government will be kept for no more than three years.

Your rights
Under the data protection legislation, you have the right:

- to be informed of the personal data holds about you and to access it
- to require us to rectify inaccuracies in that data
- to (in certain circumstances) object to or restrict processing
- for (in certain circumstances) your data to be 'erased'
- to (in certain circumstances) data portability
- to lodge a complaint with the Information Commissioner's Office (ICO) who is our independent regulator for data protection.

For further details about the information the Welsh Government holds and its use, or if you want to exercise your rights under the GDPR, please see contact details below:

Data Protection Officer:
Welsh Government
Cathays Park
Cardiff. CF10 3NQ

e-mail:
Data.ProtectionOfficer@gov.wales

Information Commissioner's Office:
Wycliffe House
Water Lane
Wilmslow
Cheshire. SK9 5AF
Tel: 01625 545 745 / 0303 123 1113
Website: https://ico.org.uk

Introduction

Continuing NHS Healthcare (“CHC”) is the name given to a package of care and support given by the NHS, though local health boards (LHBs), to people whose needs are mainly health-based. Around 5,000 people in Wales are receiving CHC at any point and it accounts for £360 million of the annual NHS budget.

Arrangements for CHC are set out in the 2014 National Framework for Continuing NHS Healthcare in Wales (the Framework). The Framework covers adults aged 18 and over, and sets out the Welsh Government’s revised policy for eligibility for CHC and the responsibilities of LHBs and local authorities (LAs). It sets out a process for the NHS, working with LA partners, to assess health needs, decide on eligibility for CHC and provide appropriate care. All LHBs and LAs in Wales will be required to follow it.

The Framework was last revised in 2014 and made a number of significant changes at that time. These included; strengthening of governance issues; stronger provisions for the Welsh Language; the assessment process and how information is recorded (through a Decision Support Tool); a strengthened role for carers; reviews of decisions and enhanced arrangements regarding retrospective claims. It also identified and set out linkages with wider policy areas outside CHC, such as mental health, learning disability and Direct Payments.

The Framework is designed to provide consistency in practice across Wales and to ensure that adults with complex care issues can receive the appropriate level of care and support for their needs.

Scope of the review of the Framework

The scope of this review has been set by the National Complex Care Board which provides strategic oversight for CHC and comprises senior representatives from each of the seven health boards in Wales, alongside Welsh Government officials. The Board’s view was that the principles supporting the existing Framework are sound and that the review should therefore aim to clarify, refine or add to the existing Framework as appropriate.

The Welsh Government established a small working group to assist in the review. The group met on a number of occasions during 2017 and 2018 to discuss potential changes to the Framework.

Membership included representatives of:

- local health boards
- local authorities
- the Public Services Ombudsman for Wales
- third sector representatives

Summary of changes

- presentational changes - a more logical structure and flow to the document, greater clarity in some areas and general updating to reflect policy and legal changes since 2014.

- the assessment of eligibility for CHC, including:
    - planning an assessment of need
    - the use of a screening tool (’the Checklist’)
    - the assessment process
    - guidance on the Decision Support Tool, including its usage and definitions
    - guidance for pandemic and emergency situations

- making a decision on eligibility
    - the relationship between an individual and the multi-disciplinary team (MDT)
    - reaching and recording eligibility decisions
    - communicating the recommendation
    - communicating the final eligibility decision

- service provision and review
    - supporting an individual in their own home
    - clarification on the relationship between Direct Payments and CHC
    - reviews of eligibility decisions for CHC

- links between CHC and wider policy areas
    - mental health
    - Deprivation of Liberty
    - transitional arrangements for children and young people entering adult CHC

- ensuring a clear and consistent approach to the handling of disputes and appeals and that these are dealt with in a timely manner

- refining the process for handling retrospective claims.

Implementation

Once the revised Framework is published, there will be a short period before any new arrangements take effect. We will be using that time to focus and build on the existing support, guidance and performance arrangements to ensure changes are implemented effectively. This will include refining and developing:

- communication tools
- an online ‘CHC toolkit’ to assist staff, including template documentation for LHBs on contracts, policies and protocols
- structured opportunities for shared learning, through learning events, newsletters and an online forum
- a national performance framework

Q1. In addition to revising the Framework, we are placing a strong emphasis on its effective implementation. Are there particular areas you would wish to see addressed in materials developed to support implementation?

Q2. The Framework as it stands is a technical document aimed at specialist professionals who oversee assessment and care provision. We would welcome your thoughts on the potential publication of a simplified Framework aimed at both practitioners and service users. Comments on its appropriateness, including suggested format, content and style are welcome.

Q3. Does the proposed Framework provide sufficient assurance about the responsibility, ownership and governance of CHC by Welsh Government, LHBs and their partners?

Q4. What approaches could be put in place nationally, regionally and locally to further develop partnership working between local health boards, local authorities and other partners in relation to CHC?

Overview of Changes

1. Greater clarity and presentational style.

Issue

The 2014 Framework was felt to be very detailed but there was opportunity to provide further clarity in some areas and to re-order the sections to better reflect the CHC process.

Proposal

We have retained the core principles of the existing Framework; namely, to put people first, involve and engage with them and their representatives throughout the process and ensure decisions affecting them are informed by evidence. There is a continued emphasis on care and support that is focused on need and that is co-ordinated and avoids any unnecessary upheaval to an individual's way of life.

Given the size and amount of detail within the Framework, it is important to convey the requirements, responsibilities and expectations as effectively as possible. We have therefore redesigned the layout and ordering of sections so that there is a natural 'flow' which mirrors the CHC process itself from start to finish:

- key principles
- clarifying roles and responsibilities
- areas for consideration prior to any assessment
- undertaking an assessment
- eligibility considerations
- service provision and review
- links to wider policy areas
- disputes and appeals
- retrospective reviews

All annexes have been moved to the end of the document and references to policy and legislation have also been updated, notably aligning requirements to the provisions within the Social Services and Well-being (Wales) Act 2014.

Q5. It was felt that some aspects of the Framework lacked clarity. Do you agree with this? If so, have we identified and addressed the right areas in the Framework to improve clarity?

2. The assessment process

Issue

We want to ensure any assessments for CHC are necessary, professional, timely and involve the individual or their representatives. Our analysis has shown a number of factors which are necessary for the successful completion of an assessment. These factors include proper planning, the involvement of the correct people and engagement and communication with the individual and/or any chosen representatives.

Proposals

The 2014 Framework set out the process of planning for and undertaking an assessment for CHC in one section. We felt this could create confusion and have clarified those areas, separating them into two distinct sections (Sections 3 and 4 respectively).

i) Planning an assessment

Under Section 3 we retain the principles set out in the 2014 Framework, while further emphasising the need for professional and clear communications to the individual. We have also provided greater clarity regarding the specific people involved in the process. Changes include:

- how the commissioning team who provide the service assess an individual's needs
- the workings of the Multi-disciplinary Team (MDT), which makes recommendations on an individual's eligibility for CHC. Specifically membership of the team, individual roles and engagement between local health boards, local authorities, the individual and their representatives.
- the responsibilities of local health boards and local authorities in supporting carers

The requirements around seeking consent have been expanded, taking best practice introduced in the English CHC Framework. We have, for example, included additional wording which sets out the requirements necessary to seek valid consent. There are also extra provisions regarding an individual's capacity to consent, particularly where an individual may have difficulty expressing their views. The expectation is set out that those involved with any assessment are familiar with the principles of the Mental Capacity Act 2005.

Our new provisions ensure individuals have access to advocacy services and set out how any information is shared, particularly for those individuals without capacity. We have, for example, clarified the Powers of Attorney and enhanced the wording around decisions taken in the ‘best interests’ of an individual, which are in line with those in the English CHC Framework. These include added guidance on responsibility for making the decision, the role of third parties (including families, advocates and carers) and wider issues to consider when making the decision and the recording of that decision.

ii) The use of a checklist (‘the Checklist’)

Although it is used for backdated, or retrospective, claims for CHC, the use of a screening tool or checklist is not mandated for contemporary assessments. It can however, be useful in specific circumstances to identify ‘triggers’ for CHC which need further consideration. For example, care home residents whose condition has changed and require an earlier than planned review. ‘The Checklist’ is referred to in the 2014 Framework, and is attached in Annex 4.

We have provided further detail on its use in this section of the new Framework and Annex 4. Its is designed to the checklist used in England and we have added detailed guidance on its use for contemporary and retrospective cases. This guidance includes when it should be used; who may complete it how it should be completed; next steps following its completion when eligibility or no eligibility has been found.

iii) The assessment of eligibility for CHC

There is no intention for policy changes made through this process to impact on the eligibility threshold for CHC, which is well-established and based on the consideration of a ‘primary health need’.

In terms of the assessment process itself, additional wording has been included to ensure screening and assessments of eligibility for CHC should be undertaken at the right time and location for the individual, when any ongoing needs are known and ideally within a community setting. New wording, which aligns to provisions for CHC in England, recognises that any consideration for CHC should only happen after an individual is discharged from hospital, should not delay the discharge process and a range of alternative care and support such as reablement or interim services should help a timely discharge.

We have also included a new section on identifying a person’s eligibility for CHC based on the totality of their needs and requiring a clear, reasoned decision which requires LHBs and LAs to consider, regardless of the outcome, whether a multi-disciplinary assessment has identified issues to be addressed.

We have also clarified and incorporated wording in the existing Decision Support Tool around conditions that are effectively controlled ("well-managed needs"), based in part on new provisions introduced in England. This notes that care and due regard should be given to such conditions, noting for example that needs may appear to be exacerbated if an individual is in an inappropriate environment because they require a particular type of care and support. Our proposals promote a joint approach between the NHS and local authorities to the assessment of need, where appropriate and for it to take into account any wider care and support needs of the individual. This would be regardless of the eventual outcome.

In line with the duties on local authorities under the Social Services and Well-being (Wales) Act 2014, there is now a strong emphasis that there should be no gap in the provision of care and consideration of eligibility.

iv) The Use of a Decision Support Tool ("DST")

We want to further clarify the use of the DST and ensure it is used appropriately as part of any assessment for eligibility.

In terms of the Framework itself, there are a number of minor changes regarding provisions that were already in the 2014 Framework. These have been reordered and re-worded slightly for greater clarification and prominence.

Examples include how the DST should not be used as a 'scoring mechanism' and that a multi-disciplinary assessment of needs must be carried out before the DST is used.

There is also additional wording to reflect enhanced provisions on the use of the DST in the draft Framework. Whilst we wish to avoid unnecessary duplication, replicating the wording of the Framework in the DST reinforces the principles set out in the Framework and ensures they are not overlooked when put into practice. For example, in both the draft Framework and draft DST we now say the following, whereas previously messages were spread across the two documents:

- any decision on eligibility must be clearly and professionally explained to an individual.
- consent should be obtained from an individual with capacity before the completion of the DST.
- the individual should be invited to be present or represented wherever practicable and given reasonable notice of completion of the DST to enable them to arrange for a family member or other person to be present, if necessary.
- the MDTs role in completing the DST.
- how the decision should be communicated.

The 12 “Domains”

Aside from wider narrative changes the 12 domains of identified need are broadly unchanged, with a few minor amendments proposed as follows:

- Behaviour – add reference to self-harm as an example.
- Mobility – revise notes. For example, replacing the reference to the 2001 National Service Framework for Older People with a more general emphasis on assessment.
- Nutrition – revise wording and examples in the low, moderate, high and severe categories.
- Psychological and Emotional Needs – clarify wording around the individual’s engagement in the care process.
- Cognition - replace the previous highest level of identified need of ‘severe’ with ‘high’.
- Drug Therapies or Medication – replace references to ‘non-concordance’ with ‘refusal or misuse of medication’.
- Other Significant Care Needs – remove the levels of need in order to better reflect its purpose to capture areas for wider consideration.

We have revisited the 2014 Decision Support Tool to reflect the change in the domains. We propose to reorder these more logically - into an order in which a person’s needs would normally be considered. There is additional wording under many of the domains to support effective completion of the DST.

iv) Pandemic and other emergency situations

We have included wording in line with UK Government policy about completing assessments in the event of the above. Where these situations occur, our proposals place priority on the safety of the patient, ensuring they receive the care they need. This would mean that LHBs should be able to choose not to undertake a CHC assessment until after the emergency period but they will retain the responsibility for the individual’s care and should work with local authorities as necessary.

Q6. The following aspects have been considerably revised:

- assessment process
- consideration of eligibility
- use of toolkits, notably the Checklist and the Decision Support Tool

Do you agree these areas, as they are proposed, are fit for purpose?

Q7. Do you think that individuals and their families are involved enough in the updated assessment process? If not, in which additional ways would you like to see the process improved?

3. Making a recommendation on eligibility

Issue

As part of the decision-making process, the MDT is required to make a recommendation to the LHB as to whether or not the individual has a primary health need. The LHB takes this recommendation into account when deciding on an individual's eligibility for CHC. This decision must be clearly communicated to the individual.

Evidence from previous cases suggests these principles have not always been applied consistently. This can lead to confusion, frustration and potentially challenge to the eventual decision.

Proposals

We are proposing to strengthen the provisions in Section 5 around how eligibility decisions are reached, recorded and ultimately conveyed to the individual. The changes proposed here are in line with some of the "Key Principles" of communication and involvement, which are set out at the front of the Framework, and which promote effective communication and involvement with the individual.

i) The relationship between the individual (and/or their representatives) and the MDT

We have introduced new wording to explicitly set out how the MDT should involve the individual and their representatives. This confirms the individual and/or their representatives cannot be members of the MDT. However, they should be fully involved in the process and be given every opportunity to contribute and attend the MDT discussions which will inform the recommendation to the LHB.

ii) Reaching and recording eligibility decisions

We have proposed stronger arrangements around the responsibilities on the MDT as part of this process.

We are reinforcing in the Framework and the DST that in cases where the LHB does not accept the MDT's recommendation, they may request and accept additional evidence and ask the MDT to reconsider its decision. By contrast, the 2014 Framework, simply stated that "Only in exceptional circumstances and for clearly articulated reasons should the LHB not accept the multidisciplinary team's expert advice on CHC eligibility".

We are proposing that where the MDT is unable to reach agreement on the recommendation this should be clearly recorded and evidenced. Although this was referred to in the DST guidance, we are now explicitly stating within the Framework that where agreement cannot be reached, practitioners should consider the higher level of a domain but with clear reasoned evidence to support this. Where additional evidence may be sought, this should not prolong the eligibility process unduly.

iii) Communicating the recommendation (to the LHB and the individual)

We have also stipulated how the MDT's recommendations should be conveyed to the LHB and the individual. Our proposed format provides clear, concise but sufficient detail to enable the LHB and the individual to understand the underlying rationale for the recommendation. Where individuals and/or their representatives are not present, then the recommendation should be communicated to them as soon as possible.

iv) Communicating the eligibility decision

We have provided a new section, setting out precisely how the final decision on eligibility should be conveyed to the individual and/or their representatives.

This information should be conveyed to the individual in writing, as soon as the final decision has been reached by the LHB. This should include a clear decision and rationale for eligibility (based on a primary health need) and be accompanied by a copy of the DST. It should also include contact details of those who can help provide any further clarification; and also set out how to request a review of any decision.

Where someone is eligible for CHC there should be an indication of the likely package of care and support they will receive to meet their needs. If they are ineligible then the letter may set out an alternative package of care appropriate to their needs.

4. Service provision and review

Issue

LHBs are responsible for the planning and provision of CHC. Any consideration cannot be taken in isolation to other services, however, and a full assessment and consideration of care and support needs will require them to work in partnership with other bodies, including local authorities.

This area presents specific challenges, not least how CHC relates to the provision of other care packages, which it is felt were not adequately covered in the previous Framework. An example of this is the use of Direct Payments (where an individual receives money and arranges for their own care). This is a popular service for those that use it but is incompatible with CHC.

Proposal

i) Supporting individuals eligible for CHC in their own home

The 2014 Framework recognises there are a number of complex packages of care being delivered in an individual's own home. This is recognised in our draft Framework where we reiterate the NHS is responsible for meeting health and social care needs of those eligible to receive CHC and wish to live at home. We have introduced new wording to clarify some of the limits of those responsibilities. For example, the NHS is not responsible for rent, food, normal utility bills and matters covered by personal income. It also stipulates LHBs cannot set arbitrary limits on care at home based on costs.

Our new wording also makes clear that whilst LHBs can take comparative costs and value for money into account, they cannot set arbitrary limits on care at home packages.

Where joint packages of care are required, LAs are reminded of their duty to meet and assess any needs they are responsible for under the Social Services and Well-being (Wales) Act.

ii) Direct Payments

In line with the principles in the previous version of the Framework, it is currently unlawful for Direct Payments to be used to purchase health care which the NHS is responsible for providing. It is not unlawful, however, for local authorities and health boards to work together to provide individuals with voice and control in respect of their health and social care needs. This includes the pooling of budgets and other mechanisms to ensure people experience seamless care.

We have introduced some further clarifications in this area. We have made it clear that every effort should be made by partner organisations to ensure that individuals are made aware that Direct Payments will no longer apply if they become eligible for CHC Funding. We have also clarified that there can be no assumption that LAs will continue to provide Direct Payments, where a CHC assessment is refused.

iii) Reviews of CHC Eligibility

An individual’s eligibility for CHC is subject to review. Reviews should follow the format of an assessment, consider all the services received and be tailored to the individual.

These are not new arrangements within the Framework but we have clarified the focus of these reviews, namely to ensure the care plans remain appropriate for the persons needs. They should be proportionate to the situation in question in order to ensure that time and resources are used effectively.

To ensure reviews are relevant, evidence-based and considered appropriately, we have included new provisions. These state that any reviews of a person’s need must be informed by the most recent DST. Any evidence of a change in those needs will require a full reassessment including a new DST by the MDT. We have placed new expectations on LHBs to consult with LAs before making any decisions on eligibility and to ensure an individual’s needs continue to be met during this reassessment of eligibility process. There should also be no unilateral withdrawal of a funding package.

We have also enhanced wording in the 2014 Framework into a separate section which sets out the expected outcomes of a review (namely meeting needs, considering eligibility for CHC and determining whether any change in needs requires a change in a care package). The new provisions stipulate the need for due consideration of a change in an individual’s location or funding of their care as part of that review.

5. Links to wider policy areas

Issue

We have retained links to other policies and areas in our draft Framework, though these have been pulled into a separate section. Given the existing Framework was written in 2014 there is a need to update and reflect any changes in these areas.

Proposals

i) Mental health

Where appropriate, we have clarified and strengthened the wording around aftercare services for Mental Health (Section 117 of the Mental Health Act 1983). The draft Framework recognises that the provision of Section 117 is shared between LAs and the NHS, although this does not necessarily mean there should be a 50/50 split in all cases. Where a patient is eligible for services under Section 117, these should be provided under Section 117 and not under CHC.

ii) Deprivation of Liberty

There are additional provisions in relation to Deprivation of Liberty (DoL). The Mental Capacity Act 2005 contains provisions that apply to a person who lacks capacity and where care arrangements amount to a deprivation of their liberty. The fact that a legal authorisation is being sought or is in place in relation to a deprivation of liberty of capacity does not affect the consideration of whether that person is eligible for CHC.

iii) Transition from children and young person to adult services

There are minor additions within this section, in order to align with proposed amendments to the Children and Young People's Continuing Care Guidance to be published later this year. We have strengthened the emphasis that the aim of transition planning is to ensure a consistent package of support, jointly designed and agreed by the young person and their carers. This should start, not just at 14, but as soon as possible where the need is already identified or as soon as possible, if problems emerge that will require ongoing care, after this age. We are aligning with their new proposals, which require a formal referral for assessment to be completed by the time a child is 16 years of age.

iv) Applying the CHC Framework to adults with a learning disability

We have amended the first paragraph in this section in line with the Welsh Government's desired outcomes.

Q8. In your view, does the proposed Framework link well with, other health and social services policy and guidance? Are there any other linkages to good guidance or innovative practice we should be making?

6. Disputes and appeals

Issue

The Welsh Government expects local health boards and their partners to work together to deliver the best possible outcomes for the citizens of Wales. Effective partnership working and integration, together with implementation of this Framework should minimise the need to proceed to formal dispute procedures.

Where disputes arise, we want to ensure there is a clear, consistent approach across LHBs in Wales in how disputes and appeals are managed. This will avoid distress being caused to individuals and their families or carers as a result.

Proposals

i) Disputes

We have now added a requirement that where there is an unresolved dispute within the MDT on a recommendation, then this should be escalated within 48 hours to ensure quick consideration of the individual's needs.

Whilst it is preferable for any disputes to be settled informally, the 2014 Framework contained provisions for LHBs and LAs to establish a protocol to resolve disputes. Our new proposals now set out various elements these protocols should contain. These include various timescales, stages, escalation procedures and a final stage, including independent arbitration.

Where disputes relate to local authorities and LHBs in different geographical areas, the dispute resolution process of the responsible LHB should normally be used in order to ensure resolution in a robust and timely manner.

ii) Appeals

In terms of appeals, LHBs are now expected to explain to individuals the arrangements and timescales for dealing with a review of the eligibility decision.

A new stipulation has been added that a request to review a decision about eligibility for either CHC or NHS Funded Nursing Care must be made within 28 days of the individual and/or their representative being informed of that decision. We propose to recognise exceptional circumstances outside this period. This deadline is designed to ensure that individuals receive the right care, at the right time and in the right place. It is felt that 28 days is appropriate - if an individual were to appeal a decision after that time it is probable that their needs have changed and a fresh assessment would be required.

Retrospective reviews

Issue

An individual and/or their representative may request a retrospective review where they contributed to the cost of their care, but have reason to believe that they may have been eligible for CHC. A retrospective review claim is different from an appeal against a current CHC assessment and decision on eligibility.

There is a historic backlog of retrospective claims, which have been managed by the National All-Wales Project Team as well as individual LHBs. From April 2019, all claims will be managed by individual LHBs and there is a need to make processes as clear and effective as possible to ensure the timely and correct resolution of those claims.

Proposals

We have previously announced exercises to 'close down' (or ‘cut-off’) the periods within which claims could be considered for eligibility for CHC. This is because as time passes, it becomes more difficult to access an individual’s care records, which is essential in order to understand their care needs for the period in question and their eligibility for CHC. Previous cut-off exercises have proven to be complex to manage. In some cases, for example, they have resulted in a sudden influx of claims to LHBs once any public announcement is made. We have therefore moved to a rolling cut-off of 12 months from the date of the claim.

At the start of the process for considering the eligibility of a retrospective claim, evidence of the claimants legal and authority and proof of payment of care fees are obtained by the LHB. Section 9 in the draft Framework proposes a new protocol for requesting records from health and social care providers. Under this, all agencies will be asked by LHBs to provide the necessary supporting records within 3 months or to confirm that they have been destroyed, lost or are unavailable for any other reason. Examples of circumstances where the LHB may consider exceptions to this practice are contained within the draft Framework.

From this point, we have provided a new two-stage process for considering a retrospective claim, developing the necessary chronology of need from the records available and the claimant’s views. This is to manage the large volume of claims and make the system more manageable. The requirements employ a checklist to identify triggers for eligibility, albeit this would not replace professional judgement in this matter.

The proposed two-stage process is as follows:

- Stage 1 - A checklist, ('the Checklist'), based on the Decision Support Tool, is applied to an individual's chronology or history of care and support needs to identify triggers for full consideration of eligibility for CHC. A trigger date may be identified at the start of the claim period or part way through to identify when the individual became eligible for CHC. If there are no triggers for consideration of eligibility, the case is closed at this point. Claimants should be sent a written explanation of the outcome.

- Stage 2 - Where triggers are found, the information in the chronology will be reviewed and assessed against the 4 primary health need indicators (nature, intensity, complexity and unpredictability).

- Once all information has been analysed, it is compiled into a document detailing the recommendation. This document is peer reviewed by a different clinician to ensure the recommendation and supporting evidence is robust and that the criteria have been consistently applied. To further ensure the timely resolution of claims, we are proposing that cases with no eligibility are peer-reviewed by "*at least one different clinician"*. The existing arrangements require two such individuals and it can prove a challenge to find mutual availability of individuals in a short space of time, and does not enhance the outcome of the review itself.

Q9. Is the proposed two-stage process for retrospective reviews appropriate and sufficiently comprehensive?

Independent Review Panel

require all cases presented to an IRP to be decided unanimously by all panel members.

Furthermore, in cases where no eligibility was found, we have introduced two new provisions to avoid any unnecessary delays in the process where no eligibility of partial eligibility was found by the IRP. In cases of no eligibility, if a claimant does not wish to attend a negotiation meeting in person, the recommendation should be discussed over the telephone or in writing as far as possible. In cases of partial eligibility, where a claimant does not wish to attend the negotiation they should also be able to discuss the recommendation over the phone, then an IRP should be convened.

Consultation response form

Your name:

Organisation (if applicable):

email / telephone number:

Your address:

Responses to consultations are likely to be made public, on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: ☐

Consultation questions

<table>
<tr><td colspan="3">**Question 1**
In addition to revising the Framework we are placing a strong emphasis on its effective implementation.
Are there particular areas you would wish to see addressed in materials developed to support implementation?</td></tr>
<tr><td>YES</td><td>PARTLY</td><td>NO</td></tr>
<tr><td colspan="3">if you have answered partly or no could you please tell us what additional information is needed?</td></tr>
<tr><td colspan="3"></td></tr>
</table>

Question 2 The Framework as it stands is a technical document aimed at specialist professionals who oversee assessment and care provision. We would welcome your thoughts on the potential publication of a simplified Framework aimed at both practitioners and service users. Comments on its appropriateness, including suggested format, content and style are welcome.

Question 3 Does the proposed Framework provide sufficient assurance about the responsibility, ownership and governance of CHC by Welsh Government, LHBs and their partners?		
YES	PARTLY	NO
If you have answered partly or no can you tell us what you recommend we change/ add?		

Question 4 What approaches could be put in place nationally, regionally and locally to further develop partnership working between local health boards, local authorities and other partners in relation to CHC?

Question 5 It was felt that some aspects of the Framework lacked clarity. Have we identified and addressed the right areas in the Framework and improved clarity?		
YES	PARTLY	NO
If you have answered partly or no, can you please tell us what area is unclear?		

Question 6

The proposed key areas of the framework are:

The following aspects have been considerably revised

- assessment process,
- consideration of eligibility
- use of toolkits, notably the Checklist and the Decision Support Tool

Do you agree these areas, as they are proposed, are fit for purpose?

YES	PARTLY	NO
If you have answered partly or no could you please tell us what additional key areas or changes you would wish to see?		

Question 7 Do you think that individuals and their families are involved enough in the updated assessment process?		
YES	PARTLY	NO
If you have answered partly or no can you give us details of what you would recommend to be added?		

Question 8 In your view, does the proposed Framework link well with other health and social services policy and guidance?		
YES	PARTLY	NO
If you have answered partly or no can you tell us what feel is missing and what you recommend we add?		

Question 9 Is the proposed two-stage process for retrospective reviews appropriate and sufficiently comprehensive?		
YES	PARTLY	NO
If you have answered partly or no can you tell us what feel is missing and what you recommend we add?		

Question 10: We would like to know your views on the effects that the new Framework would have on the Welsh language, specifically on opportunities for people to use Welsh and on treating the Welsh language no less favourably than English.

What effects do you think there would be? How could positive effects be increased, or negative effects be mitigated?

Comments

Question 11: We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, please use this space to report them:

Please enter here:

Number: WG37923

Welsh Government
Consultation Document

Children and Young People’s Continuing Care

Date of issue: 17 May 2019
Action required: Responses by 09 August 2019

Mae’r ddogfen yma hefyd ar gael yn Gymraeg.
This document is also available in Welsh.

Overview

This consultation seeks your views on the updated guidance document for Children and Young People's Continuing Care.

How to respond

This consultation will close on 09 August 2019. You may respond online, by email or by post.

Online
Please complete the online questionnaire on the consultation pages of the Welsh Government website:

Email
Please complete the consultation response form and send it to: ChildrensHealth@gov.wales

Post
Please complete the consultation response form and send it to:

Women and Children's Health
Welsh Government
Cathays Park
CF10 3NQ

Further information and related documents

Large print, Braille and alternative language versions of this document are available on request.

Contact details

For further information:

Women and Children's Health
Welsh Government
Cathays Park
CF10 3NQ

email: ChildrensHealth@gov.wales

telephone: 03000 251534

General Data Protection Regulation (GDPR)

The Welsh Government will be data controller for any personal data you provide as part of your response to the consultation. Welsh Ministers have statutory powers they will rely on to process this personal data which will enable them to make informed decisions about how they exercise their public functions. Any response you send us will be seen in full by Welsh Government staff dealing with the issues which this consultation is about or planning future consultations. Where the Welsh Government undertakes further analysis of consultation responses then this work may be commissioned to be carried out by an accredited third party (e.g. a research organisation or a consultancy company). Any such work will only be undertaken under contract. Welsh Government's standard terms and conditions for such contracts set out strict requirements for the processing and safekeeping of personal data.

In order to show that the consultation was carried out properly, the Welsh Government intends to publish a summary of the responses to this document. We may also publish responses in full. Normally, the name and address (or part of the address) of the person or organisation who sent the response are published with the response. If you do not want your name or address published, please tell us this in writing when you send your response. We will then redact them before publishing.

You should also be aware of our responsibilities under Freedom of Information legislation

If your details are published as part of the consultation response then these published reports will be retained indefinitely. Any of your data held otherwise by Welsh Government will be kept for no more than three years.

Your rights

Under the data protection legislation, you have the right:

- to be informed of the personal data held about you and to access it
- to require us to rectify inaccuracies in that data
- to (in certain circumstances) object to or restrict processing
- for (in certain circumstances) your data to be 'erased'
- to (in certain circumstances) data portability
- to lodge a complaint with the Information Commissioner's Office (ICO) who is our independent regulator for data protection.

For further details about the information the Welsh Government holds and its use, or if you want to exercise your rights under the GDPR, please see contact details below:

Data Protection Officer:
Welsh Government
Cathays Park
CARDIFF
CF10 3NQ

e-mail:
Data.ProtectionOfficer@gov.wales

The contact details for the Information Commissioner's Office are:
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Tel: 01625 545 745 or
0303 123 1113
Website: https://ico.org.uk/

Introduction

This consultation seeks your views on the updated guidance document *Children and Young People's Continuing Care.*

A small number of children and young people may have very complex health needs. These may be the result of congenital conditions, long-term or life-limiting or life-threatening conditions, disability, or the after-effects of serious illness or injury. A number of children and young people will have complex mental health or a learning disability requiring specialist therapeutic input or placement provision.

Most needs can be met by the care which is routinely provided by LHB's, or in some cases, Welsh Health Specialised Services. However, for a small number of children, their needs are such that they cannot be met by these existing universal or specialist services by a case management approach. An additional package of support may be needed. This package of additional support has come to be known as continuing care. This framework supports LHB's in determining if a child's needs are such that they require such a package of continuing care.

Continuing Care is defined as care provided over an extended period of time to a person to meet physical or mental health needs which have arisen as a result of illness (any disorder or disability of the mind and any injury or disability requiring medical or dental treatment or nursing). The continuing care process begins when there is an emerging recognition that a child or young person may have continuing care needs that cannot be met through existing universal or specialist services alone. Children and young people can be referred for assessment through a number of different routes, settings and care pathways.

Background

The current Children and Young People's Continuing Care Guidance (the 2012 guidance) dates from 2012 and is designed for use by all those planning and providing children's continuing care services in health boards, local authorities and their partners.

The legislative landscape has changed significantly since 2012 as several important pieces of legislation have been introduced that have direct relevance to continuing care. These include the Social Services and Well-being (Wales) Act 2016 and the Additional Learning Needs and Education Tribunal (Wales) Act 2018. There is therefore a need to produce revised guidance that takes full account of this legislation.

Welsh Government became increasingly aware that practitioners in health boards and local authorities were finding the 2012 guidance unhelpful and felt there was a focus on process at the expense of actual outcomes. We concluded there was a need to review the 2012 guidance and produce a revised version that clearly put the child at the heart of the process.

To support the development of the revised guidance and also to seek views from practitioners on the issues they had been encountering, Welsh Government held a workshop event in the SWALEC Stadium on 4 October 2018. The event was very successful, with approximately 80 attendees from a range of health and social services settings across Wales. The outputs from the day confirmed that the 2012 guidance was considered outdated and that there was a real need for revised guidance to be introduced.

To ensure the views of people who were involved in the day to day operation of the continuing care system in Wales were fully reflected, officials established a small task and finish group consisting of practitioners from health and social services teams across Wales to draft the revised guidance.

The draft updated Children and Young People's Continuing Care Guidance is attached to this consultation. We would welcome your feedback and views and have included some specific questions which we would ask that you answer.

Consultation questions

Q1.	**Is the guidance clear as to who Children and Young People's Continuing Care is for and are the criteria for eligibility clear?**
Q2.	**Does the check list at Annex B clearly identify those children and young people eligible for Continuing Care?**
Q3.	**Is the guidance and the tools sufficiently clear for the identification of need to be looked at in a multi-agency way?**
Q4.	**Is the process from identification of need, through to assessment clear within the guidance?**
Q5.	**Does the guidance allow you to understand what information should be used when conducting assessments?**
Q6.	**Does the guidance provide clarity on how to involve the correct stakeholders to develop a suitable programme of work in support of a child or young person who needs Continuing Care?**
Q7.	**Is the role of the Multi-agency Panels clear?**
Q8.	**The nominated children and young people's health assessor makes a recommendation, following consensus of the multi-disciplinary team meeting, as to whether the child or young person has continuing care needs that cannot be met by existing universal or specialist services and will require a package of care involving bespoke planning and funding arrangements.**

i. Do you support that the MDT should both:

- a- Make the recommendation of eligibility?
- b- Recommend the care package based on assessed need?

Q9.

The timelines have been increased from the guidance in the 2012 document to reflect current working practice.

i. Are the revised timelines realistic bearing in mind the plans to roll out the Welsh community care information system (WCCIS)?

Q10.

The children and young people's health assessor should be a health practitioner with the relevant skills and competencies to undertake assessments within the scope of their own practice. This role may be a dedicated role within a continuing care team or a practitioner within a community children's nursing team, learning disability team or CAMHS team. LHB's will need to ensure that the health assessor role is properly resourced and supported to make a recommendation.

i. Do you agree with this view that assessments must be led by practitioners who have the necessary skills and competency to assess within the scope of their practice?

Q11.

The completed assessment with recommendations and costed options should be quality assured in line with health board governance arrangements.

i. Do you support that governance arrangements should be set out within the guidance?

ii. Do the key points cover all aspects of quality assurance?

Q12.

Best practice supports that disputes are resolved as quickly as possible. The interests of the child is paramount and no child should be denied access or have access to the appropriate health care delayed as a result of a dispute. LHB's and LA's must have dispute resolution built into their agreed continuing care pathway

i. Should the guidance outline a dispute resolution pathway?

ii. Should there be formal agreement across health boards for peer review and independent assessment?

Q13.

Does the guidance provide a clear legal position on Direct Payments and in what circumstances their use might be appropriate?

Q14.	**Is the guidance clear enough that the use of pooled budgets should be considered as a mechanism for ensuring timely provision of care?**

Q15.	**We would like to know your views on the effects that the draft Children and Young People Continuing Care Guidance would have on the Welsh language, specifically on opportunities for people to use Welsh and on treating the Welsh language no less favourably than English.**

Q16.	**Please also explain how you believe the draft Children and Young People Continuing Care Guidance could be formulated or changed so as to have positive effects or increased positive effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language, and no adverse effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language.**

Q17.	**We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, please use this space to report them.**

Responses to consultations are likely to be made public, on the internet or in a report. If you would prefer your response to remain anonymous, please tick here:

DRAFT

The Children and Young People's Continuing Care Guidance

May 2019

Section 1

The Children and Young People's Continuing Care Guidance – An introduction

This guidance is intended to assist Local Health Boards (LHB's), Local Authorities (LA's) and their partners (for example Children's Hospice, Action for Children, Barnardo's, specialist educational provision) to plan and support children and young people's continuing care needs.

It is intended to support understanding of the range of potential need - physical and learning disabilities, mental health needs, autism or behaviour which may be considered challenging - and how meeting those needs with a package of continuing care may fit with other types of support. It can assist LHB's in understanding their responsibilities towards children and young people with complex needs, and in reaching agreement with their local authority partners.

It provides advice based on existing practice across the country on undertaking a holistic assessment of the child or young person's needs. The guidance is intended to support agencies, such as health, education and social care in meeting their statutory duties under the National Health Service (Wales) Act 2006 (NHS Act 2006) and the Social Services and Wellbeing (Wales) Act 2014 (SSWBA). LHB's have autonomy as to how they fulfil this function, and what process they adopt but adherence to the principles of this framework should ensure consistency and fairness.

The children and young people's continuing care process should:

- Ensure that leaders and staff are aware of and adhere to the principles of children's rights and wellbeing in line with The United Nations Convention on the Rights of the Child;

- Make the child or young person and their parents and carers the focus of the continuing care process using person centred practice and a "what matters" approach, in line with the Social Services and Well-being (Wales) Act 2014;

- Recognise that children and young people's continuing care is part of a graduated response to meeting the needs of children and young people. Joint assessment processes must be supported to reduce the possibility of multiple or repeated assessment or fragmented care;

- All children and young people who are deemed eligible for continuing care will have outcomes recorded in a plan of care, for example a care and support plan/ care and treatment plan or an individual development plan (IDP). These will be reviewed and measured in line with statutory responsibilities set out in the SSWBA, the Mental Health (Wales) Measure 2010 and the Additional Learning Needs and Educational Tribunal Wales Act 2018;

- Follow local pathways which are agreed and jointly owned by LHB's, LA's and their partners,

- In line with the Welsh Language (Wales) Measure 2011, Welsh language services should be built into planning and delivery and Welsh language services should be offered to Welsh speakers without them having to request it.

The guidance comprises of the following:

- A definition of children and young people's continuing care and its place within support for children with complex needs.

- Legislation and policy for LHB's and LA's to include statutory responsibilities.

- The principles, timelines and the phases involved in assessing and arranging provision of continuing care. It also considers transition from child to adult services.

- A range of assessment tools to aid identification of continuing care needs in children and young people. This includes a nursing assessment and an eligibility support tool which explores needs using a person centred approach.

- A governance framework for the continuing care pathway from assessment to delivery and evaluation of care.

- The roles and responsibilities of the LHB, health assessor and other professionals involved in a child or young person's care.

Section 2

Children and Young People's Continuing Care – An overview

> ***A continuing care package will be required when a child or young person has long-term needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone.***

A small number of children and young people may have very complex health needs. These may be the result of congenital conditions, long-term or life-limiting or life-threatening conditions, disability, or the after-effects of serious illness or injury. They may have technology-dependence requiring nursing input. A number of children and young people will have complex mental health or a learning disability requiring specialist therapeutic input or placement provision.

Most needs can be met by the care which is routinely provided by LHB's, or in some cases, Welsh Health Specialised Services (WHSSC (an example would be Specialist Tier 4 services for Mental Health). However, for a small number of children, their needs are such that they cannot be met by these existing universal or specialist services by a case management approach. An additional package of support may be needed. This package of additional support has come to be known as continuing care. This framework supports LHB's in determining if a child's needs are such that they require such a package of continuing care.

An important principle of continuing care is that it is **additional** to care which is provided either as a universal service, or a specialised service. **It is not an alternative**. It is needed because universal or specialised services do not fully meet a child or young person's needs, due to their complexity. An assessment of needs should be undertaken on the basis that it is believed that these existing services are insufficient to meet a child or young persons' needs. An assessment for continuing care, and agreement of eligibility, should not be undertaken to remove an effective existing package of support, or shift commissioning responsibility between health and social care.

This guidance is designed to build on existing good practice where it exists and to provide clear guidance for areas where processes and partnerships are less well developed.

The child or young person with continuing care needs should have a clearly structured care pathway, should form part of the continuum of care which starts with universal services and into specialist services. This is clearly outlined in guidance for regional partnership boards for the integrated commissioning of services for families, children and young people with complex needs 2018[1]*.
*
Where there are consistent or recurring identified gaps in universal and specialist services, LHB's may consider commissioning services to meet an identified population need rather than using an individual approach through continuing care.

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[1] Welsh Local Government Association (WLGA) 2018 Guidance for Regional Partnership Boards - Integrated Commissioning of Services for Families, Children and Young People with Complex Needs

2.1 Differences between children and young person's continuing care (CYP CC) and NHS Continuing Healthcare (CHC)

It is important to recognise, and reflect in practice, that children and young people's continuing care covers young people up to their eighteenth birthday. Thereafter, young people with very complex needs *may* be eligible for NHS Continuing Healthcare and NHS-funded Nursing Care, for which there is a National Framework for Adult Continuing Healthcare 2014 and supporting guidance and tools. http://www.cciss.org.uk/home

The convention of referring to children's 'continuing care' has developed over time to reflect the broad similarities of the two approaches. However, there are fundamental differences.

In particular, NHS Continuing Healthcare (CHC) is a complete package of ongoing care arranged and funded solely by the NHS through Local Health Boards (LHBs), where an individual's primary need has been assessed as health-based. The NHS is consequently responsible for providing for all of the individual's assessed health and associated social care needs, including accommodation, if that is part of the overall need.

If a child or young person is found to be eligible for children and young people's continuing care (CYP CC,) **the LHB is not the responsible body for funding any social care which may be needed - this remains a LA responsibility**. A LHB and a LA may therefore jointly fund care to meet a child or young person's needs – as part of a joint health and social care package. Additionally, the NHS Continuing Healthcare framework should not be used in relation to children and young people (except when anticipating the needs of a young person approaching their eighteenth birthday, see Section 4 below).

Although a child or young person may be in receipt of a package of continuing care, they may not be eligible for NHS Continuing Healthcare or NHS-funded Nursing Care once they turn eighteen.

2.2 The children and young people's continuing care process

The continuing care process comprises of four phases. Assessment, decision-making, arrangement of provision and review.

Examples of screening and assessment tools are to be found in Annex B.

Assessment

The assessment is led by a children and young people's health assessor nominated by the LHB, who will draw on the advice of other professionals and may undertake a pre-assessment to determine whether or not a full assessment is necessary. The assessor considers all relevant evidence to make a holistic assessment of the child’s needs, including:

- The preferences of the child or young person and their family / carers and advocate where appropriate. This should be in accordance with the fundamental principal of the Social Services and Wellbeing (Wales) Act 2014 of Voice and control – putting the individual and their needs, at the centre of their care, and giving them a voice in, and control over reaching the outcomes that help them achieve well-being;

- Holistic assessment taking account of assessments such as a nursing assessment and the care and wellbeing assessment;

- Reports and risk assessments from the multi-disciplinary team.

Best practice supports that a multidisciplinary team meeting is convened and the information above is collated and used to determine the unmet needs using a person centred approach. The multi disciplinary team should consist of professionals who know the child (for example Learning Disability Nurse, Community Children’s Nurse, Occupational Therapist, Speech and Language Therapist, Occupational Therapist, Social Worker, Support Worker and Teacher) and can actively contribute to the plan of care. This team will include representation from both the LHB and the LA.

The nominated children and young people’s health assessor makes a recommendation, following consensus of the multi-disciplinary team meeting, as to whether the child or young person has continuing care needs that cannot be met by existing universal or specialist services and will require a package of care involving bespoke planning and funding arrangements.

The recommendation of continuing care eligibility and a summary of the care package required with costed options should be produced in preparation for the decision making phase of the process. Best practice supports robust quality assurance is built into the continuing care pathway in line with LHB’s governance framework. Further advice on different agencies responsibilities for provision of care is included in this guidance.

Decision making

The second phase involves a multi-agency decision making panel considering the evidence and the assessor’s recommendation, to decide if the child or young person has a continuing care need.
The decision making panel agrees on what care will be provided, what resources are required to deliver it and what needs to be commissioned, again taking into account the recommendation of the assessor.

Arrangement of care package

This is followed by the **development of a package of care.** Once a decision has been made and communicated, LHB’s and LA’s as appropriate, will need to make the necessary logistical, funding and contractual arrangements to initiate the delivery of provision of the package of care.

Provision of a package of care should begin as soon as possible following a decision being made and the child or young person and their family being informed. Under no circumstances should care be withheld whilst funding agreements are being made.
On occasion a child or young person will need to commence a package of care pending a decision on continuing care eligibility. An example of this may be where a specialist placement is required and a child commences this placement prior to continuing care eligibility being agreed at the multi-agency decision panel. In this circumstance the LA may recoup the health costs incurred over the interim period to the date of the panel decision.

Review

The continuing care process does not end with the provision of a package of continuing care. Ongoing case management is required for those children or young people in receipt of continuing care and reviewing the package of care is an important part of the arrangement of the provision phase. A lead professional should be nominated to case manage and coordinate the care package

Reviews of a child or young person's continuing care needs should be an opportunity for assessment of needs and how they are being addressed by the package of continuing care provided. It should be made clear to the child or young person and their parents that reviews are designed to ensure that the child or young person's continuing care needs are being met and that they are not financially motivated.

2.3 Timeline for children and young people's continuing care process

Phase	Step	Summary of key actions	Time-scale
Assessment phase	Identify	Child or young person with possible continuing care needs is referred to the LHB Screen referral if necessary Fast track if necessary	0-1 week
	Assess	Nominated children and young peoples health assessor collates multiagency assessments, reports, risk assessments	1-3 weeks
Decision making phase	Recommend	Multiagency meeting held and recommendation made for eligibility and package of care outlined Assessment, recommendations and costed options are quality assured within LHB governance framework	3-5 Weeks
	Decide	A multi-agency decision	6 weeks

		making forum considers the recommendations and costed options and decides on the package of care for the child or young person where continuing care is identified.	
Arrangement of provision phase	Inform	Child or young person and family informed of the decision	5 days
	Deliver	Providers for package of care identified and commissioned Carers training and monitoring arrangements outlined	This will be dependent on complexity commissioning disabled grant funding
	Review	Care package reviewed at 3 months following initial assessment, then annually	3 months

Section 3

Children and Young People's Continuing Care Pathway

An example of a LHB pathway is included in Annex A

3.1 Step 1: Identify

Referrals may be made by a variety of professionals including professionals in primary, secondary and tertiary care, Child Adolescent Mental Health Services (CAMHS), Community children's nursing teams, learning disability teams as well as social services, education and voluntary sector providers. Professionals in all relevant settings should be able to provide evidence on a child's needs and the current input from universal and specialist services.

Consent of the child, young person or parent must be sought. It should be made explicit to the individual that this consent includes the sharing of information; the organisations privacy notice must be made available in line with General Data Protection Regulation (GDPR).

The competency and rights of young people older than 16 years in respect to consent needs to be taken into account and, where appropriate, a mental capacity assessment and best interest decision undertaken.

https://gov.wales/docs/dhss/publications/130417consenten.pdf

Information should be available for families with age appropriate information available for children and young people; this should include information on referral and the process. An example is included in Annex B.

There should be a clear process for referral into children and young people's continuing care available for professionals to include how they will submit assessments or reports. This may be through multi-agency referral panels or health panel. Where the continuing care need has been emerging over a period of time and the child or young person is known to a range of agencies and professionals, the care and support plan should be attached to the referral. Ideally with the increasing move to integrated IT systems (WCCIS) these plans will be shared across agencies.

A checklist may be used to consider referrals pre-assessment and a suggested template is included in Annex A. Where there is clear evidence of unmet need this will not be necessary and there should be no delay in the assessment process. The decision on whether or not to proceed to a formal assessment should be made within 2 weeks of the referral being received and be fully documented. In cases of any doubt a full assessment is necessary.

For children and young people being discharged from acute settings, early consideration should be given to whether there is a continuing care need and planning should be developed in collaboration with local care providers.

Children and young people who are at end of life should not have barriers to receiving care and any applications for a package of care should be fast tracked. Equally there should be no barriers for looked after children being placed within specialist provision.

3.2 Step 2: Assessment

The children and young people's health assessor is the health professional allocated to lead the assessment process on behalf of the LHB.

The children and young people's health assessor should be a health practitioner with the relevant skills and competencies to undertake assessments **within the scope of their own practice.** This role may be a dedicated role within a continuing care team or a practitioner within a community children's nursing team, learning disability team or CAMHS team. LHB's will need to ensure that the health assessor role is properly resourced and supported to make a recommendation.

The skills required by the assessor should include as a minimum:

- Sound knowledge of children and young people's continuing care;
- Knowledge of the principles of children's rights and wellbeing in line with The United Nations Convention on the Rights of the Child;
- An understanding of child and young people's development;
- Experience of working with children young people and their families;
- Experience of assessing children and young people and their families within the scope of their own practice;
- Well developed leadership qualities;
- Listening skills;
- An understanding of local universal and specialist services and commissioning processes for continuing care and specialist provision where this applies (e.g. mental health);
- knowledge of planning and delivery of services;
- Mental capacity and best interest decision making.

The nominated children and young people's assessor is responsible for undertaking an assessment using **three broad areas of assessment** which will combine to provide a holistic multi-agency assessment of need. Each is important to determine if there is a need for continuing care.

1. The preferences of the child or young person and their family

The child, young person and their family should be supported to be partners in the assessment process and assessed using a person centred approach. Care is often highly invasive of the family home and the needs and preferences of all the family members should be sought as far as possible.

The health assessor is responsible for identifying and capturing the child or young person's and their families' preferences. This may require the child having access to advocacy services and should link to the child or young person's care and well being assessment.

Consideration must be given to the child, young person or the family's first language, and if necessary, an interpreter arranged. Parents with learning disabilities or communication difficulties require appropriate support from adult services.

The carer's assessment should consider the family capacity for resilience; this relates to a families ability to care for the child or young person and is not a judgement on parenting ability. Family circumstances, the health needs of other family members and the proposed environment of care should be considered.

Equally, there needs to be open and honest conversation about parenting responsibilities and the families expectations of what a package of care may look like, acknowledging equitable and fair use of resource.
Where a child or young person may require support to give a view or opinion, or their views are different from those of their parents, the possibility of advocacy services should be discussed.

2. Holistic assessment of the child, young person and their family including carer assessment

The children and young person's assessor undertakes a health assessment and/or collates existing assessments from the professionals in the child's multi-disciplinary team. The health assessor may need to get additional expert advice and there may be a need to commission specialist healthcare assessments.

In instances where social and education assessments have not already been undertaken the assessor should liaise with the appropriate professionals to instigate an assessment in these areas but be mindful that assessments should be appropriate and proportional as outlined in the SSWBA.

3. Reports and risk assessments from the multidisciplinary team

The assessor is responsible for collating the reports and risk assessments in preparation for the multi-agency team meeting.

The input of the third sector should be considered in the assessment phase, as appropriate.

The results of continuing care assessments should be shared with the child or young person and their family. Everyone who contributes to an assessment should be fully aware of its intended use and distribution.

3.3 Step 3: Decision making

It is recommended that the above assessments are brought together within a multiagency meeting and a person centred and needs based approach used to outline the assessed needs. This may be with the use of a tool which identifies the child or young person’s needs, which of these may be met through universal and specialist services and those which may require a package of care. An example of a tool is included in Annex B

The child or young person and their family, along with an advocate if required, are invited to attend the multi-agency meeting; ideally this meeting can be part of a statutory care planning meeting, for example, a school review or care and support meeting or a looked after child (LAC) review . Prior to the multi agency team meeting best practice would support that children, young people and their families have written information on the Multi Disciplinary Team (MDT) and decision making process (Annex B)

The multi-agency meeting will be facilitated by the children and young people’s health assessor or a continuing care or team manager. All key agencies should have input and/ or representation at the meeting. A recommendation for eligibility will be made by the multiagency team. The recommendation for eligibility must be made first before moving on to the details around the care package.

The package of care should be needs led and the proposed package should meet the identified health needs. This may involve innovative ways of working across agencies and should build on existing universal and specialist services.

Children, young people and their families should have clear advice on what a package of care may look like with realistic expectations about a sustainable long term package of care.

No discussions about funding responsibilities should be had at the multi agency team meeting.

Following the multi-agency team meeting, the children and young person’s assessor will summarise the following recommendations:

- Whether the MDT supported eligibility for children and young people’s continuing care;
- The care package options with costings;
- Any other issue which may be relevant to the provision of a holistic package of care e.g. any training requirements, home adaptation etc.

3.1.1 Quality Assurance of Assessments

The completed assessment with recommendations and costed options should be quality assured in line with LHB governance arrangements. This may be with a dedicated professional within a LHB or a using a multi-agency team approach. Key points for consideration are as follows:

- Evidence that the assessment process has been followed in line with the locally agreed multi-agency continuing care pathway;
- Record kept of timelines from referral to decision making;
- A record of the quality of the assessment;
- The sustainability of each care option has been considered;
- An outline of the governance arrangements for ensuring quality and contingency plans in the event of breakdown of care;
- Best practice for quality assurance should include completion of a checklist to ensure the locally agreed process has been followed. This will include recording timelines, quality and quantity of evidence which is current. Options for care may be outlined with associated governance to ensure quality maintained.

3.1.2 Multi-agency Decision Making Forum

The completed assessment and recommendations is presented to a multiagency decision making forum. The multi-agency decision making forum should be independent from those involved in assessment and is made up of key decision making health and LA professionals including education. A single panel (forum) could consider LA resource requests alongside continuing care provided the members have the right knowledge and experience.

The multi-agency decision making forum will make a decision to support the recommendation or may seek further information. A decision should be made within six weeks of the commencement of the assessment.

If the assessment is of insufficient quality, or lacks evidence to make a decision, further assessment may be requested. If a decision is made subsequently that the child or young person meets continuing care eligibility and requires a health component within the package of care, the LHB should reimburse the other parties back to the date of the multi agency team meeting.

In some instances, for example end of life, where time is critical there may be a need for a nominated senior professional with this dedicated function, to decide to proceed with putting in place a package of continuing care, pending endorsement of the decision by the panel.

Following the panel’s decision, the child or young person and their family/ carer should be notified verbally within 5 working days to be followed by clear written explanation for the decision within 7 working days.

3.1.3 Funding responsibilities and joint working

Services provided as part of the package for children and young people with continuing care needs will be arranged by the LHB, LA’s and their partners as appropriate, enabling the child or young person to function optimally within their family, community, education or care setting.

All partners are responsible for funding their own contributions to the continuing care package in line with their statutory functions. Ideally this should happen through pooled or shared funding in accordance with the SSWBA and subsequent partnership arrangements regulations. Whatever model is used there must be robust arrangements to ensure timely decision making about funding. It is unacceptable for care to be delayed due to interagency disputes about funding responsibilities.

All LHB's should have joint arrangements in place with their relevant LA's as part of the joint commissioning process which could provide a route for ensuring referrals can easily be made, and information shared, to support continuing care and social care assessments. The pathway for assessing a child or young person's needs must be understood and agreed with all partners. For transparency, the process should be available in a document which allows all those involved to be familiar with the process.

For children and young people with the very complex needs which result in a continuing care need, the aim should be to ensure that the health care, and social care which the child or young person needs, are part of a single package of care, and the LHB and LA should endeavour to facilitate this.

However, there is often uncertainty as to the boundaries of health care and social care; this is not just an issue for continuing care, but it is a consistent challenge facing commissioners of care for children and young people with very complex needs, as the support provided will usually be in the home, and support is not only to ensure health and wellbeing, but to mitigate the impact of disability on daily living.

The Haringey judgement (see Annex C) indicated that there are limits to what care should be funded by the LA, 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 extend to meeting essential medical needs. Social care should not be a substitute for health commissioned care to meet that need.

In his judgement, Mr. Justice Ouseley was willing to apply the 'Coughlan criteria' – which relate to NHS Continuing Healthcare – to determine whether a LA or the health commissioner should provide services to a child in need of continuing care. These indicate that there is no precise legal line between care which can and cannot be provided by the LA. The distinction will depend on the facts of the individual case, and taking into account the nature and quality of the services required, and the quantity and continuing of the services. The Coughlan judgement also confirmed that a LA can commission nursing services, provided they are properly classified as part of social care, and provided the NHS has not agreed to provide them (for example, if the care is very much incidental or ancillary to the provision of accommodation).

Section 47 of the Social Services and Well-being (Wales) Act 2014 (SSWBA) incorporates the first limb of the 'Coughlan criteria' and provides that a LA may not meet a persons needs for care and support which is required to be provided under a health enactment, unless doing so would be incidental or ancillary to doing something else to meet those needs.

The list below gives some examples of how different elements of a care package might fall to the relevant commissioner. It is not an exhaustive list, and reflects where services which are more likely to require joint commissioning. It does not include the full range of services which might feature in an Individual Development Plan.

Figure 3. Elements of a care package across health, social care and education Example: a child with complex needs who is immobile, incontinent and has a gastrostomy and is dependent on ventilator support overnight

Health	**Local Authority**	
	Social Care	**Education**
Community children’s nursing support for family Nursing assessment	Care and well-being assessment Care and support plan Carers assessment	ALN - Statutory assessment Individual development plan
Training and assessment of competency of carers	Administration of medication and gastrostomy feeds	Support assistant undertakes gastrostomy feeds
Supply of all consumables (gastrostomy and feeding equipment, pads)	Home adaptations including hoists Support to apply for grants	Adaptations required in school environment
Nursing package of care overnight due to assessed risk for airway management at night e.g. 5 nights	Short breaks e.g. two evenings a week	
Transport to hospital appointments	Assistant to apply for mobility grant	Transport to school or residential respite
Team around the Child		
One care plan – regular review		
Occupational Therapist Physiotherapist Speech and language therapist Dietitian Community Paediatrician Community children’s nurse	Social worker Support worker	Support worker ALN-Co

3.1.4 Complaints and Dispute Resolution

Where a child or young person is found not to have a need for continuing care, a clear written rationale for any decision should be provided to the child or young person and family following a verbal conversation. Ideally, the process of engagement before this point should have informed the expectations of the family.

The child or young person and their family should be informed of their rights and of the complaints procedure in the event of a decision which does not meet their preferences and or expectations.

The NHS complaints procedure “putting things right–raising a concern” about health services from April 2011 described at www.puttingthingsright.wales.nhs.uk is as applicable for children as it is for adults. In addition, the complaints procedures of other agencies are also applicable. Children who wish to make a complaint should have information on advocacy services and access to an advocate if they wish.

LHB’s and LA’s must have dispute resolution built into their agreed continuing care pathway.

Best practice supports that disputes are resolved as quickly as possible. The interests of the child is paramount and no child should be denied access or have access to the appropriate health care delayed as a result of a dispute.

The initial aim is always to encourage joint conversations within the multi-disciplinary team to support local resolution and escalation when required back to the multi-agency decision making forum for advice and support.

3.4 Step 4: Arrangement of provision

Once a decision has been made to provide a package of care, LHB’s and or LA’s, as appropriate, will need to make the necessary logistical, funding and in some instances contractual arrangements to initiate the delivery of provision of the package of care. There should be no delay in the provision of care and the development of the package of care will need to consider the following:

- Place of care;
- Sustainability and long term outcomes;
- The skill mix of staff (the complement of nurses, health care assistants or carers within the package) ;
- Staff competency and training of parents, carers;
- Equipment;
- Care plans and risk assessment;
- Contingency plans and ability to flex the package of care up and down to meet any temporary increase in need;
- Ongoing case management of the care package, identification of the lead professional.

3.5 Step 5: Review

The child or young person’s continuing care package should be reviewed at three months after commencing the care and annually thereafter, or when circumstances have changed. If there has been a significant change, a full assessment is necessary. The child, young person and their family should be able to request a review at any time.

Best practice supports that where the child is subject to statutory review there should be a synchronised approach to review meetings so that a single review covers the holistic needs of the child or young person.

All reviews should be transparent, involve the child or young person and their family and adhere to the principles of children’s rights and wellbeing set out within

The United Nations Convention on the Rights of the Child. Reviews are an opportunity to update the multi-agency care plan and this should be shared with the child or young person and their family as appropriate.

Reviews of a child or young persons continuing care needs are an opportunity for assessment of needs and how they are being addressed by the package of continuing care provided. It should be made clear to the child or young person and their parents that reviews are designed to ensure the child or young persons continuing care needs are being met and are not financially motivated.

However, reviews should be responsive to changes in a child or young person's fundamental need as there will be cases where successful management of a condition has permanently reduced or removed an ongoing need. The responsibility to commission care is not indefinite as needs may change and this should be made clear to the child, young person and their family. As always, transparency of process and involvement of the child or young person and their family is essential to maintain fairness and consistency of the review.

In instances where the successful management of a continuing care need has permanently reduced or removed an ongoing need, this will have a bearing on the child or young person's need for continuing care. However, the continuing care process should not marginalise a need just because it is being successfully managed but where the underlying need continues unreduced.

In instances where transition back into universal or specialist health services is appropriate, the child or young person and their family should be supported throughout this transition, ideally from within their existing care team. Early engagement with other services is essential for proactive planning and ensuring a smooth transition.

Section 4

Transition to adult services

All LHB's must work with their partners to ensure that there are robust transition pathways in place for all young people with complex needs. There should be active engagement of all agencies in the strategic development and oversight of their local transition processes, and that their representation includes those who understand and can speak on behalf of adult NHS Continuing Healthcare. LHB's should ensure that adult NHS continuing health care is appropriately represented at all transition meetings to do with individual young people whose needs suggest that they may be eligible for NHS Continuing Healthcare (CHC).

Transition is an area that can cause great distress for children their parents and carers. When some children move from children services to adult services they experience uncertainty about future care provision and support and also the loss of income due to changes in benefits.

The assessment of a child's continuing care needs must consider the outcomes necessary to enable the child or young person to get the best from life. The outcomes should be specific, deliverable and linked directly to the child's wishes. They should include where appropriate, outcomes for transition, through key changes in a child or young person's life, such as changing schools, moving from children's to adult and/or from paediatric services to adult health, or moving on from further education to adulthood.

Once a young person reaches the age of eighteen, they are no longer eligible for continuing care for children. The National Framework for the Continuing NHS Healthcare and the supporting guidance and tools are used to determine whether the adult has a "primary health need" and is therefore eligible for NHS Continuing Healthcare or, if not eligible for NHS Continuing Healthcare, whether they are eligible for NHS-funded Nursing Care.

It is important that young people approaching adulthood and their families are aware that eligibility for children's continuing care does not pre-suppose eligibility for NHS Continuing Healthcare.

Every child or young person with a package of continuing care approaching adulthood should have a plan for transition to adult or universal health services or to a more appropriate specialised or NHS Continuing Healthcare.

Key principles for transition from children's to adult's services for young people using health or social services are outlined in NICE guidance (2016) and support best practice which equally applies to young people with continuing care needs.

Children's services should identify those children with potential eligibility for NHS Continuing Healthcare and should notify the appropriate adult complex care teams. Ideally this should occur when the child reaches the age of 14 years, especially if the young person's needs are likely to remain at a similar level into adulthood. There must be recognition that there may be a cohort of young people whose needs are being met through universal and specialist services and therefore are not in receipt of children and young people’s continuing care but who may meet eligibility for adult NHS Continuing Healthcare.

Once the young person reaches 16 years of age there should be a formal referral for screening to the appropriate adult NHS Continuing Healthcare team.

At 17 years of age the screening tool should be used to determine potential eligibility for adult NHS Continuing Healthcare, followed by a full assessment for adult NHS Continuing Healthcare to determine a primary health need wherever applicable, so that an effective package of care can be commissioned in time for the individual turning 18 years of age. If needs are likely to change, it may be appropriate to make a provisional decision and then to re-check it by repeating the process as adulthood approaches.

Children’s services will need to work jointly with Adult services to ensure that assessment and care planning reflects the needs of the young person and to ensure a smooth transition to adult services and at 18 years of age, transition to adult NHS Continuing Healthcare, including the funding responsibilities, or to universal or specialist services should have been made. As above, a re-check of the assessment process is undertaken if necessary.

A key aim is to ensure that a consistent package of support is provided during the years before and after the transition to adulthood. The nature of the package may change because the young person’s needs or circumstances change. However, it should not change simply because of the move from children’s to adult services or because of a switch in the organisation with planning or funding responsibilities.
Where change is necessary, it should be carried out in a phased manner, in full consultation with the young person. No services or funding should be withdrawn unless a full assessment has been carried out of the need for adult health and social care services, including the funding responsibilities.

Section 5

Legislation and policy in relation to statutory responsibilities

Whilst LHB's and LA's should have due regard to statutory and legal frameworks, this must not hinder collaborative thinking and joint working practices. The child or young person must remain at the heart of any care planning.

5.1 NHS (Wales) Act 2006

Children and young people's continuing care is an approach to fulfilling the statutory duty on a local health board under the NHS (Wales) Act 2006 (as amended by the Health and Social Care Act 2012), to provide, to the extent they consider necessary to meet all reasonable requirements:

- medical and nursing services;
- 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, and;
- such other services or facilities as are required for the diagnosis and treatment of illness.

The provision of continuing care may support LHB's in meeting other statutory duties.

5.2 Mental Health Act 1983 After-care Section 117

Chapter 33 of the Code of Practice for Wales to the Mental Health Act, 2016 sets out guidance in relation to After- Care Section 117.
Paragraph 33.2 of the Code of Practice explains that:
"Section 117 of the Act requires local health boards and local authorities, in co-operation with other relevant non-statutory agencies, to provide, or arrange for the provision of, after-care to patients detained un hospital for treatment under section 3, 37, 45A, 47 or 48 who cease to be detained and leave hospital. This includes patients granted leave of absence under section 17 and patients subject to community treatment orders (CTOs). It applies to people of all ages, including children".

A young person discharged from inpatient care may have a continuing care need, due to their psychological and emotional needs, or behaviours which challenge.
It is essential that continuing care assessments consider all areas of a child or young person's health needs. It is not simply an assessment for complex *physical* needs, or learning disability.

In relation to children and young people with mental health needs, there will already be mechanisms for referral to local CAMHS, or Tier 1 or 2 mental health providers. No assessment of continuing care should be made on the grounds of mental health needs without a prior referral and appropriate assessment by universal or specialised mental health services. Clearly, any consideration of whether or not a child needs additional support for a mental health need cannot be given without evidence from mental health professionals, resulting from targeted support. Similarly, where mental health needs are being met through an existing intervention or interventions, these should not be terminated to allow a service to be commissioned as continuing care.

The principle of continuing care, as care needed to meet additional needs, which cannot be met by universal or specialised services, must be respected. It must not be used as an alternative to appropriate commissioned interventions. **Continuing care cannot be a catch-all to compensate for long waits or pressures in other areas of health provision, or for children and young people which have not experienced necessary specialised support.**

5.3 Behaviours that challenge

LHB's have an important role in relation to children and young people with learning disability and autism, and behaviours which challenge. The NICE guidelines on challenging behaviour and learning disabilities, call for health and local authority commissioners (and professionals in education, health and social care), to work together to develop care pathways for people with a learning disability and behaviours which challenge.

The national commissioning board guidance on the Commissioning of Services for people with a Learning Disability: Good Practice Guidance (2017) gives commissioning advice for commissioners to support people with a learning disability to lead ordinary lives and may be a useful tool for planning continuing care for children and young people with behaviours that challenge.
https://www.wlga.wales/commissioning-guidance-for-people-with-learning-disabilities

As outlined in the previous section, the continuing care process should seek for parity between the approach to physical and mental health. Continuing care may be needed where existing services are not sufficient to deliver the best outcomes for a child or young person, and bespoke care is needed. Children and young people should, wherever possible, receive the support and services they need to continue to live with their family, in their own home or as close to home as possible. LHB's should recognise the potential role of continuing care in making a crucial difference to a child at risk of admission.

Behaviours which challenge a care domain used within the assessment process, reflecting that LHB's may have a commissioning role in relation to support for a child or young person with these needs. LHB's should not assume that such needs are a blanket responsibility of the LA; equally, they should not be tasked with providing health funding to support social and emotional needs, or educational or social care provision. As mentioned above, commissioners would need to consider – through a multidisciplinary team meeting, or Team Around the Child meeting - what specialist services are currently providing to support the needs of a child with behaviour which challenges – before seeking to assess for continuing care.

Multi-agency care plans, which explore options prior to a potential admission (or shortly afterwards, where an urgent admission was unavoidable), should indicate likely needs for health support, and can inform an assessment for continuing care. Obviously, following discharge, a child or young person's support however commissioned, should be part of a broader care and support pathway, including health, social care, education, and access to family life.

Joint arrangements for commissioning for ALN provide another opportunity for ensuring commissioners collaborate on supporting children and young people with challenging behaviour. The support needed by children and young people with a learning disability, autism or both, with behaviour that challenges, may be provided under an IDP, with health, social care and educational input.

5.4 Additional Learning Needs and Educational Tribunal (Wales) Act 2018

The Additional Learning Needs and Education Tribunal (Wales) Act 2018 (ALNET Act) makes provision for a new statutory framework for supporting children and young people with additional learning needs (ALN). This replaces existing legislation surrounding special educational needs (SEN) and the assessment of children and young people with learning difficulties and/or disabilities (LDD) in post-16 education and training. The ALNET Act also continues the existence of the Special Educational Needs Tribunal for Wales, which provides for children, their parents and young people to appeal against decisions made by the LA in relation to their or their child's ALN, but renames it the Education Tribunal for Wales.

The ALNET Act creates:

a) a unified legislative framework to support all children of compulsory school age or below with ALN, and young people with ALN in school or further education (FE);
b) an integrated, collaborative process of assessment, planning and monitoring which facilitates early, timely and effective interventions; and
c) a fair and transparent system for providing information and advice, and for resolving concerns and appeals.

The ALNET Act supports a single statutory plan (the individual development plan (IDP)) and increased collaborative working with children, young people and their families, including education, health and social services who will need to work together to deliver efficient, effective, child-centred support for learners with ALN. Whilst most children with ALN will not require any specific health involvement because their ALN will not be health related, where it is relevant and appropriate, advice and assistance may be sought from health professionals. In particular, LHB's or NHS Trusts will be under a duty to consider whether there is a treatment or service that is likely to be of benefit to addressing the learner's ALN and, if so, secure the provision of that treatment or service. That treatment or service will need to be included in the learner's IDP.

The Act will be supported by a new statutory ALN Code. The Code will facilitate national consistency by ensuring that the new ALN system has a set of clear, legally enforceable parameters within which local authorities and those other organisations responsible for the delivery of services for children and young people with ALN, must act. It will, therefore, be a type of subordinate legislation, and confer duties and rights on those subject to it. The Code will also set out practical guidance on how the statutory duties will be carried out, which will be supported by best practice illustrations.
Further information may be accessed via the link below

https://beta.gov.wales/additional-learning-needs-transformation-programme-frequently-asked-questions

5.5 Social services and Wellbeing (Wales) Act 2014

The Social Services and Well-being (Wales) Act came into force on 6 April 2016.

The SSWBA provides the legal framework for improving the well-being of people who need care and support, and carers who need support, and for transforming social services in Wales. It transforms the way social services are delivered, promoting people's independence to give them stronger voice and control.

The fundamental principles of the SSWBA are:

- Voice and control – putting the individual and their needs, at the centre of their care, and giving them a voice, and control over reaching the outcomes that help them achieve well-being.
- Prevention and early intervention – increasing preventative services within the community to minimise the escalation of critical need.
- Well-being – supporting people to achieve their own well-being and measuring the success of care and support.
- Co-production – encouraging individuals to become more involved in the design and delivery of services.

Children and Young People**:** The legal framework builds on the National Assembly's unique approach to children's rights and secures their voice and their participation in decisions about their care and support. The SSWBA and the secondary legislation bring a new focus to meeting the needs of children and young people.
LHB's and LA's must ensure they take account of their duties and obligations under the SSWBA when delivering Continuing Health Care for Children and Young People.
The SSWBA supports person centred approaches to assessing continuing care need and planning care which should include the following:

- The child or young person's circumstances (presenting need);
- The child or young person's personal outcomes (Goals);
- Barriers (what is preventing the child or young person achieving their outcomes);
- Risks;
- Strengths and capabilities (the skills, capacity, support and materials available to the child or family from within themselves, their wider family and their community).

5.6 Children's Social Care

Continuing care is intended as provision of essential health support needed by a child or young person's complex needs. It is not intended to be social care provision or any other form of non-clinical support. Where a carer is providing support in the home as part of a package of continuing care, they should not be providing social care support, or acting as a childminder, unless such a role is explicitly part of a joint package agreed

with the LA, or alternatively, the support constitutes health-funded respite (on which see below).
It is essential that families do not rely on continuing care support to fulfil their primary caring responsibilities for a child or young person (e.g. to allow them to go out or to go to work). Equally, social care support should not be providing what is a primarily health care (see Annex C for more detail on the Haringey judgement on this point). A continuing care package is only intended to provide support for an individual child or young person with complex needs, and should not support siblings.

5.7 The Care and Support (Direct Payments) (Wales) Regulations 2015

Local authorities can fund individuals in order for them to purchase their own care. Direct Payments give people greater choice, and control of their lives. They can choose what, how and when support is provided, and who provides it. Direct payments can be used as an alternative to, or alongside services commissioned by the local authority. The payments are used to support social care, however may be used to meet health care needs which are incidental and ancillary to provision of the care being provided by the local authority and as described in R v Haringey 2005.

5.8 Children with Continuing Care in Hospital and School

A child or young person in receipt of a package of continuing care may be admitted to hospital (for example, to a paediatric intensive care unit). In such cases, depending on the child or young person’s needs, it may be appropriate to suspend the package of care, if appropriate day-to-day care meeting the child’s needs is provided by the hospital. A LHB should avoid a situation in which it is effectively paying for care twice in the same setting.

Obviously, where admission is for routine care such as an operation, unrelated to a child’s continuing care need and the hospital may not be providing the support needed to meet the child’s continuing care needs, and the package should continue, with adaptation as necessary for the new setting. As always, the change in setting would not change the responsibility of the primary carer.

As part of the governance of children’s complex needs in general, the LHB should ensure there are clear expectations on tertiary settings to share information with the continuing care team where a child with continuing care or complex needs is admitted.

Continuing care may be provided whilst a child or young person is in an educational setting, and it is important to ensure that when continuing care is provided, consideration is given to the educational needs of a child or young person. Ensuring a child with complex needs receives essential health support to attend school or college may be delivered through existing community health services, such as community nursing, special school nursing, or palliative care. If an IDP is not necessary, a care and support plan should be in place covering the health care needed, how it is to be delivered, and all essential information for school and community services in support.

It is important that the LHB is not tasked with providing continuing care simply as an alternative means of ensuring the child or young person is able to access education in a particular setting. LA’s have a statutory role in relation to support children to access school or education elsewhere: under section 19 of the Education Act 1996[i] a LA must make arrangements for the provision of education at school or otherwise, for children who by reason of illness would not receive a suitable education unless such arrangements were made. Joint working between the LHB and the LA – if not already established for delivering an IDP - is usually essential to ensure the needs of a child or young person with very complex needs allows them to remain in school, and continuing care may be part of the support required.

WG guidance on supporting learners with medical needs is outlined in guidance below:
http://learning.gov.wales/docs/learningwales/publications/170330-healthcare-needs-en.pdf

5.9 Short Breaks and Respite

LA's have a statutory duty to provide breaks from caring, known as short breaks, to the carers of disabled children to allow the carers to undertake education, training or any regular leisure activity, meet the need of other children in the family more effectively, or carry out day to day tasks which they must perform in order to run their household.

LHB's may commission similar respite care for children with complex needs or disabilities. Respite care can be an important part of the health local offer. Indeed, packages of continuing care are often by their nature, providing respite – for example, when overnight care is provided to allow parents to sleep.

LHB's need to ensure that when considering what support a child or young person needs as part of a package of continuing care, they consider also the respite care which might benefit the family or carer.

The assessment of the level of need must recognise that where a child or young person requires constant supervision or care which is largely provided by family members, there will be a need for professional support to allow the family time off from their caring responsibilities, and this may require a social care assessment, and agreement, between the LHB and the local authority of their respective contribution.

Glossary

Assessment

A multi-agency process in which the needs of a child or young person and their family are identified and their impact on daily living and quality of life is evaluated. The children and young people's health assessor is responsible for undertaking a health assessment and collating existing assessments to present a holistic picture of the child or young person's continuing care needs.

If there is no existing assessment, the children and young people's health assessor should liaise with the appropriate professionals to instigate assessments and then use these reports to inform the holistic assessment of the child or young person's continuing care needs.

Behaviour which challenges

The NICE quality standard QS101 *Learning disabilities: challenging behaviour* states that: '*Some people with a learning disability display behaviour that challenges. 'Behaviour that challenges' is not a diagnosis and is used in this quality standard to indicate that although such behaviour is a challenge to services, family members and carers, it may serve a purpose for the person with a learning disability (for example, by producing sensory stimulation, attracting attention, avoiding demands and communicating with other people). This behaviour often results from the interaction between personal and environmental factors and can include aggression, self‑injury, stereotypic behaviour, withdrawal and disruptive or destructive behaviour.*'

NICE use the following definition of behaviour which challenges, taken from Eric Emerson, *Challenging behaviour: analysis and intervention in people with learning disabilities* (Cambridge University Press, Cambridge, 1995).

'Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.'

https://www.nice.org.uk/guidance/qs101/chapter/Introduction

Children and young people's continuing care

A package of care needed over an extended period of time for children or young people because of disability, accident or illness, which cannot be met by universal or specialist services alone. Children and young people's continuing care is likely to require services from health and local authority children and young people's services. The term continuing care is used to highlight the similarities to NHS Continuing Healthcare, and to indicate the long-term nature of the support needed, as it is unlikely that the needs will lessen over time.

Children and young people's health assessor

A health practitioner experienced in children and young people's health and skilled in the health assessment of children who leads on the assessment phase of the continuing care process. Following the completion of the assessment phase, the children and young people's health assessor will produce recommendations for presentation to a multi-agency decision-making forum for them to reach a decision on whether continuing care is needed and, if so, what package of continuing care to provide. If a continuing care need is identified it is for the LHB and the LA to decide what services each will deliver and fund or commission.

Children's palliative care
An active and total approach to care, from the point of diagnosis or recognition, throughout the child's life. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of Short Breaks and care through death and bereavement.

Complexity
This is concerned with how the needs present and interact to increase the skill needed to monitor the symptoms, treat the condition(s) and /or manage the care. This can arise with a single condition or can also include the presence of multiple conditions or the interactions between two or more conditions

Consent
If a child who is under 16 does not have the capacity to give consent, someone with parental responsibility can consent for them, but that person must have the capacity to give consent.
Where there are concerns that an individual may have significant ongoing needs, and that the level of appropriate support could be affected by their decision not to give consent, the LHB should discuss with the local authority the implications, as in any other case where consent for treatment is withheld. If the young person is 16 or over, the Mental Capacity Act may apply.
If one person with parental responsibility gives consent and another does not, the healthcare professionals can choose to accept the consent and perform the treatment in most cases. If the people with parental responsibility disagree about what is in the child's best interests, the courts can make a decision. If a parent refuses to give consent to a particular treatment, this decision can be overruled by the courts if treatment is thought to be in the best interests of the child.

If the local authority has reason to believe that the child is suffering or likely to suffer significant harm, they could apply to the court under the Children Act 1989 for either:

- an emergency protection order on the basis that the significant harm would occur should the child not receive care;
- an interim care order if the harm or likely harm could be attributed to the care given by the parents.

There will be some young people whose needs are such that they will inhibit their ability to engage with the assessment process or to give consent. In such cases parental responsibility should be sought. For young people 16 and over, the **Mental Capacity Act** (see below) may apply and clinicians should make a best interest assessment.

Continuing care needs
There are no clear definitions of continuing care needs but it is generally recognised that they include multiple health needs where care pathways require co-ordination because of the complexity of service provision and input from local authority children's and young people's services.

Intensity
This relates to both the extent (“quality”) and severity (degree) of the needs and the support required to meet them, including the need for ongoing care.

Mental Capacity Act
The Mental Capacity Act (MCA) is designed to protect and empower individuals who may lack the mental capacity to make their own decisions about their care and treatment. It is a law that applies to individuals aged 16 and over. The Mental Capacity Act Code of Practice provides detailed guidance on how to undertake assessments of what is in a person’s best interests. There is also an NHS factsheet http://www.nhs.uk/conditions/social-care-and-support-guide/pages/mental-capacity.aspx.

The NICE guideline covers decision-making in people 16 years and over who may lack capacity now or in the future. It aims to help health and social care practitioners support people to make their own decisions where they have the capacity to do so. It also helps practitioners to keep people who lack capacity at the centre of the decision-making process.
https://www.nice.org.uk/guidance/NG108

Multi-agency decision-making forum
The multi-agency decision-making forum will comprise professionals from different funding agencies involved, including LHBs and LA’s. The forum will take into consideration the recommendations and proposed options for packages of continuing care. If a continuing care need is identified, it is for the agencies involved to decide what services each will commission and fund.

Nature
This describes the particular characteristics of a child or young person’s needs (which can include physical, mental health, or psychological needs), and the type of those needs. This also describes the overall effect of those needs on the child or young person, including the type (“quality”) of interventions required to manage them.

NHS Continuing Healthcare
A package of ongoing care that is arranged and funded solely by the NHS where the individual has been found to have a ‘primary health need’ as set out in the statutory guidance (as opposed to a need for local authority care). Such care is provided to an individual aged 18 or over, to meet needs that have arisen as a result of disability, accident or illness. Where an individual has a primary health need and is therefore eligible for NHS continuing healthcare, the NHS is responsible for providing all of that individual’s assessed health and social care needs – including accommodation, if that is part of the overall need

Package of continuing care
A combination of resources, planning, co-ordination and support designed to meet a child or young person’s assessed needs for continuing care.

Parental responsibility
All the rights, powers, responsibilities and authority that by law a parent of a child has in relation to the child and his/her property. Throughout the document references to

“family” include those with parental responsibility. As defined by the Children Act 1989 (see http://www.legislation.gov.uk/ukpga/1989/41) a person with parental responsibility for a child could be:

- the child’s parents;
- the child’s special guardian (under a special guardianship order);
- the child’s legally appointed guardian;
- a person named in a child arrangements order as a person with whom the child is to live;
- a local authority designated to care for the child (under a care order); or
- a local authority or person with an emergency protection order for the child.

Specialised services
Health services which are specialised and target specific groups. Specialised services usually address a range of factors e.g. diagnosis of a rare or serious condition; severity; other underlying conditions; complications and developmental age. Examples include Tier 4 Child & Adolescent Mental Health Services and specialist neuroscience services for children and young people, including neurosurgery. Note that a specialised service, although usually needed for a small number of people, is not a bespoke service; unlike continuing care, it is not commissioned for an individual.

Universal and specialist services
Universal Services are services which are available to all children and young people no matter what their circumstances and include provision by health, education and voluntary services.
Examples include:
Health visiting;
GP services;
Nursery;
Primary and Secondary School;
Cub Scouts;
Play schemes.

Specialist services are specific services which generally have referral criteria and require both referral and regular review. Children and young people may move in and out of these services dependent on need.

Examples include:
Occupational Therapy
Learning Disability Team
Community Paediatrician
Community Children’s Nursing
School Action
School Action Plus
Team around the Family (TAF)
Integrated Disability Team
Children with Disability team

Unpredictability
This describes the degree to which needs fluctuate, creating challenges in managing them. It also relates to the level of risk to the persons health if adequate and timely care is not provided. Someone with unpredictable healthcare need is likely to have either a fluctuating, or unstable or rapidly deteriorating condition.

ANNEX A
Children and Young People Continuing Care Pathway (example)

Referral criteria identified

- **Emerging need recognised at child or young persons review**
- **Discharge planning identifies increased health need which may require a bespoke package of care**

⇩

Referral form completed and sent to continuing care coordinator / central triage point. Referral logged. Co-ordinator sends letter of receipt to referrer.

⇩

Referral discussed in referral/triage meeting. This meeting includes representation from health, social services and education. Referrer and family receive decision in writing. If referral declined the rationale for this is explained.

⇩

Once the referral is accepted a health assessor is identified. This is the professional who has the necessary skills and experience to assess the child/ young person's specific needs.

⇩

Health assessor collates assessments and reports. Undertakes health assessment. Maintains contact with the child, young person and family.

⇩

Multi-disciplinary Team (MDT) Meeting held. Recommendation made on eligibility for children and young peoples continuing care. Package of care discussed and recommendation made.

⇩

The completed assessment and recommendations from the MDT are quality assured to ensure that the evidence submitted supports the recommendation made by the MDT. The package of care is outlined with costed options. Liaison with other agencies at this time to discuss feasibility and sustainability of the package of care – for looked after children and specialist placements this may be via the local complex needs panels.

⇩

The assessment is presented to the multi-agency decision making panel for multi-agency sign-off. Letter written to child/ young person/ family to confirm decision.

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Information leaflet
Information for families about referral for children and young people's continuing care

What is continuing care?
Continuing Care is generally a defined as package of care provided to children or young people to meet physical or mental health needs that cannot be met by existing services alone. The package of care will be health focused but may have input from education, social services and sometimes others.

What are the eligibility criteria?
The child must be under the age of 18 years and usually resident in the Local Health Board area.

Why has my child been referred for continuing care?
Professionals (for example a community children's nurse or Learning Disability Nurse) working with your child may have identified increased health needs which require extra support.
This may have been discussed with you at a review or discharge planning meeting

Who can make a referral?
Anyone can make a referral for consideration of eligibility for Continuing Care. This is often a health professional or social worker.
The young person and/or family will need to consent to the process.
The referrer will receive written acknowledgement of the referral.

What happens to the referral?
A health assessor will be assigned to your child; often this is a health professional known to you, for example the community children's nurse or a therapist.

How will I know if the referral is appropriate?
The health assessor will present the referral to a multi-agency meeting who will make a decision on this. Sometimes further information is required before the referral is accepted.
A decision will be sent to the referrer in writing. They will let you know the outcome

My child's referral has not been accepted, Can I appeal against the decision?
If you are not happy about the decision please discuss this with the referring professional who should be able to explain the reason to you.

My child's referral has been accepted, what happens now?
A health assessor will be in contact with you to arrange a more in-depth assessment, often this is a health professional known to you. You and your child's views and opinions will be part of this assessment.

What is the process?
Assessments from health and other professionals involved in your child's care will be collected by the health assessor. Your child may have had numerous assessments and as long as these are still current there would be no need to ask other professionals to reassess. The health assessor will meet with your child to ensure all health information is identified. A meeting, called a multi disciplinary team (MDT) meeting, is then held to discuss the findings and summarise all identified needs. You will be invited to this meeting.

Health needs which are unmet and require specific management will be considered for continuing care. The MDT meeting will make a recommendation on whether your child is eligible for children and young peoples continuing care. The type of care package that may be needed is also recommended by the MDT.

The assessments and recommendations made by the MDT are presented to a multi agency decision making forum. This forum is made up of senior representation from the local health board and the local authority. This forum examine the evidence submitted and make a decision in regard to eligibility.

If a continuing care need is identified, it is for the LHB and the LA to decide what services each will plan, deliver and fund.

How long does the process take?

The process from referral to decision making will take up to 6 weeks. In some instances the decision will be "fast tracked" to ensure a child receives the care needed at the time.

A decision in writing will be sent to you following presentation of your child's case at the forum.

Preparing the package of care

Once the decision is made the package of care will need to be arranged and the time this takes will depend on the type of care needed. Sometimes a team of carers need to be employed and have specific training to meet your child's health care needs; this can take a number of months. Your health team will keep you informed of the progress of this.

Can you appeal against the decision of the Panel?

Yes, if you feel that the assessment was not an accurate reflection of your child's needs please contact and discuss this with your health assessor in the first instance.

In some instances you may be offered an independent review of the collated assessments.

Should you feel that the matter cannot be resolved locally please use the NHS complaints procedure "Putting Things Right – Raising a Concern about Health Services from April 2011" described at:

www.puttingthingsright.wales.nhs.uk

Or ask your health assessor for a leaflet detailing contact numbers.

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ANNEX B

Checklist for consideration of Children and Young People’s Continuing Care eligibility

The Children and Young People’s continuing Care guidance applies to children and young people whose health needs cause them to require a bespoke multi agency package of continuing care **that cannot be met by existing universal or specialist services alone.** Although the main reason for such a package will derive from the child or young person’s health needs, they are likely to require multi agency service provision involving input from education, social services and sometimes others.

The continuing care process begins when there is an emerging recognition that a child or young person may have continuing care needs that cannot be met through existing universal or specialist services alone.

This checklist is not a substitute for the continuing care process and the outcome does not necessarily indicate eligibility for continuing care, however it will support practitioners to consider when a full holistic assessment is required and there may be indication for children and young people’s continuing care.

This checklist must be used in conjunction with a nursing assessment or working knowledge of the child / young person.

On completion of the checklist the health assessor will inform the referrer and child / young person and their family /carer of the decision.

Personal Details

Date of Completion	
Patients Name	
Date of Birth	
NHS Number	
Gender	
Permanent Address	
Telephone Number	
Current Residence (if not permanent address)	
Name of representative (Parent/carer)	
Name of referrer	

Date of referral	

Summary of the referral with child or young person’s situation, relevant history and current needs, including clinical summary and identified significant risks.

Please list the multi-agency universal and specialist services which input into the child’s / young person’s care. Examples of universal services: GP, Dentist, Health Visitor, School nurse, Education. Specialist services: CCN Service, Enteral Feeding Team, Specialist Nurses, OT, Physio, Salt, Dietitian, Community consultant, Specialist consultant, Social services.

Care Domains
Behaviours which challenge

Description (appropriate to age)	**Score =**	**How is this need currently being met?**
No evidence of challenging behaviour or Some incidents of challenging behaviour that are manageable and do not pose a significant risk or barrier to intervention. The child or young person is usually compliant with care. Or Challenging behaviour that follows a predictable pattern and can be managed by a skilled carer or care worker* who is able to maintain a level of behaviour that does not pose a risk to self or others.	C	
Challenging behaviour (severity or frequency) that requires specialist clinical assessment, advice and review. Or Challenging behaviour (severity or frequency) that poses a significant risk to self and/or others and that requires special skill from daily carers and prompt responses to manage the number of levels of incidents or risks. NBV the behaviour may be evidenced on a frequency basis, or it may be that the withdrawal of skilled support would result in those behaviours reoccurring.	B	
Behaviour (severity or frequency) that poses an		

immediate risk to self and others requiring urgent specialist intervention to reduce or manage risk and needs a highly specialist multi-agency program of intervention.	A	

Cognition

Description (appropriate to age)	**Score=**	**How is this need currently being met?**
No evidence of developmental or learning problems, confusion or disorientation. or Cognitive impairment which requires some supervision, prompting or assistance with more complex activities of daily living appropriate to age, but awareness of basic risks that affect their safety is evident.	C	
Cognitive impairment (which may include comprehension or memory issues) that requires some supervision, prompting and/or assistance with basic care needs and daily living activities. Some awareness of needs and basic risks is evident. The child or young person is usually able to make choices appropriate to needs with assistance. However, the child or young person has limited ability even with supervision, prompting or assistance to make decisions about some aspects of their lives, which consequently puts them at some risk of harm, neglect or health deterioration.	B	
Cognitive impairment that may include marked comprehensive or memory issues and maybe lack of understanding of time and place. The child or young person has awareness of only a limited range of needs and basic risks. The child or young person finds it difficult even with supervision, prompting or assistance to make decisions about key aspects of their lives, which consequently puts them at high risk of harm, neglect or health deterioration. Or Although they may be able to indicate some wishes on a limited range of issues they are unable to make choices appropriate to need on most issues, even with supervision, prompting or assistance.	A	

Psychological and Emotional Needs

Description (appropriate to age)	**Score=**	**How is this need currently being met?**
No additional psychological or emotional needs apparent for age and development stage. Or Mild depressive or anxiety symptoms, periods of distress which respond to prompts and reassurance. OR Requires prompts to motivate self towards activity and to engage in care plan and/or daily activities.	C	
Depression, anxiety or anger which results in periods of distress which do not readily respond to prompts and reassurance. OR Withdraws from social situations. Demonstrates difficulty in engaging in care plan and/or daily activities.	B	
Rapidly fluctuating moods of depression, necessitating specialist support and intervention, which have a severe impact on the child or young person's health and well being to such an extent that they cannot engage with daily activities such as eating, drinking, sleeping or which place the child or young person at risk: OR Acute and/or prolonged presentation of emotional/psychological deregulation, poor impulse control placing child, your person or others at serious risk, and/or symptoms of serious mental illness that places the young person at risk to his/her self and others; this will include high-risk, intentional self-harming behaviour.	A	

Communication

Description (appropriate to age)	**Score=**	**How is this need currently being met?**
Communicates clearly, verbally or non verbally appropriate to development. Has a good understanding of their primary language. May require translation if English not their first language or the ability to communicate through the medium of Welsh if that is their preferred language. Able to understand or communicate clearly, verbally or non verbally within their primary language appropriate to their development level. Or	C	

Requires prompting to communicate their needs. The child or young person's ability to understand and communicate is appropriate for age and recognised developmental milestones. Special effort may be needed to ensure accurate interpretation of needs or may need additional support visually, either through touch or with hearing. Carers may be able to anticipate needs through non-verbal signs due to familiarity with the child or young person. Expressive or receptive language.		
Communication about basic needs is difficult to understand or interpret, even when prompted, unless with familiar people and requires regular support.	B	
Requires frequent or significant support from carers and professionals to enable the child to either understand or communicate basic needs, requirements or ideas, even with familiar people.	A	

Mobility

Description (appropriate to age)	**Score**	**How is this need currently being met?**
Independently mobile as appropriate for age and development stage (with or without aids). Or Able to stand as appropriate for developmental age, but needs some assistance and, requires support to access curricular or extra -curricular activities. Or Completely unable to stand but able to assist or co-operate with transfer and/or repositioning by one carer or care worker to a level appropriate for developmental age.	C	
Unable to move in a developmentally appropriate way. Cared for in one position (bed or chair) and due to risk of physical harm, loss of muscle tone, tissue viability or pain on movement needs careful positioning, and is unable to assist or needs more than one carer to reposition or transfer. OR At high risk of injuries, requiring a structured management plan to minimise risk, appropriate to the stage of development. OR Involuntary spasms placing themselves and carers at risk.	B	
Completely immobile and unstable clinical condition such that on movement or transfer there is a high risk of serious physical harm. OR	A	

Where the positioning is critical to physiological functioning or life		

Nutrition, Food and Drink

Description (appropriate to age)	**Score=**	**How is this need currently being met?**
Able to take adequate food and drink by mouth to meet all nutritional requirements. Appropriate to developmental age. or Some assistance required above normal for their age. **OR** Needs supervision, prompting, encouraging with food and drinks above normal requirement for age. **OR** Parent, carer, child or young person needs support and advice about diet because of underlying condition which may create a greater chance of non-compliance, including limited undertaking of consequences of food or drink intake. **OR** Needs feeding when this is not normal developmentally, but is not time consuming.	C	
Needs feeding to ensure adequate intake of food and takes a long time (including liquidised feed). Specialised feeding plan developed by speech and language therapist. **OR** Unable to take adequate food and drink by mouth, most nutritional requirements taken by artificial means e.g. via a non-problematic tube feeding device, naso-gastric tube included.	B	
Dysphagia requiring management plans with additional skilled intervention to ensure adequate nutrition or hydration and minimize the risk of choking and aspiration and maintain airway e.g suction **OR** Problems with intake of food and drink, requiring intervention to manage nutritional status. Unintended weight loss placing the child or young person at risk and needing skilled intervention OR Problems relating to a feeding device that requires skilled assessment and review. or All fluids and nutritional requirements taken by intravenous means	A	

Continence and Elimination

Description (appropriate to age)	**Score=**	**How is this need currently being met?**
Continent of urine and faeces (appropriate to age) Or Continence care is routine on a day-to-day basis and age appropriate: Incontinence of urine managed through e.g medication, regular toileting, pads use of penile sheath etc. AND Is able to maintain full control over bowel movements or has a stable stoma and may have occasional faecal incontinence.	C	
Continence care is routine but requires monitoring to minimise risks, e.g those associated with urinary catheters, frequent double incontinence and/or the management of severe or recurrent constipation or urinary infection or self catheterisation.	B	
Continence care is problematic and requires timely intervention by a skilled practitioner or trained carer OR Intermittent catheterization OR Is regularly incontinent of faeces several times a day or has a stoma that needs attention several times a day Or Requires peritoneal/haemodialysis to sustain life	A	

Skin and Tissue Viability

Description (appropriate to age)	**Score=**	**How is this need currently being met?**
No evidence of pressure damage or skin condition Or Evidence of pressure damage and pressure or a minor would requiring treatment or Skin condition that requires clinical re-assessment less that weekly.	C	
Open would(s), responding to treatment OR Active skin condition requiring a minimum of weekly re-assessment and which is responding to treatment OR High risk of skin breakdown, which requires preventative intervention from skilled carer or care worker several times each day without which skin	B	

integrity would break down Or Open wound(s), not responding to treatment and require a minimum of daily monitoring/re-assessment OR Active skin condition, which requires a minimum of daily monitoring or re-assessment		
OR Specialist dressing regime, several times weekly in place, which is responding to treatment. Requiring regular supervision by a Consultant Or Life threatening skin conditions or burns requiring complex distressing routines over a prolonged period.	A	

Breathing

Description	**Score=**	**How is this need currently being met?**
Normal breathing (age appropriate rate) no issues with shortness of breath Routine use of inhalers, nebulisers, etc	C	
Episodes of acute breathlessness, which do not respond to self-management and need specialist recommended input Requires the use of a low level oxygen therapy each night or oxygen via a facial or nasal mask or other therapeutic appliances to maintain airflow to prevent secondary health issues OR Has profoundly reduces mobility leading to increased susceptibility to chest infection OR Requires daily physiotherapy to maintain optimal respiratory function	B	
Is able to breathe independently through a tracheotomy that they can manage themselves or with the support of carers/parents. Has patent but sub-optimal airway without tracheotomy tube OR Is able to breathe unaided during the day but needs to go on a ventilator for supportive ventilation – the ventilation can be discontinued for up to 48 hours without clinical harm OR Is on Continuous Positive Airways Pressure (CPAP) Has frequent hard to predict apnoeas AND/OR Severe life threatening breathing difficulties Extreme difficulties in breathing (or a tracheotomy), which requires aspiration to maintain airway, by a fully trained carer or a tracheotomy that requires frequent suction and is essential for breathing AND/OR Requires ventilation at night for very poor respiratory function has respiratory drive and would survive	A	

accidental disconnection but would not be well and require hospital support or Unable to breathe independently, requires permanent mechanical ventilation Has no respiratory drive when asleep or unconscious and requires ventilation and 1:1 support whilst asleep, as disconnection would be fatal A highly unstable tracheotomy, frequent occlusions, difficult to change tubes		

Drugs Therapies and Medicines

Description	**Score=**	**How is this need currently being met?**
Parent, informal carer or self-administered medication	C	
Requires a suitably trained member of formal carer, teaching assistant or nurse to administer medicine due to:- • Age • Non compliance • Type of medicine • Route of medicine • Place where medication is to be given Or Requires administration of medicine regime by a registered nurse or care worker specifically trained for this task AND Monitoring because of potential fluctuation of the medical condition that can be non-problematic	B	
Has a drug regime that requires management by a registered nurse (within prescription) due to a fluctuating and/or unstable condition or symptom management or Has a medicine regime that requires daily management by a registered nurse and reference to a medical practitioner to ensure effective symptom management associated with rapidly changing/deteriorating condition or Has a medicine regime that requires daily management by registered nurse and reference to a medical practitioner to ensure effective symptom and pain management associated with a rapidly changing/deteriorating condition, where 1:1 monitoring of symptoms and their management is required	A	

Seizures or Altered States of Consciousness (ASC) Description	**Score**	**How is this need currently being met?**
No evidence of seizures or ASC. Or History of seizures or ASC but none in the past 3 months. Medication (if any) is stable.	C	
Occasional seizures or periods of unconsciousness that have occurred within the last three months which require the supervision of a carer or care worker to minimise the risk of self-harm.	B	
ASC or seizures that result in unconsciousness and that may require frequent (more than monthly) skilled intervention to reduce the risk of harm and may require the administration of medication by a registered nurse or specially trained carer. Or Severe uncontrolled seizures daily or more resulting in unconsciousness that does not respond to treatment and results in a high probability of risk to self or others. Requires daily intervention by a registered nurse who will use clinical judgement to select and implement from a range of appropriate interventions to manage seizures and treat any related risks	A	

Other significant care needs to be taken into consideration:
There may be circumstances, on a case-by-case basis, where a child or young person may have particular needs which do not fall into the care domains described above. It is the responsibility of the assessor to determine and record the extent and type of these needs. The severity of the need and its impact on the child or young person need to be weighted, using the professional judgement of the assessor, in a similar way to the other domains. This weighting also needs to be used in the final decision.

Outcome

Care Domain	**C**	**B**	**A**
Challenging Behaviour			
Cognition			
Psychological and Emotional Needs			
Communication			
Mobility			
Nutrition, food and Drink			

Continence			
Skin & Tissue Viability			
Breathing Drug Therapies			
Drug Therapies			
Altered States of Consciousness			
Other significant care needs			

A score of mainly C's would indicate that care needs are low and /or routine and could be met through core services. A score of mainly B's may indicate the need for continuing care depending on level of input required and skills. May require full assessment for consideration for children and young people's continuing care. Mainly A's would indicate nursing needs and consideration for children and young people's continuing care.

Recommendation	**Please tick as appropriate**	**Rationale**
The identified health needs can be met through existing universal and / or specialist services		
The identified health need cannot be met through existing universal and / or specialist services and a full assessment for children and young people's continuing care is required		

Signature of health assessor:

Date:

The referrer and the child / young person and / or family/carers must be informed of the outcome and decision to proceed or not proceed with continuing care process. A rationale must be given.

****

Assessment Tool – from NWIS (awaiting sign off)

National – Community Nursing - Childrens Assessment

CCIS ID		NHS No		Referral No	
First Name		Middle Name		Last Name	
Date of Birth:		Age		Age if Estimated	
Gender			Nationality		
Religion			Ethnicity		
Primary Address					
Post Code		Email Address			
Home Phone		Mobile Phone		Work Phone	
Preferred Language		Preferred Contact Method		Interpreter Required	

Assessment Date

DD MM YYYY

Date(s) Child/young person and family members seen/interviewed

Date	**Name**	**Was the child/young person seen at interview**
		Yes ☐ No ☐

Medical History

Medical History

Current Medication

Client Allergies

Allergy Type	Allergen - What Substance Caused the Reaction	Reaction	Start Date and Time	Level

Medical History

Medical History

Current Medication

Client Allergies

Allergy Type	Allergen - What Substance Caused the Reaction	Reaction	Start Date and Time	Level

WHAT MATTERS

What matters to me (the child/young person)

What is stopping you from achieving the things that matter to you?

Views of Others Who Know Me

What Outcomes am I trying to achieve

I think that (my) parent(s)/corporate parent/family member/carer/advocate/other could provide support in the following ways

What additional support does the child/young person require?

MAKING EVERY CONTACT COUNT (MECC)

The making every contact count (MECC) lifestyle information resource is available at the MECC Public Health Wales website

Available here http://www.wales.nhs.uk/sitesplus/888/page/65550

ⓘ MECC Public Health Network

Mental Health/Emotional Well Being

Have you recently been feeling of low mood/depressed?	Comments
Do you ever feel anxious?	Comments
Do you ever feel lonely?	Comments

Exercise

Are you physically active?	Comments

Nutrition

Do you require any healthy eating advice and support?	Comments
Do you drink alcohol?	If yes, how much?
Does the patient require any support with reducing their alcohol consumption? If yes, please consider drug and alcohol services	Comments

Smoking

Are you a smoker or vape user?	If yes, do you require support to reduce or quit smoking?

	https://www.helpmequit.wales/

Medication

MECC - Medication

Are you up to date with your immunisations?	Comments

Mental Health/Emotional Well Being

Have you recently been feeling of low mood/depressed?	Comments
Do you ever feel anxious?	Comments
Do you ever feel lonely?	Comments

Exercise

Are you physically active?	Comments

Nutrition

Do you require any healthy eating advice and support?	Comments
Do you drink alcohol?	If yes, how much?
Does the patient require any support with reducing their alcohol consumption? If yes, please consider drug and alcohol services	Comments

Smoking

Are you a smoker or vape user?	If yes, do you require support to reduce or quit smoking? https://www.helpmequit.wales/

Medication

MECC - Medication

Are you up to date with your immunisations?	Comments

COMMUNICATION DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

COGNITIVE/NEUROLOGICAL DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

Is there an Epilepsy care plan?

Title	Type	Sub Type	Owner	Status
Epilepsy Care Plan	Health	Health - Incoming Correspondence	David Hopkins	Active

LAC Legal Status

Start Date (item 6)	Reason (item 7)	Legal Status (item 8)	End Date (item 11)

MENTAL CAPACITY

Tool Tip:
For children under 16 consider Fraser Guidelines and Gillick Competency. For young people aged 16 and over consider Mental Capacity.

Is the patient aged 16 or over?

Do you have any concerns about the patients capacity to engage in this assessment or cognitive ability?

Is it temporary or permanent

Does the individual lack the understanding of the consequences of making or not making the decision?

Is the individual unable to understand the information being provided?

SPIRITUAL DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

Is there a Paediatric Advance Care Plan

SLEEP DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

PAIN DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

Has a pain assessment been completed?

NUTRITION DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

Is there a concern about the child's height and weight?

How is the child/young person fed?

Is there a dietetician feeding regime?

MENTAL CAPACITY

Tool Tip:
For children under 16 consider Fraser Guidelines and Gillick Competency. For young people aged 16 and over consider Mental Capacity.

Is the patient aged 16 or over?

Do you have any concerns about the patients capacity to engage in this assessment or cognitive ability?

Is it temporary or permanent

Does the individual lack the understanding of the consequences of making or not making the decision?

Is the individual unable to understand the information being provided?

PERSONAL CARE DOMAIN

Patient Concerns are

Nurse's Comments/Observations

Has puberty commenced?

Are there any issues around sexual health?

ORAL HEALTH

Child/young person/carer concerns are

Nurse's Comments/Observations

Has an oral assessment been undertaken?

Are there oral health issues?
If yes please complete ORAL ASSESSMENT TOOL

SKIN DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

Pressure Sore Predictor Score (PSPS)

RISK ASSESSMENT SCORING TOOL

BUILD AND WEIGHT FOR HEIGHT	MOBILITY
APPETITE	ELIMINATION
SKIN CONDITION	DRUGS

Total Risk Score
Low Risk (0-5) Medium Risk (6-10) High Risk (11 or more)

Pressure Sore Predictor Score (PSPS)

RISK ASSESSMENT SCORING TOOL

BUILD AND WEIGHT FOR HEIGHT	MOBILITY
APPETITE	ELIMINATION
SKIN CONDITION	DRUGS

Total Risk Score
Low Risk (0-5) Medium Risk (6-10) High Risk (11 or more)

BLADDER AND BOWEL DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

If products are supplied, please give details

MOBILITY DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

BREATHING DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

DRUG THERAPIES AND MEDICATION DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

OBSERVATIONS

Client Height & Weight

Date/Time Taken	Weight Kilograms	Height Metres	Head Circumference	Length Centimetres	Date/Time Of Next Screening	BMI Score	Owner

Physical Observation

Date & Time Taken	Temperature (Celsius)	BP (Systolic)	Blood Pressure Reading Type	BP (Diastolic)	Second BP Systolic	Second BP Reading Type	Second BP Diastolic	Pulse	Respiration	O2 Saturation	Peak Flow	Blood Sugar Levels (mmols/Litres)

24 Hour Care Regime as indicated by child/young person/ parent/ carer

Time	Activity	By Whom
01:00		
02:00		

03:00		
04:00		
05:00		
06:00		
07:00		
08:00		
09:00		
10:00		
11:00		
12:00		
13:00		

14:00		
15:00		
16:00		
17:00		
18:00		
19:00		
20:00		
21:00		
22:00		
23:00		
24:00		

Specialist Equipment

Item	Manufacture	Amount	Purchased by	Service Due Date

CCIS ID		NHS No		Referral No	
First Name		Middle Name		Last Name	
Date of		Age		Age if	

Consumables Equipment Required

Item	Size	Amount per month	Supplied by

SOAP

SOAP / Case Note

Birth:				Estimated	
Gender			Nationality		
Religion			Ethnicity		
Primary Address					
Post Code		Email Address			
Home Phone		Mobile Phone		Work Phone	
Preferred Language		Preferred Contact Method		Interpreter Required	

Was the child or young person involved in the completion of the DST **YES**/**NO**

Does the child / young person have an independent advocate or parent representative? (From 14 years all CYP should be referred for independent advocacy**) YES/NO**

If yes, did the representative attend the completion of the DST **YES/NO**

Has a mental capacity assessment been undertaken?
(this will apply to YP from 16 years who are unable to make some or all decisions) **YES/NO**

Contact details of the representative (name, address and telephone number)

Name	**Details**

Personal Details
Summary pen portrait of the child or young person's situation, relevant history and current needs, including clinical summary and identified significant risks, drawn from the multidisciplinary assessment.

Summary of **child or young person's** view of their care needs and whether they consider that the multidisciplinary assessment accurately reflects these:

Summary of **carer's** view of care needs and support they need as carer and whether they consider that the multidisciplinary assessment accurately reflects these.

Personal Details

Note below whether and how the child, young person, parent/carer (or their representative) contributed to the assessment of their needs. If they were not involved, record whether they were not invited or whether they declined to participate.

List the assessments and other key evidence that were taken into account in completing the DST, including the dates of the assessments:

Evidence	**Date**

MDT member's and Health Assessor's name and contact details

Name	**Profession/Designation**	**Contact Details**	**Signature**

Primary Health Needs Approach
When examining domains of care it is recommended to use the four headings as outlined below in order to capture the service, staff and skill resource which may be required to meet the child's needs. This also allows for discussion on parental resilience and capacity for care. The aim is to identify the needs which remain unmet after consideration of universal and specialist services

Nature: This describes the particular characteristics of a child or young person's needs (which can include physical, mental health, or psychological needs), and the type of those needs. This also describes the overall effect of those needs on the child or young person, including the type ('quality') of interventions required to manage them.

Intensity: This relates to both the extent ('quantity') and severity (degree) of the needs and the support required to meet them, this would also including the need for short break support where care is constant and demanding.

Complexity: This is concerned with how the needs present and interact to increase the skill needs to monitor the symptoms, treat the condition(s) and/or manage the care. This can arise with a single condition or can also include the presence of multiple conditions or the interactions between two or more conditions. There should be discussion on those tasks which may be delegated and the training needs and governance arrangements which may need to be put in place. Where a task cannot be delegated health may need to consider a bespoke package of care.

Unpredictability: This describes the degree to which needs fluctuate, creating challenges in managing them. It also relates to the level of risk to the person's health is adequate and timely care is not provided. Someone with an unpredictable healthcare need is likely to have either a fluctuating, or unstable or rapidly deteriorating condition. This may help form the type of care package required and the level of expertise needed by a trained carer.

Role of Health Care Assessor: The nominated children and young people's health assessor **should lead the assessment phase** of the continuing care process on behalf of the providers. The nominated children and young people's health assessor should be a health practitioner experienced in children and young people's health who also has experience and expertise in health assessment, a thorough working knowledge of the policy on the Guidance, and well-developed leadership qualities. To ensure appropriate, fair and consistent assessment, the nominated children and young people's health assessor should have relevant skills and competencies in:

- Children and young people’s continuing care.
- Child and young people’s development.
- Assessing children and young people and their families/carers.
- Working with children and young people and their families/carers.

The health assessor is responsible for ensuring that the child/young person and their family are informed about the process from assessment to the decision by the multi-agency decision making panel. Consent must be obtained from the child/YP and/or their family and should include consent to share information with other professionals and partner agencies.

Care Domains

This document aims to bring assessment information together in a format which puts the child / young person at the centre of care planning. Where possible this summary of need should be used within a multi - disciplinary meeting and outcomes embedded into the child/ young person’s care plan.

The 10 domains should build a picture of the child/ young person’s overall needs and how these are currently being met or how they may be met through existing services. When a need remains unmet after examination of available universal and specialist services there may be a need for a bespoke package of care.

1. Behaviours that Challenge

Behaviour, compared with children of the same age, of such intensity, frequency, or duration that the physical safety of the person or others is likely to be placed in ‘serious jeopardy’ and behaviour which is likely to impair a child’s personal growth, development, family life and which represents a challenge to services, families and to the children themselves, however caused.

1. Describe the actual needs of the child/young person (this may be referenced to the supporting evidence).

2. How is this need currently being met?

3. What is working?

4. What further interventions or referrals are required for unmet need?

Nature *What is happening now? What are the risks? What is required to reduce risk?*	**Complexity** *What is the level of skill needed to manage the behaviours? What training can be put in place to ensure carers have skills needed to support child/young person?*

Unpredictability *Is the behaviour pattern predictable?* *Can a care worker follow a prescribed plan of care?*	**Intensity** *Are behaviours frequent with high risk of injury to self / others?* *What would be the result of withdrawal of intensity of support?*

2. Psychological and Emotional Needs

Beyond what is normally expected at this age use this domain to record the child or young person's psychological and emotional needs and how they contribute to the overall care needs, noting the underlying causes. There should be evidence of whether or not the child or young person has already got a diagnosed psychiatric disorder, and whether there have been recent changes in psychological needs and their impact on the child or young person's health and well being. To avoid double weighting, difficulties with behaviour that are not clearly related to underlying mental health difficulties should be considered under the **'Challenging Behaviour Domain' and not this domain.** Where the child or young person is unable to express their psychological/ emotional needs (even with appropriate support) due to the nature of their overall needs, this should be recorded and a professional judgement made based on the overall evidence and knowledge of the child or young person.

1. Describe the actual needs of the child or young person (this may be referenced to the supporting evidence).

2. How is this need currently being met?

3. What is working?

4. What further interventions or referrals are required for unmet need?

Nature *Is there a diagnosis or symptoms of a serious mental illness?* *What would the consequences be if current support was withdrawn?*	**Complexity** *Is specialist support/ referral required?* *What level of skill is required to help the child/young person engage in care or daily activities?*
Unpredictability	**Intensity**

What are the risks to this child/young person? Is there history of self -injurious behaviours?	*What is the level of monitoring required to support this child/young person?*

3. Communication

Some children and young people will have long term communication difficulties which can be anticipated and managed through familiarity with the child or young person. This domain should clearly identify how the child or young person usually communicates and any changes in communication. If children or young people have communication needs these should be reflected in the MDT assessment. This section relates to difficulties with expression and understanding, not with the interpretation of language.

For some children and young people their first language is Welsh. To ensure that they can express themselves and that information is communicated effectively it is important that they are able to use their own language in accordance with the Welsh Language (Wales) Measure 2011. This would equally apply to children and young people who are unable to communicate through the spoken word.

From 14 years advocacy should be offered to young people as part of their transition to adult services.

1. Describe the actual needs of the child or young person, this may be referenced to the supporting evidence.

2. How is this need currently being met?

3. What is working?

4. What further interventions or referrals are required for unmet need?

Nature *What is the level of disability for this child/young person?* *What are the risks to the child if unable to communicate even basic needs?*	**Complexity** *What support is required to ensure the child/young person's basic needs are understood?*
Unpredictability *Do carers need to anticipate all care needs?*	**Intensity** *Does the child/young person require high levels of support over a 24hr period?*

4. Mobility

This section considers children and young people with impaired mobility. Where mobility problems are indicated, an up-to-date Moving and Handling and Falls Risk Assessment should exist or have been undertaken as part of the current assessment process and the impact and likelihood of any risk factors considered.

1. Describe the actual needs of the child or young person, this may be referenced to the supporting evidence.

2. How is this need currently being met?

3. What is working?

4. What further interventions or referrals are required for unmet need?

Nature *Is there a history of fracture due to immobility?*	**Complexity** *What are the skills and training required for moving and handling?* *Is positioning critical to physiological functioning or life?*
Unpredictability *Is moving and handling unpredictable due to involuntary spasms?*	**Intensity** *How often does the child/young person require change of position?*

5. Nutrition, Food and Drink

Where Children and Young People are at risk of malnutrition, dehydration and/or aspiration they should either have an existing assessment of these needs or have had one carried out as part of the assessment process with any management and risk factors supported by a management plan. Such assessments must be evidence based and used in conjunction

with clinical judgement.
Well established enteral feeding via gastrostomy is a safe method of feeding and children/ young people would no longer be considered at risk

1. Describe the actual needs of the child or young person, this may be referenced to the supporting evidence.

2. How is this need currently being met?

3. What is working?

4. What further interventions or referrals are required for unmet need?

Nature *What are the risks associated with the current feeding needs?* *Is there potential for reduction of risk?*	**Complexity** *What are the skills and training required to undertake this task?* *Can this task be delegated to a carer with training and assessment of competency?*
Unpredictability *Is there a history of choking and aspiration?* *How is this risk managed?*	**Intensity** *Is the feed plan intense? How many feeds a day? How many flushes including access for medication?*

6. **Continence and Elimination**

Where continence problems are identified, a full evidence based continence assessment exists or has been undertaken as part of the assessment process, any underlying conditions identified, and the impact and likelihood of any risk factors evaluated.

1. Describe the actual needs of the child or young person, this may be referenced to the supporting evidence.

2. How is this need currently being met?

3. What is working?

4. What further interventions or referrals are required for unmet need?

Nature *What are the long term implications for the child/young person?*	**Complexity** *Are there identified tasks associated with continence which require specialist skills?* *Can these skills be delegated to a support worker?*

Unpredictability	**Intensity** *Is there evidence of the child /young person requiring frequent interventions in regard to continence care?*

7. Skin and Tissue Viability

Evidence of wounds should derive from an evidence based wound assessment or tissue viability assessment completed by an appropriate professional. Here, a skin condition is taken to mean any condition which affects or has the potential to affect the integrity of the skin. Wound management should be supported by a care plan identifying the wound with a regular evaluation of the treatment given, documented on a wound assessment chart. This chart should clearly state the wound dimensions and appearance. A rationale for the type of dressing should also be provided. This domain should consider the relationship with other domains including mobility and nutrition.

1. Describe the actual needs of the child or young person, this may be referenced to the supporting evidence.

2. How is this need currently being met?

3. What is working?

4. What further interventions or referrals are required for unmet need?

Nature *Is there a diagnosis which requires regular supervision by a consultant or specialist nurse?*	**Complexity** *Is there a complex dressing routine to manage a chronic skin condition?*
Unpredictability *Is there evidence that management of skin is unpredictable?*	**Intensity** *Is there high risk of skin breakdown which requires preventative intervention from a skilled carer?*

8. Breathing

Evidence of breathing difficulties should derive from a clinical assessment by the appropriate professional e.g Respiratory nurse. Here a breathing condition is taken to mean any condition which affects respiratory and the impact that this may have on a child or young person's ability to independently undertake activities of daily living. In determining the level of need, it is the knowledge and skill required to manage the clinical need that is the determining factor.

1. Describe the actual needs of the child or young person, this may be referenced to the supporting evidence.

2. How is this need currently being met?

3. What is working?

4. What further interventions or referrals are required for unmet need?

Nature *Is the child/young person ventilated / dependent on tracheostomy / oxygen?*	**Complexity** *What is the level of skill and training required to support this care need?* *Can the task be safely delegated?*
Unpredictability *Is there a history of apnoea?* *Does the child/young person have an unstable airway?* *What are the risks?*	**Intensity** *How often are the interventions carried out in relation to airway management?* *Is there a requirement for 24hr support?*

9. Drugs Therapies and Medicines

There is an expectation that parents / guardians will retain responsibility for the management and administration of prescribed medications. Where medication regimes are complicated by changing dosages, large numbers of medications and varying routes of administration.
In some situations, a child or young person or their carer will be managing their own medication and this can require a high level of skill.

1. Describe the actual needs of the child or young person, this may be referenced to the supporting evidence.

2. How is this need currently being met?

3. What is working?

4. What further interventions or referrals are required for unmet need?

Nature *Is the child/young person's condition managed primarily through medication?*	**Complexity** *Does the administration of medication involve specialist skill?* *Is specialist training required?*
Unpredictability *Is there frequent change to prescriptions, involving titration of medicines on a daily basis?*	**Intensity** *Is there a large volume of medicines which need to be administered over a 24hr period?*

10. Seizures or Altered States of Consciousness (ASC)

ASCs can include a range of conditions that affect consciousness.

1. Describe the actual needs of the child or young person; this may be referenced to the supporting evidence.

2. How is this need currently being met?

3. What is working?

4. What further interventions or referrals are required for unmet need?

Nature .	**Complexity** *What is the skill set required to adhere to the care plan? Can training and assessment of competency meet this need?* *Is identified treatment plan complex?*
Unpredictability *How well controlled are seizures?* *What are risks in relation to child/young person's safety?*	**Intensity** *How much time is spent over 24hr period managing seizure activity?*

Other significant care needs to be taken into consideration:
There may be circumstances, on a case-by-case basis, where a child or young person may have particular needs which do not fall into the care domains described above. It is the responsibility of the assessor to determine and record the extent and type of these needs. The severity of the need and its impact on the child or young person need to be weighted, using the professional judgement of the assessor, in a similar way to the other domains. This weighting also needs to be used in the final decision.

Outcomes which can be met through universal and specialist services

Outcome 1:		
What needs to be done?	**By whom**	**By when**
Outcome 2:		
What needs to be done?	**By whom**	**By when**
Outcome 3:		
What needs to be done?	**By whom**	**By when**

Evidence of unmet needs and plan of action

Action 1:		
How can this be met?	**By whom**	**By when**

Recommendation in regard to eligibility for children and young people's continuing care:-

Name	Role	Signature

Annex C: Summary of the Haringey case

A summary of the judgment in R (on the application of D and another) v Haringey London Borough Council ('the Haringey case') is presented here for reference and should be taken into account when deciding on and putting in place packages of continuing care.

The Haringey case considered the scope of a local authority's duties under the Children Act 1989 to provide nursing care for a disabled child in order to offer respite for the child's mother, and the case clarified the divide between health provision and social care provision in that context.

R (on the application of D and another) v Haringey London Borough Council [2005] All ER (D) 256

This case was about a 3-year-old child who required, among other things, a tracheotomy (a tube in the throat), which needed suctioning three times a night, and constant carer availability to deal with the tube if it became disconnected. The child's mother was fully trained in how to clear the tube through suctioning, how to change the tapes that held the tube in place and how to change the tube.

Haringey Primary Care Trust (HPCT) provided 20 hours of respite care per week. Various assessments indicated that further respite care should be given. Haringey London Borough Council (HLBC) accepted that additional provision was required, and agreed to provide an extra 10 hours a night of respite care, although it maintained that the service provided was a health service and should therefore be provided by HPCT. HPCT argued that HLBC did have the power to provide the service, and that the extra care was, in its view, not necessary. The care was provided by qualified nurses, although it could have been provided by non-medically qualified people if they had received the appropriate training.

Mr Justice Ouseley was willing to apply the Coughlan criteria, used to determine whether a local authority or a PCT should provide required services to an adult in need of continuing care, equally to children (despite the fact that the social services care regime for children was regulated by the Children Act 1989 and not the National Assistance Act 1948). In his opinion, relevant factors were the 'scale and type of nursing care', 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 an authority can be expected to provide.

Continuing NHS Healthcare

The National Framework for Implementation in Wales

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Section 1: Introduction to CHC

This document sets out the arrangements for the effective and efficient delivery of Continuing NHS Healthcare (CHC) in Wales.

CHC is a complete package of ongoing care arranged and funded solely by the NHS through local health boards (LHBs), where an individual's primary need has been assessed as health-based. It is one element of a range of care services for those with complex needs. Given the nature and intensity of those needs these services account for a significant proportion of NHS healthcare overall.

CHC can be provided in any residential or non-residential setting and is part of the continuum of care and support that an individual with complex needs may move in and out of.

CHC is different from 'NHS Funded Nursing Care' (FNC) which is aimed towards people in nursing homes. The provision of FNC derives from Section 49 of the Health and Social Care Act 2001 (now replaced in relation to Wales, by Section 47(4) and (5) of the Social Services and Well-being (Wales) Act 2014), which excludes nursing care by a registered nurse from the services which can be provided by local authorities. The decision on eligibility for FNC should only be taken when it is considered that the person does not fall within the eligibility criteria for CHC.

This framework (the 'Framework') sets out the arrangements for CHC in Wales.. It stipulates that LHBs have the lead responsibility for CHC in their local area. They must, however, work with local authorities (LAs), other NHS organisations and independent/voluntary sector partners to ensure effective operation of the Framework.

This Framework replaces the previous version published in 2014. It is supported through:

- public information leaflets
- a national joint training programme
- the online Complex Care Information & Support Site www.cciss.org.uk
- governance and accountability arrangements
- a national performance framework

This Framework refers to various legislative, regulatory and statutory guidance and some of these will be revised over time. The interpretation of the guidance in this document should therefore take into account future changes.

Key Messages

K1 For individuals who are eligible to receive it, Continuing NHS Healthcare (CHC) is an entitlement. It is essential to aim for a decision on eligibility to be right first time. Incorrectly denying someone eligible for CHC access to their entitlement can potentially have a negative impact on a person's health and incur significant financial costs for them, leading to distress for them and their families. It may also result in retrospective claims which can be expensive and time consuming.

K2 The sole criterion for determining eligibility for CHC is whether an individual's primary need is a health need.

K3 This Framework sets out the process for the NHS, working with local authority (LA) partners, to assess an individual's health needs and to ensure that the appropriate care is provided to meet those needs.

K4 Individuals may require services from both the NHS and their LA. The NHS is responsible for assessing, funding and providing services to meet the needs of its population. LAs are responsible for the provision of social services and there may be a charge to the individual for some of these.

K5 There must be a clear and transparent rationale to support the decision-making process.

K6 Individuals and their families/representatives must be fully involved and informed throughout the assessment process.

K7 The services provided in response to assessed need must be proportionate to need and effectively co-ordinated, in order to avoid unnecessary disruption to the individual and their family.

The National Framework

Nature and Purpose

1.1 The Welsh Government published the *Continuing NHS Healthcare – the National Framework for Implementation in Wales* in 2014). It sets out the Welsh Government's policy for eligibility for Continuing NHS Healthcare (CHC), and the responsibilities of NHS organisations and LA's under the Framework and related matters.

1.2 The effective date for implementation of this revised Framework is [ ] and it will replace the current publication.

1.3 This Framework sets out a process for the NHS, working together with LAs and other partners, to assess health needs, decide on eligibility for CHC and provide appropriate care. It is accompanied by the Complex Care Information & Support site www.cciss.org.uk and will be supported by a training programme.

1.4 The Framework provides a consistent foundation for assessing, commissioning and providing CHC for adults across Wales. This is to ensure that there is a consistent, equitable and appropriate application of the process for determining eligibility.

1.5 The assessment and provision of care for children and young people is addressed in the Welsh Government's Children and Young People's Continuing Care Guidance.

Action

1.6 Following publication, the Framework allows for a 6-month period to enable the NHS and partner organisations time to embed in their practices. In that time, the following actions under **paras 1.7 to 1.10** should take place:

1.7 **NHS bodies must**:

- confirm to the Welsh Government that they adhere to the principles and processes in this Framework.
- ensure all relevant staff are fully aware of the procedures for assessing, determining eligibility and providing CHC services, through participation in the national joint training programme;

- ensure the national information leaflets provided on the Complex Care Information & Support (CCISS) site www.cciss.org.uk are made available in a range of formats to individuals in need of care and their families and carers.

- review their current assessment, quality assurance, discharge processes and commissioning arrangements to ensure they comply with this Framework.

1.8 **LAs must**:

- consider how their current practice fits with the responsibilities set out in this Framework and make any necessary changes.

1.9 **NHS bodies and LAs must**:

- work together in partnership when reviewing existing processes and services to ensure best outcomes for individuals;

- consider where CHC responsibilities require clear arrangements to be made with provider organisations and ensure that these are built into purchasing and contracting processes;

- comply with their responsibilities as set out within this Framework;

- as part of their responsibilities for assessment, care and support planning and commissioning, they must communicate the requirements of the Framework to service providers across all sectors. This will help them to, for example, identify individuals with continuing health care needs.

Review of the Framework

1.10 The Welsh Government gives a commitment to review the Framework within five years of implementation and to issue additional or interim guidance where this is required.

Note: At the time of publication, the NHS Funded Nursing Care in Care Homes Guidance 2004[1] remains in effect. This will, however be subject to review during the lifetime of this Framework.

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[1] WHC 2004(024)

Governance Arrangements

Strategic Oversight

1.11 The effective delivery of CHC is a key component of LHB business. Each LHB must identify a named executive, at director level, who is responsible for monitoring performance and maintaining strategic oversight.

1.12 The named director must have access to the data and management information required to enable them to undertake this role effectively.

1.13 Each LA should have a named link with equivalent organisational status. They must liaise closely with their LHB director with responsibility for CHC and be responsible for reporting to their scrutiny committee or equivalent.

1.14 Both LA and LHB Directors should actively engage with local independent sector providers, to ensure the views and experiences of providers are included as part of the scrutiny process.

Reporting Arrangements

1.15 The responsible director should present, as a minimum, an agreed quarterly performance report, either to their board or to an appropriate board-level committee, copied to the Welsh Government. The director should escalate required actions for which the board will be held to account.

1.16 These reports should also be shared with local authorities through the appropriate regional partnership board. These boards, introduced under Part 9 of the Social Services and Well-being (Wales) Act, are designed to improve well-being outcomes and make best use of resources to support sustainability. They are required to prioritise the integration of services in a number of areas, including complex needs, older people and carers. As such they will monitor the pressures, activity, expenditure, and outcomes achieved across the health and social care sector, within their respective regional partnership board areas.

1.17 LHBs are required to utilise an agreed national performance framework which can be accessed via the Complex Care Information & Support (CCISS) site www.cciss.org.uk and includes the self-assessment tool developed by the Wales Audit Office.

Organisational Responsibilities

The Welsh Government

1.18 The Welsh Government will work with LHBs to collate national reports as appropriate and will provide the support mechanisms required to share learning and promote improvement.

Local Health Boards

1.19 LHBs have a role in establishing and maintaining governance arrangements for consideration of CHC eligibility and purchasing and securing care, as they do in other policy areas of health care.

1.20 LHBs are responsible for:

- ensuring consistency in the application of the National Framework for CHC;
- promoting awareness of CHC;
- implementing and maintaining good practice, ensuring quality standards are met and sustained;
- providing necessary training and development opportunities for practitioners;
- identifying and acting on issues arising in the provision of CHC;
- informing commissioning arrangements, both on a strategic and individual basis;
- ensuring best practice in assessment and record keeping; and,
- provision of strategic leadership and organisational and workforce development, and ensuring local systems operate effectively and deliver improved performance.

1.21 Access to assessment, decision-making and provision should be fair and consistent. There should be no discrimination on the grounds of race, disability, gender, age, sexual orientation, religion or belief, or type of health need (for example whether the need is physical, mental or psychological). LHBs are responsible for ensuring that discrimination does not occur and should use effective monitoring to monitor this issue.

1.22 LHBs who contract with other organisations and, in particular, the independent sector, are responsible for ensuring that the quality and range of services are sufficient to meet the individual’s assessed needs. LHBs must arrange regular reviews to ensure those services remain fit for purpose.

1.23 In order to assess the consistency of decision-making on CHC eligibility and to support continuous service improvement across Wales, LHBs are expected to participate in an annual self-assessment and external audit exercise which will be co-ordinated by the Welsh Government and supported with materials on the CCISS site www.cciss.org.uk.

Section 2: Policy and Law

Continuing NHS Healthcare (CHC) in Context

2.1 Continuing NHS Healthcare (‘CHC’) is a package of care arranged and funded solely by the NHS, where it has been assessed that the individual’s primary need is a health need.

2.2 CHC is just one part of a continuum of services that local authorities (LAs) and NHS bodies need to have in place to support people with health and social care needs. CHC is one aspect of care which people may need as the result of disability, accident or illness to address both physical and mental health needs.

2.3 The ongoing assessment and review process should be explained to the individual and/or their representative from the outset and confirmed in writing. Communication tools and template letters for various stages of the process can be accessed via the CCISS site www.cciss.org.uk.

2.4 CHC should not necessarily be viewed as a permanent arrangement. Care provision should be needs and outcomes-led and designed to maximise ability and independence. Any care package, regardless of the funding source, should be regularly reviewed in partnership with the individual and/or their representatives to ensure that it continues to meet their needs. Health and social care professionals involved in arranging the care package must have open conversations with the individual and/or their representative, describing the options to be considered and reflecting the principles and requirements set out in the Sustainable Care Planning Model (see www.cciss.org.uk).

Responsibilities of the NHS and Local Authorities

2.5 The NHS is responsible for assessing, arranging and funding a wide range of services to meet the health care needs, both short and long term, of the population. In addition to periods of acute health care, some people need care over an extended period of time, as the result of disability, accident or illness to address physical and/or mental health needs. These services are normally provided free of charge.

2.6 LAs also provide a range of services to support their local population, including people who require extended care. These services include accommodation, education, personal and social care, leisure and other services. LAs may charge for care services in accordance with regulations under the Social Services and Well-being (Wales) Act 2014 and the Welsh Government’s Code of Practice on Charging and Financial Assessment.

2.7 It is the responsibility of the LA to ensure that any potential impact on the individual in terms of charging should be explained at the earliest opportunity.

2.8 The fact that someone has health needs which are beyond the powers of a LA to provide for, does not, of itself, mean that the individual is eligible for CHC.

2.9 If an individual does not meet CHC eligibility they can still access a range of health and social care services. These can be both part of mainstream services, or individually planned to meet specific needs.

2.10 When an individual has been assessed as having a primary health need, and is therefore eligible for CHC, the NHS has responsibility for funding the full package of health and social care. Where the individual is living at home, this does not include the cost of accommodation, food or general household support.

2.11 Local health boards (LHBs) and LAs have responsibilities to ensure that the assessment of eligibility for, and provision of, CHC takes place in a consistent manner and the process is actively managed to avoid unnecessary delays. The timing and place of assessment must be carefully considered. It should ensure that the individual’s potential for recovery and rehabilitation has been maximised, prior to assessment for CHC. Options to be considered include step-down/intermediate care facilities in the community or, where it is considered clinically safe to do so, in the person’s own home with intensive short-term support. There should be no delays due to disputes concerning which agency should fund. Partners can use a joint or pooled budget to fund the placement in the short-term, and this fund can be replenished once the funding responsibilities have been determined.

2.12 Individuals do not have an indefinite right to occupy a hospital bed, or specialist bed commissioned by the NHS, when they no longer clinically require it. LHBs may move an individual to a more appropriate setting whilst any dispute process is being progressed, or help the individual to choose an appropriate placement.

The Legal Framework

Legislation and Case Law

2.13 Primary legislation governing the health service does not use the terms "continuing care", "Continuing NHS Healthcare" or "primary health need". However, Section 1 of the National Health Service (Wales) Act 2006 requires Welsh Ministers to continue the promotion in Wales of a comprehensive health service, designed to secure improvement in:

(i) the physical and mental health of the people of Wales; and,

(ii) the prevention, diagnosis and treatment of illness.

2.14 Deciding on the balance between local authority and health service responsibilities with respect to long-term care has been the subject of key court judgments. This Framework reflects relevant Welsh legislation with particular emphasis on the various provisions contained within the Social Services and Well-Being (Wales) Act 2014 ("The SSWB Act"). These replaced the legislation reported in and court decisions on previous cases, namely:

(i) The decision of the Court of Appeal in *R v North and Est Devon Health Authority ex parte Coughlan [1999]* "The Coughlan Judgment".

(ii) The decision of the Court of Appeal in *R v. Bexley NHS Care Trust ex parte Grogan [2001] "*The Grogan Judgment".

The key points from these judgments are included for contextual reasons in **Annex 1**.

(iii) Section 47 of the SSWB Act, formerly Section 49 of the Health and Social Care Act 2001

The Duties of the NHS and Local Authorities

2.15 Welsh Ministers are under a duty to provide throughout Wales, to such extent as they consider necessary to meet all reasonable requirements, “such services for, or facilities for the prevention of, illness, the care of persons suffering from illness and after-care of persons who have suffered from illness as they consider are appropriate as part of the health service”[2]. This includes accommodation for the purposes of health services provided under that Act. NHS organisations (amongst others) carry out this function on behalf of the Welsh Ministers.

2.16 What is appropriate to be provided as part of the health service therefore has to be considered in the light of the overall purpose of the health service - to improve physical or mental health and prevent, diagnose or treat illness.

2.17 Under Part 3 of the SSWB Act, each LA is under a duty to assess the needs of an adult where it appears that the adult may have needs for care and support[3]. An adult’s needs may be met by providing or arranging the provision of different types of care and support including accommodation in a care home, as well as adults home or in the community or through the provision of information and advice [4].

2.18 Where, the LA is satisfied, on the basis of the needs assessment, that a person has eligible care and support needs they must then, in conjunction with the person, determine how those needs are met.

2.19 If an NHS body is assessing an individual’s needs (whether or not potential eligibility for CHC has been identified) and the assessment indicates a potential need for care and support services that may fall within a LA’s responsibilities, it should notify the authority of this and invite it to participate in the assessment process.

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[2] Section 3, particularly Section 3(1)(e) of the National Health Service (Wales) Act 2006

[3] Social Services and Well-being (Wales) Act 2014, Section 19

[4] Social Services and Well-being (Wales) Act 2014, Section 34

Extent of Local Authorities' Powers

2.20 Section 47(1) of the SSWB Act provides that a LA may not meet a person's needs for care and support by providing or arranging for a service which is required to be provided under a health enactment, unless doing so would be incidental or ancillary to doing something else to meet those needs. Section 47(1) of the Act provides that "nursing care" means "a service which involves either the provision of care or the planning, supervision or delegation of the provision of care, but does not include a service which, by its nature and in the circumstances in which it is to be provided, does not need to be provided by a registered nurse".

2.21 Section 47(4) of the SSWB Act provides that a LA may not meet a person's needs for care and support by providing or arranging for the provision of nursing care by a registered nurse.

Equality and Human Rights Legislation

2.22 The Equality Act 2010 (the Equality Act) brings together discrimination law introduced over four decades through legislation and regulations. It replaces most of the previous discrimination legislation, which is now repealed. The Equality Act covers discrimination because of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation. These categories are known in the Equality Act as 'protected characteristics'.

2.23 The Equality Act received Royal Assent on 8 April 2010 and came into force in October 2010. The Equality and Human Rights Commission also published codes of practice which cover discrimination in services and public functions as set out in Part 3 of the Equality Act, and which became law on 6th April 2011.

2.24 Part 3 is based on the principle that people with the protected characteristics defined in the Equality Act should not be discriminated against when using any service provided publicly or privately, whether that service is for payment or not.

2.25 Under the Human Rights Act 1998 (HRA) it is unlawful for public authorities to act in a way which is incompatible with certain rights under the European Convention for the Protection of Human Rights and Fundamental Freedoms (referred to in the HRA as "the Convention rights"). Public authorities will therefore be in breach of the HRA if they act in a way which is incompatible with the Convention rights in any area of their activity, including service provision or employment and work-related activities.

2.26 Human rights issues can arise in relation to the exercise of any public function or the provision of any public service which engages a person's Convention rights, for example rights under Article 8 of the Convention (right to respect for private and family life). If a public authority or any other body discriminates when carrying out a function of a public nature which engages a Convention right, this can amount to a breach of the HRA because discrimination in the enjoyment of Convention rights is a breach of the Convention (under Article 14). Where such discrimination is based on a characteristic protected under the Equality Act it is likely also to be a breach of the Equality Act.

2.27 LHBs and LAs have statutory duties to have due regard to the need to promote equality and human rights and ensure it is integral to the way in which health and social care is prioritised and delivered. This should allow people to enjoy quality of life and to be treated with dignity and respect. Such objectives will be supported by:

- Equality of access to care and support, meaning that LHBs and LAs should not preclude anyone from having an assessment for community health and social care services, if their needs appear to be such that they may be eligible for support.

- Equality of outcomes from care and support, meaning that within the same area, individuals with similar levels of needs should expect to achieve similar quality of outcomes, although the type of support they choose to receive may differ depending on individual circumstances.

- Equality of opportunity**,** meaning that LHBs and LAs should work together with individuals to identify and overcome any barriers to economic and social participation within society.

Section 3: Before an Assessment for CHC

Underpinning Principles

3.1 No guidance will address all of the potential situations that can present when assessing and meeting an individual's complex needs. There will be occasions when a degree of interpretation is required to apply the guidance in real-life cases. Where this does occur, practitioners must be able to demonstrate that they have applied the underpinning principles detailed below.

3.2 This should be read alongside the Social Services and Well-being (Wales) Act 2014 (SSWB Act) codes of practice, particularly those relating to

- Part 3 Assessing the Needs of Individuals[5]; and,
- Part 4 Meeting Needs[6].

Principle 1: People First.

3.3 Individuals who turn to health and social care providers when they have complex needs have to know and experience that their best interests and rights are the primary focus of the people assessing, making decisions and supporting them. The focus will be manifested in the dignity and respect shown to them as individuals. Individuals who have a primary health need are entitled to CHC funding. They should therefore feel supported throughout the process of determination of eligibility and be confident that they will receive the quality of care required to meet their needs.

Principle 2: Integrity of Decision-making

3.4 Members of the Multi-disciplinary Team (MDT) **(see paras 3.28 to 3.31)** are responsible for the integrity of their assessments, expert professional advice and decisions which should be underpinned with a clear rationale. Assessments can only be challenged on the basis of their quality. They cannot be challenged on financial grounds.

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[5] http://gov.wales/docs/dhss/publications/151218part3en.pdf
[6] http://gov.wales/docs/phhs/publications/160106pt4en.pdf

Principle 3: No decisions about me without me.

3.5 Individuals are the experts in their own lives. Including them and/or their carers (be they paid or unpaid) as empowered co-producers in the assessment and care planning process is not an optional extra. Where the available care options carry financial or emotional consequences, professionals must not avoid honest and mature conversations with the individual and/or their representative. Professionals must be mindful that some individuals may need support or advocacy to express their wishes, feelings and aspirations.

Principle 4: No delays in meeting an individual's needs due to funding discussions.

3.6 The individual must not experience delay in having their needs met because agencies are not working effectively together. Joint funding and pooled budget options must be considered wherever these can promote more agile, and as a consequence, more efficient responses to individual needs and preferences. Commissioners have a responsibility to resolve concerns/disputes at the earliest opportunity.

Principle 5: Understand diagnosis, focus on need.

3.7 Individuals do not define themselves by their medical or clinical diagnosis and nor should the professionals who are supporting them. Health and social care providers must work together to gain a holistic understanding of need and the impact on the individual's daily life. The aim of assessment, treatment and the planning and commissioning of longer-term care should be to deliver quality and tailored support which maximises independence and focuses on what is most important from the perspective of the individual and their carers.

Principle 6: Co-ordinated care & continuity.

3.8 Fragmented care is distressing, unsafe, wasteful and costly. It can result in unnecessary change to living arrangements, which in turn creates instability and insecurity. Every effort must be made to avoid disruption to care arrangements wherever possible, or to provide smooth and safe transition where change is required in the best interests of the individual. Where an individual whose care was arranged through Direct Payments becomes eligible for CHC funding, the health board must work with them in a spirit of co-production and make every effort to maintain continuity of the personnel delivering the care, where the individual wishes this to be the case.

3.9 The individual and their carers must have a named contact for advice and support, who can co-ordinate a prompt response to any change in need.

Principle 7: Communicate.

3.10 The vast majority of complaints, concerns and disputes have poor communication at their core. It is unacceptable for professionals to claim not to have time to communicate – it will take longer to put the situation right later and trust will have been broken. The individuals seeking our help and their carers will, by the nature of the interaction, require clear communication and support.

3.11 Extra care must be taken to communicate carefully and using the preferred means of communication with the individual. Information also needs to be provided in the most appropriate formats, such as English or Welsh, including copies of relevant assessment and care planning documentation.

3.12 Where possible, the professional should attempt to establish the preferred means of communication of any individual prior to undertaking any assessment. Assessments together with any provision of care and support services have to be linguistically sensitive.

3.13 Users and carers will be empowered if they are able to speak with staff in their -preferred language. It is important to recognise the concept of language as an integral element of a person’s care and ability to participate in all its aspects as equal partners. Effective communication is a key requirement of assessment and the provision of any support required. In Wales, services must be offered in ways that are compliant with the Welsh Language Standards

3.14 The same considerations apply to British Sign Language (BSL) users. The evidence suggests that BSL users prefer to communicate directly with professionals who can communicate fluently in BSL when discussing care and support needs. Many local authorities employ special social workers who work with deaf people and can communicate in BSL. Most local authorities employ specialist social workers for deaf people and can assist with assessments.

3.15 In cases where professionals cannot communicate directly in BSL, interpreters will have to be used either directly or via video computer link.

3.16 All professionals involved in an assessment of the needs of people with severe speech and communication difficulties will need to establish the preferred means of communication before starting the assessment. Assessment specifically concerned with communication may require the assistance of the National Centre for Electronic Assistive Technology.

3.17 Any decision on eligibility must be clearly and professionally explained to an individual. See **Communicating the Decision on Eligibility** (**paras 5.14 to 5.16**)

Key Roles and Responsibilities

3.18 In implementing the principles detailed above, all of those involved have key roles and responsibilities to play. These include the following.

The person whose needs are being assessed.

3.19 It is essential that the individual whose needs are being assessed is central to the assessment and care planning process. They are the expert in their own lives and situation. The assessment will by its nature often be triggered by illness or other life event and every effort must be made by the professionals involved to support the individual to participate in discussions which will impact on their future. This relies on the individual providing honest information, expressing their views and aspirations, and being open if they require further explanation, or there are issues that the team need to understand to effectively meet their needs.

The person’s carer/family members/representative

3.20 The individual’s family and unpaid carers and/or appointed representative will have an important contribution to make in assessing their needs and advocating on their behalf. It is vital they engage in the assessment and planning process and professionals must make every effort to facilitate their involvement. In order to achieve the best possible outcome for the individual, including support for recovery and maintenance of independence, carers/family/representatives will be expected to respond to reasonable requests for information and/or to attend the multi-disciplinary meeting in a timely manner. Where there are a number of family members involved, a key contact should be nominated, who will then be responsible for communicating with other family members.

3.21 Further information is set out in **Section 4,** particularly **paragraph 4.20** onwards.

Care Co-ordinator/Lead Professional

3.22 The Care Co-ordinator is the named individual responsible for co-ordinating the whole process of assessment for longer-term care, including gathering evidence to inform the decision on CHC eligibility.

3.23 They must ensure that the individual and/or their representative is kept informed of the process and fully involved in discussions about their care. Where the Care Co-ordinator changes there should be a formal handover of relevant information.

3.24 The Care Co-ordinator is most likely to be a health professional and it will be important to maintain continuity where for example, the individual has a progressive disease and specialist key professional. This person-centred approach would suggest that it may also be acceptable for a social worker with a long-standing relationship with the individual and the family to act as Care Co-ordinator. This would be subject to inter-agency agreement, with the final decision on who acts as Care Co-ordinator resting with the LHB.

3.25 It is acknowledged that the role of Care Co-ordinator/Lead Professional can be complex and challenging. The expertise of specialist Discharge Liaison Nurses will be invaluable in providing guidance and support to this function.

3.26 The ‘Care Co-ordinator’ role can be referred to as the Lead Professional. We use the term ‘Care Co-ordinator’ in this document but it reads across to the Lead Professional function.

3.27 We note that the term ‘Care Co-ordinator’ has specific meaning in relation to care and treatment planning for people with mental health needs. Whilst the same professional may also co-ordinate the CHC assessment, they are different functions.

A more detailed description of the Care Co-ordinator function can be found at **Annex 2.**

Multi-disciplinary Team members

3.28 Multi-disciplinary Team (MDT) members are responsible for working with the individual and/or their representatives to undertake a thorough and objective assessment of their needs, for providing expert advice to the LHB regarding eligibility for CHC and for making recommendations as to the setting and skill set required to deliver the co-produced care plan.

3.29 The MDT works together to collate and review the relevant information on the individual’s health and social care needs. The MDT uses this information to help clarify individual needs, through the completion of the Decision Support Tool (**DST, see paragraphs 4.55 to 4.60**) and then works collectively to make a professional judgement about the eligibility for CHC, which will be reflected in its recommendation. This process is known as a multi-disciplinary assessment for eligibility for CHC.

3.30 Members of the MDT are responsible for the integrity of their assessments, professional advice and decisions which should be underpinned with a clear rationale. They may be challenged on the quality of their assessment, if for example there are gaps in the information required. They must not be subjected to pressure to change their professional views due to financial constraints.

3.31 Details around the make-up and responsibilities of the MDT are at **paragraphs 4.27 to 4.35**.

Commissioning team

3.32 The commissioning of services to meet the needs of individuals with CHC needs cannot be undertaken in isolation to the commissioning of other similar services. LHBs and LAs, for example, should have an integrated approach to the commissioning of residential and nursing home care, to exercise maximum influence over the development of provision. They will also need to work closely with providers to ensure that an appropriate range of services are in place to respond to the needs of their population. Partners may use formal partnerships with pooled funding arrangements to underpin their integrated approach to commissioning.

3.33 Each LHB will have a robust mechanism in place for commissioning the services required to meet the individual's needs, as detailed in the assessment and care plan. It must consider and balance the preferences of the individual, the views of their family/representative(s) and the NHS Wales Sustainable Care Planning Policy (available on the CCISS site www.cciss.org.uk). It will have the responsibility for identifying and addressing gaps in local service provision.

3.34 Further details on commissioning are to be found under Service Provision and Review (Section 6).

Advocacy

3.35 The Independent Mental Capacity Advocate (IMCA) has a statutory role to support and provide legal safeguards for vulnerable individuals who lack the mental capacity to make important specific decisions about their care and circumstances. This may include serious medical treatment or change of residence, for example, moving into a care home. LHBs and LAs have a duty under the Mental Capacity Act 2005 (MCA) to instruct and consult an IMCA if those concerned are individuals who lack capacity in relation to the decision being made and who have no family or friends available (or appropriate) to represent them.

3.36 The Mental Health (Wales) Measure 2010 expanded the statutory provision of an Independent Mental Health Advocate (IMHA) already given to those detained under the Mental Health Act 1983 to include people receiving inpatient care and treatment on a voluntary/informal basis. People subject to Community Treatment Orders or Guardianship under the Mental Health Act 1983 are also entitled to the IMHA provision.

3.37 Where an individual does not meet the criteria for the support of an IMCA, and regardless of whether or not they lack capacity, they may still wish to be supported by an advocate. LHBs and LAs should ensure individuals are made aware of local advocacy services and services that may be able to offer advice and support. LHBs also need to consider whether any action should be taken to ensure adequacy of advocacy services for those who are eligible or potentially eligible for CHC. In addition, an individual may choose to have a family member or other person, who should operate independently of LHBs and LAs, to act as an advocate on their behalf.

3.38 The Code of Practice on Advocacy under Part 10 of the SSWB Act sets out the requirements for LAs to ensure that access to advocacy services and support is available to enable individuals to engage and participate when LAs are exercising statutory duties in relation to them; and to arrange an independent professional advocate to facilitate the involvement of individuals in certain circumstances.

Carers

3.39 The Welsh Government has set out the importance of improving the lives of carers across Wales through setting out three national priorities of: supporting life alongside caring; identifying and recognising carers; and providing information advice and assistance.

3.40 The important role played by carers is recognised by both central and local government, irrespective of how the cared-for individual has their care funded. LHBs and LAs have a joint responsibility to identify, and work in partnership with, carers and young carers so that they can be better supported to continue with their caring role, if they are willing and able to do so.

3.41 A carer is anyone who, usually unpaid, looks after a friend or family member in need of extra help or support with daily living, for example, because of illness, disability or frailty.

3.42 Healthcare professionals and social care practitioners should be proactive in identifying carers and be sensitive to the level of support they need and desire. This empathetic approach should be reflected in any checklist and/or full assessment of eligibility for CHC with carers and family members involved where appropriate.

3.43 Where unpaid carers are being asked, or are offering, to provide support, LHBs and LAs have a duty to assess and must offer the carer an assessment for support where it appears to them that the carer may have needs for support. This will include an assessment of the extent to which the carer is able and willing to continue to assume the role. Under the 2014 SSWB Act, carers will:

- have a right to an assessment of their needs for support without the need to formally request an assessment (a local authority’s duty to assess is triggered where it appears that the carer may or will have needs as part of their caring role);

- have a right to support where their need is one that meets with eligibility criteria set out in regulations; and,

- where they have eligible needs, have a statutory support plan which the local authority must review on a regular basis.

3.44 When an LHB is supporting a home-based package where the involvement of a family member or friend is an integral part of the care plan, it should agree with the carer the level of support they will provide. It should also undertake an assessment of the carer’s ability to continue to care, satisfying themselves that the responsibilities on the carer are appropriate and sustainable, and establish whether there is an ‘appearance of need for support’, which would mean that the carer should be referred for a carer’s assessment.

3.45 Consideration should also be given to making a referral for a separate carer’s assessment by the relevant local authority. Under the SSWB Act, all NHS bodies have a reciprocal duty to cooperate with local authorities in exercise of their respective functions relating to carers. Of particular relevance is the local authority’s duty to conduct a carer’s assessment ‘on the appearance of need for support’. This means that where, on the basis, of the steps above the LHB believes that there may be a need for support, a referral should be made. This may be particularly relevant where the carer has needs in relation to education, leisure or work (unrelated to their caring role) as these fall outside the scope of CHC but can be addressed through provisions in the SSWB Act.

Consent

3.46 Where the individual concerned has capacity, their informed consent should be obtained before the start of the process to determine eligibility for CHC. This consent will need to encompass permission to undertake the CHC assessment process and also to the ‘sharing and processing of data’ (i.e. sharing relevant personal information between professionals in order to undertake the eligibility assessment for CHC and, where appropriate, for audit and monitoring of decisions). For consent to be valid for these purposes it must be:

- **Explicit.** Consent must be expressly confirmed and recorded in writing, in a very clear and specific statement of consent, which is prominent and kept separate from other information.

- **Specific.** It should be made clear to the individual to what they are being asked to consent (e.g. just to having a Checklist completed or to the full assessment of eligibility process as well, if their Checklist is positive) and whether their information will be obtained and shared for a specific aspect of the eligibility consideration process or for the full process. Also, it needs to be explained that, subject to their consent, their personal information will be shared between different organisations involved in their care in order to complete the assessment of eligibility for CHC.

- **Informed**. The individual should be informed about what the CHC eligibility assessment process involves, what information will be obtained, and who it will be shared with before the start of the process to determine eligibility for CHC.

- **Freely given.** This means consent must be given voluntarily by an appropriately informed person who has both the capacity and authority to consent to the intervention in question. It also means giving people genuine ongoing choice and control over how their personal information is used and shared. In the context of CHC this means that the individual must have the capacity to consent freely and voluntarily to the CHC eligibility assessment process as set out in this Framework. The individual should have a choice about whether or not to consent, and consent must not be conditional on the individual agreeing to something that is not related to the CHC eligibility assessment process.

- **Can be withdrawn**. The individual must be made aware that they can withdraw their consent at any time, and made aware of the process for doing so, and that this includes withdrawing consent to share information.

3.47 It should be explained that, depending on the information in question, the decision to withdraw or withhold consent to share information might affect whether it is possible to complete the CHC eligibility assessment.

Refusal to Consent to the CHC Assessment (see Figure 1)

3.48 An adult with capacity is entitled to refuse an assessment. If, after providing relevant information and discussing all the options and consequences, an individual refuses an assessment this fact should be documented on the consent form and patient notes. The record should include the stated reasons for the refusal, if given by the person. Although focussed on examination and treatment issues, LHBs should take into account the principles of the guidance 'Patient Consent to Examination and Treatment[6]' when consenting to an assessment.

3.49 If the individual has already signed a consent form, but then changes their mind, this should be noted on the form and preferably signed by them. Professionals should ensure that the individual realises that they are free to change their mind and accept the assessment at a later stage.

3.50 If an individual does not consent to an assessment of eligibility for CHC, or changes their mind following an assessment, the individual and/or their family must be informed of the potential effect this will have on the ability of the LHB or LA to provide appropriate services.

3.51 The key consequence of refusing an NHS CHC assessment is that the NHS cannot become responsible for arranging and funding the entire care package and therefore providing care services that are free to the individual. The individual's long-term care requirements may be met by the NHS and LA sharing responsibility and, as a result, the individual may be charged for a contribution to the local authority arranged services. The individual must be provided with a detailed care plan setting out who will provide which services and what they may be charged.

3.52 Consenting to the CHC assessment process is not a pre-commitment to accepting any subsequent offer of CHC funding. This offer will be made by the LHB to the individual following an assessment and if they are found to be eligible. At this point the individual can decline to accept the offer. In these circumstances the LHB cannot become solely responsible for arranging and funding the individual's future care because they have not agreed to it.

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[6] WHC (2008) 10 'Patient Consent to Examination and Treatment' (revised Guidance)

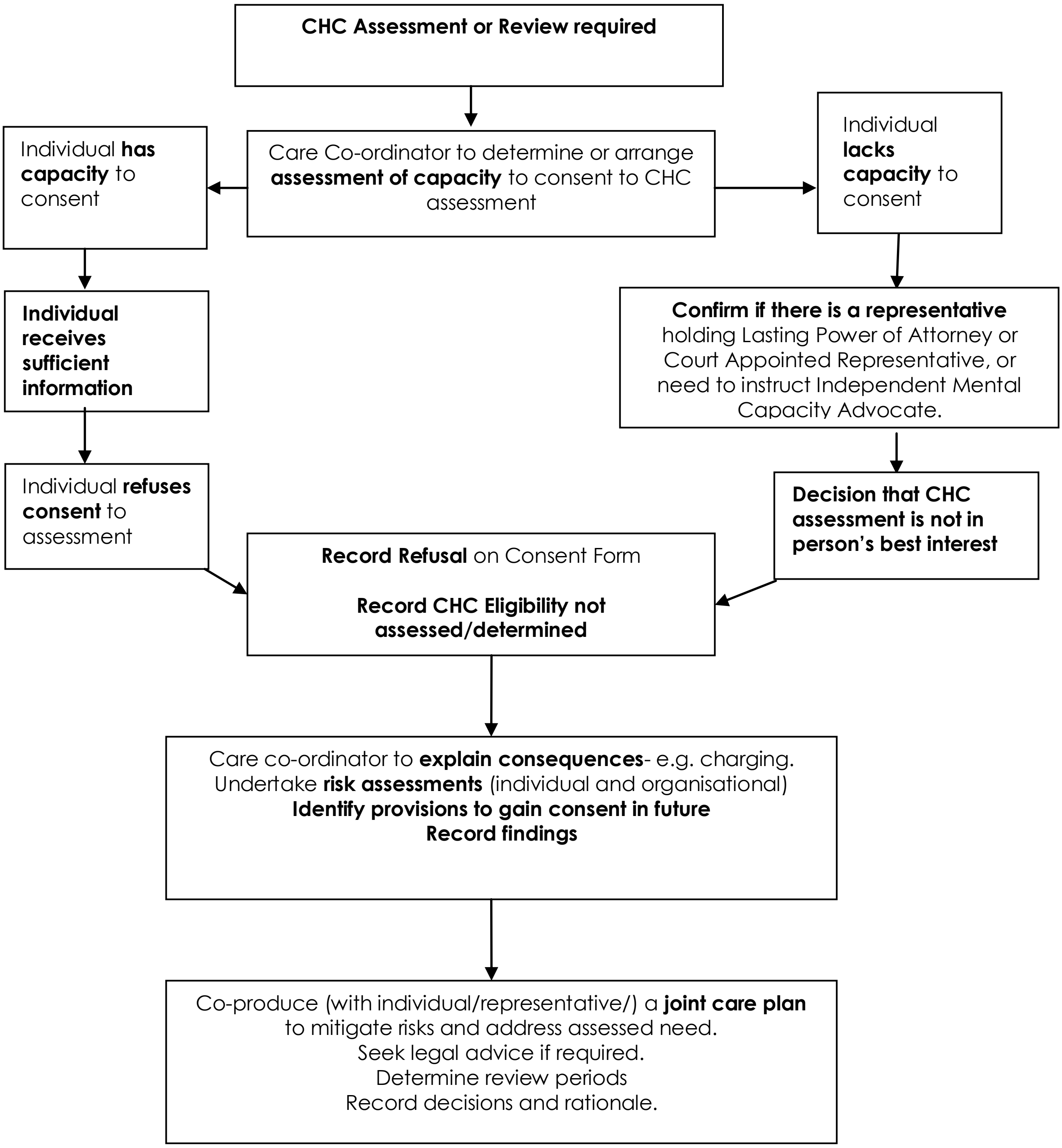
3.53 When an individual has the capacity to make a health care decision and has decided to refuse an assessment or care package, follow-up should be arranged with the Care Co-ordinator, so that they have the opportunity to have a change of mind. The responsible clinician(s) should be told that an assessment or care package was offered and refused.

3.54 In the case of individuals lacking capacity, it is important to record whether there is potential for their capacity to make the decision to be restored and when review should take place.

3.55 Where there are concerns that an individual may have significant ongoing needs, and that the level of appropriate support could be affected by their decision not to give consent, the appropriate way forward must be considered jointly by the LHB and the LA, taking into account each organisation’s statutory legal powers and duties. Where necessary, each organisation should seek legal advice.

3.56 Although refusal of consent only occurs in a minority of cases, LHBs and LAs should consider developing jointly agreed protocols on the processes to be followed. These should provide clarity regarding approaches such as the use of existing assessments and other information to determine each organisation’s responsibilities and the appropriate way forward.

Figure 1 **Refusing Consent for CHC Assessment***



***This process can also be followed where an assessment has been undertaken and the individual then changes their mind or refuses a CHC care package**

Capacity

3.57 If there is a concern that the individual may not have capacity to give their consent or to participate effectively in the decision-making process, this should be determined in accordance with the Mental Capacity Act 2005 and the associated Code of Practice. The five key principles of the Mental Capacity Act 2005 (Section 1) to be considered are:

- **A presumption of capacity**: every adult has the right to make his or her own decisions and must be presumed to have capacity to do so, unless it is proved otherwise.

- **Individuals being supported to make their own decisions**: a person must be given all practicable help before anyone treats them as not being able to make their own decisions.

- **Unwise decisions:** just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision.

- **Best interests:** an act done or decision made under the Act for or on behalf of a person who lacks capacity must be in their best interests **(see paragraphs 4.19- 3.76).**

- **Least restrictive option:** anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

3.58 It is important to be aware that just because an individual may have difficulty in expressing their views or understanding some information, this does not in itself mean that they lack capacity to make the decision in question. Appropriate support and adjustments, for example, using alternative methods of communication, should be made available to the person in compliance with the Mental Capacity Act 2005, and with disability discrimination legislation.

3.59 LHBs and LAs should ensure that all staff involved in CHC assessments are appropriately trained in Mental Capacity Act 2005 principles and responsibilities. Where the assessor is not familiar with Mental Capacity Act principles and the person appears to lack capacity the assessor should consult their employing organisation and ensure that appropriate actions are identified. Where there is complexity or uncertainty in considering the application of the Mental Capacity Act, all assessors should seek appropriate advice within their organisation.

3.60 Language barriers must not be considered a determinant of mental capacity. Consideration must therefore be given to language skill or preference as the medium for undertaking the assessment and appropriate provisions made.

Sharing of Information

Individuals without capacity

3.61 Under the Data Protection Act 2018, the General Data Protection Regulations 2018 and the Mental Capacity Act 2005, an applicant with an Enduring or Lasting Power of Attorney (EPA or LPA) registered with the Court of Protection may, in general, exercise the patient’s rights of access to records on behalf of that patient. However, this is only for information necessary to carry out their duties as an attorney or deputy. There is an important distinction between:

a) Someone acting as LPA (health and welfare) who will generally be able to exercise the patient's rights of access to health and social care records in order to make informed decisions about their health and welfare. This includes being able to consent (or refuse consent) to the CHC process and to sharing information with relevant professionals involved in the process. The Power of Attorney (POA) has to be registered and this type of POA can only be used if the individual has lost the capacity to make the relevant decision about their health and welfare.

b) Someone with Enduring Power of Attorney (EPA) or someone acting as LPA (property and finance).The EPA or LPA has to be registered but can be used with the donor's permission to help them make decisions about property and finance even if they still have capacity to make such decisions themselves. More usually, the POA (property and finance) or EPA is used once the individual has lost capacity. Because CHC can have a significant impact on an individual's finances someone with this type of LPA or an EPA may well have legitimate reason for having access to health and social care records but **only** in so far as these are necessary for them to make a particular decision at a particular time regarding property and finance. An obvious example would be for them to have sufficient information to decide whether or not they agree with the eligibility decision made and whether or not to seek a review of that decision. Any health or welfare records which are not directly relevant should not be shared as they may contain sensitive information which the individual would not have wanted shared with the person to whom they gave the right to manage their financial affairs. Generally speaking, the information that they are likely to need should be contained within the Decision Support Tool and the assessments which underlie it.

3.62 If someone states that they have such authority the assessor should request sight of a certified copy of the original Deputyship Order or registered LPA and check the wording of the order to confirm that the person does have the relevant authority stated.

3.63 Attorneys and deputees must also act in the person's best interests in accordance with the Mental Capacity Act.

Individuals with capacity

3.64 Where an individual has capacity to make their own decisions, they have the right to be consulted about what information they want shared with relatives/advocates who may be supporting them. The individual can specify they do not want all information shared.

Information from Third Parties

3.65 LHBs often hold information from third parties to inform a comprehensive review (current or retrospective) of an individual's eligibility for CHC. These records typically include care home records, GP notes and records from the local authority (social services).

3.66 The NHS has a duty to protect the privacy of the individuals named in those records but also has a duty as a data controller to consider whether it is reasonable to disclose those records. Any such disclosure will be the minimum information necessary to satisfy the purposes of the disclosure, for example to enable an applicant to contribute usefully to the review process for CHC. Those providing information as part of the CHC process should be reminded of their duties under the Data Protection Act 2018, the General Data Protection Regulations 2018, and Access to Health Records Act 1990 and should be made aware of how the information they provide will be used and shared. In particular, the LHB should ensure that those providing information are asked to confirm that:

- The information provided pertains only to the individual concerned (i.e. it does not include personal/health information about anyone who is not the subject of the CHC assessment and/or review)

- The information provided does not include any information which, if disclosed, would likely cause serious harm to any individual, (be that physical or mental harm). The test for serious harm is fairly strict and goes beyond being uncomfortable or unpleasant

3.67 If there is any information in medical records which an individual has provided on the basis that it would not be shared with anyone in any circumstances, it should remain confidential unless disclosure is sanctioned by a Court Order.

3.68 Any information relating *to* third parties (i.e. information which identifies another individual other than the patient) should be redacted unless that other individual is a professional, has consented to the disclosure, or, in *all the circumstances*, it is reasonable to disclose that third's party's information without consent.

Best interest decisions

3.69 An individual's capacity to make decisions may fluctuate, and there may be circumstances where an individual presents with a temporary loss of decision-making capacity. In these circumstances a decision needs to be made as to whether it would be in the person's best interests whether to proceed with the assessment and sharing of information or to delay seeking consent until capacity is regained. If this is the case, the best interests' decision to be made may also include whether to provide an interim care or support package.

Making the 'best interests' decision

3.70 Where a 'best interests' decision needs to be made, the decision-maker must take into account the views of any relevant third party who has a genuine interest in the individual's welfare (if it is reasonable and practicable to consult them). This will normally include family, friends and advocates. The decision-maker should be mindful of the need to respect confidentiality and should not share personal information with third parties unless it is considered in the best interests of the individual for the purposes of the CHC assessment of eligibility. Where the individual has made an 'advanced statement' to the effect that they do not want personal information shared with specific individuals, this should be taken into account in assessing the individual's best interests.

3.71 Although the decision-maker must take account of the views of relevant third parties, those consulted (including family members) do not have the authority to consent to or refuse consent to the actions proposed as a result of the best interests' process. The responsibility for the decision rests with the decision maker, not with those consulted. Where there is a difference of opinion between the decision-maker and those consulted, every effort should be made to resolve this informally. However, this process should not unduly delay timely decisions being made in the person's best interests.

3.72 In making the best interests decision in such circumstances the decision maker should be mindful of the following factors:

- Whether the patient will regain capacity in the near future? If so, is it possible to delay the CHC process until that patient is able to deal with the process themselves, or provide consent to deal with others?
- What are the relevant circumstances – i.e. would it appear reasonable for example that the particular applicant is acting for the patient?
- What evidence is there of the patient's wishes and feelings? For example, is there any evidence which would suggest that they did not want information shared with the particular applicant?
- Are there any objections or views of others which should be taken into account?

Recording the best interests decision

3.73 The best interests decision should be recorded. The person leading the assessment is responsible for making this decision and should bear in mind the expectation that everyone who is potentially eligible for CHC should have the opportunity to be considered for eligibility. A third party cannot give or refuse consent for an assessment of eligibility for CHC, or for sharing information, on behalf of a person who lacks capacity, unless they have a valid and applicable LPA - Health and Welfare or they have been appointed as a Deputy LPA - Health and Welfare by the Court of Protection.

3.74 Where an LA is involved with an individual who lacks mental capacity and an advocate has been appointed, that advocate has a statutory right of access to confidential health and social care information relevant to their advocacy role and function. An advocate would not be appointed solely for the purpose of an CHC assessment. However, where an advocate has already been appointed their role and function legitimately extends, with the individual’s consent, to supporting that individual through the CHC assessment process up to the point at which a decision is made that they are eligible for CHC. Where a person has been assessed as eligible for CHC and no other provisions (e.g. safeguarding) apply, the role of the advocate will cease and the LHB will need to consider whether any other advocacy support is required.

3.75 Where an Independent Mental Capacity Advocate (IMCA) has been appointed by a LA for an individual who is or subsequently becomes subject to an CHC assessment , the IMCA's role remains limited to the purpose for which they are appointed under the Mental Capacity Act (e.g. in relation to potential accommodation move or serious medical treatment). The IMCA has a statutory right of access to confidential health and social care information relating to the purpose for which they have been appointed. An IMCA would not be appointed solely for the purposes of an CHC assessment.

3.76 Where a person, such as a solicitor or advocate, is acting on behalf of an individual with mental capacity or on behalf of a registered attorney (EPA or LPA) or court appointed deputy for someone who lacks mental capacity then the person may also exercise the rights of access as described in **paragraph 3.61** as long as appropriate consent has been given to that person.

The Use of ‘the Checklist’

3.77 The Checklist is the CHC screening tool which can be used in a variety of settings to help practitioners identify individuals who may need a full assessment of eligibility for CHC. It is essential that the appropriate consent is sought prior to commencing this process

3.78 LHBs must take reasonable steps to ensure that individuals are assessed for CHC in all cases where it appears that there may be a need for such care. Although not mandatory, if an initial screening process is used to identify where there may be a need for such care, then the Checklist is the only screening tool that can be used for this purpose. The Checklist encourages proportionate assessments of eligibility rationale is provided for all decisions regarding eligibility.

3.79 Completion of the Checklist is intended to be relatively quick and straightforward. It is not necessary to provide detailed evidence along with the completed Checklist. There are two potential outcomes following completion of the Checklist:

- a **negative Checklist**, meaning the individual does not require a full assessment of eligibility, and they are not eligible for CHC; or
- a **positive Checklist** meaning an individual now requires a full assessment of eligibility for CHC. It does not necessarily mean the individual is eligible for CHC.

3.80 In order to comply with the ethos of this Framework, the use of the Checklist must not replace professional judgement or dialogue with the individual and their family/representative.

3.81 The Checklist can also be accessed via the Welsh Government’s website www.wales.gov.uk and the CCISS site www.cciss.org.uk

When to use a checklist?

3.82 Screening for CHC should be at the right time and location for the individual and when the individual’s needs are known. This will help practitioners to correctly identify individuals who require a full assessment of eligibility for CHC.

Who can complete a checklist?

3.83 The Checklist can be completed by a variety of health and social care practitioners, who have been trained in its use. This could include, for example: registered nurses employed by the NHS, GPs, other clinicians or LA staff such as social workers, care managers or social care assistants.

3.84 Care homes should contact the relevant CHC team to arrange for a Checklist to be completed for their residents. However, where an LHB has an agreed protocol in place with a care home then other arrangements for completion of checklists may apply.

The role of the individual in the screening process

3.85 The individual should be given reasonable notice of the intention to undertake the Checklist and should normally be given the opportunity to be present on its completion, together with any representative they may have.

3.86 Before the Checklist is completed, it is necessary to ensure that the individual and / or their representative, understands that the Checklist does not indicate that the individual will be eligible for CHC - only that they are entitled to be assessed for eligibility.

How the Checklist should be completed

3.87 The Checklist requires practitioners to record a brief description of the need and the source of evidence used to support the statements selected in each domain. This could, for example, be by indicating that specific evidence for a given domain was contained within the inpatient nursing notes on a stated date. This will enable evidence to be readily obtained for the purposes of the MDT if the person requires a full assessment of eligibility of CHC.

3.88 The principles of ‘well-managed need’ (**see paras 4.50 to 4.54**) apply equally to the completion of the Checklist as they do to the Decision Support Tool.

What happens after the Checklist?

3.89 Whatever the outcome of the Checklist - whether or not a referral for a full assessment of eligibility for CHC is considered necessary – the outcome must be communicated clearly and in writing to the individual or their representative, as soon as is reasonably practicable. This should include the reasons why the Checklist outcome was reached. Normally this will be achieved by providing a copy of the checklist.

What happens following a negative Checklist?

3.90 A negative Checklist means the individual does not require a full assessment of eligibility and they are not eligible for CHC.

3.91 If an individual has been screened out following completion of the Checklist, they may ask the LHB to reconsider the Checklist outcome. The LHB should give this request due consideration, taking account of all the information available, and/or including additional information from the individual or carer, though there is no obligation for the LHB to undertake a further Checklist.

3.92 A clear and written response should be given including the individual's (and, where appropriate, their representative's) rights under the NHS Complaints Procedure if they remain dissatisfied with the position.

What happens following a positive Checklist?

3.93 A positive Checklist means that the individual requires a full assessment of eligibility for CHC. It does not necessarily mean the individual is eligible for CHC.

3.94 An individual should not be left without appropriate support while they await the outcome of the assessment and decision-making process. A person only becomes eligible for CHC once a decision on eligibility has been made by the LHB. If, at the time of referral for an CHC assessment, the individual is already receiving an ongoing care package (however funded) then those arrangements should continue until the LHB makes its decision on eligibility for CHC, subject to any urgent adjustments needed to meet the changed needs of the individual. In considering such adjustments, LAs and LHBs should have regard to the limitations of their statutory powers.

3.95 Where the Checklist has been used as part of the process of discharge from an acute hospital and has indicated a need for full assessment of eligibility, a decision may be made at this stage to provide other services initially and then to carry out a full assessment of eligibility at a later stage. This should be recorded. The relevant LHB should ensure that full assessment of eligibility is carried out once it is possible to make a reasonable judgement about the individual's ongoing needs. This should be completed in the most appropriate setting – whether another NHS setting, the individual's home or some other care setting. In the interim, the relevant LHB retains responsibility for funding appropriate care.

3.96 Once an individual has been referred for a full assessment of eligibility for CHC then, irrespective of the individual’s setting, the LHB has responsibility for coordinating the process until the decision on funding has been made. The LHB should identify an individual (or individuals) to carry out this coordination role, which is pivotal to the effective management of the assessment and decision-making process. By mutual agreement, the coordinator may either be an LHB member of staff or from an external organisation.

Section 4: The Assessment of Eligibility for CHC

Right Process

4.1 CHC is just one part of a continuum of services that local authorities and LHBs need to have in place to support people with health and social care needs. It is a package of care arranged and funded solely by the NHS, where it has been assessed that the individual's primary need is a health need.

4.2 Establishing that an individual's primary need is a health need requires a clear, reasoned decision which is based on evidence of needs from a comprehensive assessment. There is therefore no separate assessment process for CHC, and health and social care practitioners involved are expected to comply with existing Welsh Government and practice guidance on assessment and care planning including:

- Social Services and Well-being (Wales) Act 2014 codes of practice relating to Part 3 Assessing the Needs of Individuals[7] and Part 4 Meeting Needs[8]
- The Care Programme Approach for Mental Health Service Users
- NAFWC 17/2005 Hospital Discharge Planning Guidance
- Passing the Baton: A Practical Guide to Effective Discharge Planning (2008).

4.5 Individuals should refer to the guidance above directly and it can be accessed via the CCISS site www.cciss.org.uk. There is no attempt to replicate in this Framework.

4.6 A summary overview of the assessment and CHC eligibility decision-making process is provided at **Annex 3**.

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[7] http://gov.wales/docs/dhss/publications/151218part3en.pdf

[8] http://gov.wales/docs/phhs/publications/160106pt4en.pdf

The Right Place - When and Where to Assess

4.7 The MDT, working in partnership with the person and their carer(s), must consider the optimum environment in which the assessment for longer-term care should take place in order to maximise the individual's potential for independence.

4.8 Screening and assessment of eligibility should commence when the individual's ongoing needs are known. The core underlying principle is that individuals should be supported to access and follow the process that is most suitable for their current and ongoing needs.

4.9 Care must be taken to ensure that no premature presumptions are made regarding the requirements for long-term care whilst the individual is acutely unwell.

4.10 Assessments can take place in either hospital or non-hospital settings. Nevertheless, they should normally occur when the individual is in a community setting. 'Home first' should be the default position and rehabilitation / reablement to support the retention of as much independence as possible, must always be considered.

Discharge from Hospital

4.11 As a matter of principle, no-one should be discharged from an acute hospital environment to a new care home placement, as reflected in Welsh Government Hospital Discharge Planning Guidance (NAFWC 17/2005) [9]. An assessment in an acute hospital may not always reflect an individual's capacity to maximise their potential.

4.12 Using an 'adopt or justify' approach, in circumstances where it is deemed clinically inappropriate to provide a period recovery / reablement prior to, or as part of, the assessment for long-term care, the rationale must be clearly recorded. Scrutiny of such cases should be included in the LHB's CHC audit and performance framework.

4.13 In the majority of cases, it is preferable for eligibility for CHC to be considered after discharge from hospital when the person's ongoing needs should be clearer. The aim in most cases will be for the individual to return to the place from which they were admitted to hospital, preferably their own home. It should always be borne in mind that an assessment of eligibility for CHC that takes place in an acute hospital might not accurately reflect an individual's longer-term needs. This could be because, with appropriate support, the individual has the potential to recover further in the near future. It

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[9] NAFWC 17/2005 Hospital Discharge Planning Guidance

could also be because it is difficult to make an accurate assessment of an individual’s needs while they are in an acute services environment.

4.14 Where an individual is ready to be safely discharged from acute hospital it is very important that this should happen without delay. Therefore, the assessment process for CHC should not be allowed to delay hospital discharge.

4.15 There should be consideration of whether the provision of further NHS-funded services is appropriate. This might include therapy and/or rehabilitation, if that could make a difference to the potential of the individual in the following few months. It might also include intermediate care or an interim package of support in an individual’s own home or in a care home. In such situations, assessment of eligibility for CHC should usually be deferred until an accurate assessment of future needs can be made. The interim services (or appropriate alternative interim services if needs change) should continue in place until the determination of eligibility for CHC has taken place. There must be no gap in the provision of appropriate support to meet the individual’s needs.

Right People.

4.16 The assessment process should draw on those who have direct knowledge of the individual and their needs.

4.17 When it becomes apparent, through discussion with the individual, their carers and the Multi-disciplinary Team (“MDT”), that longer-term support to meet complex needs is likely to be required on discharge (or in the community if the person is at home), a named care co-ordinator/lead professional must be identified.

4.18 The Care Co-ordinator is the named individual responsible for co-ordinating the whole process of assessment for longer-term care, including gathering evidence to inform the decision on CHC eligibility.

4.19 The Care Co-ordinator is most likely to be a health professional and it will be important to maintain continuity where, for example, the individual has a progressive disease and specialist key professional. This person-centred approach would suggest that it may also be acceptable for a social worker with a long-standing relationship with the individual and the family, to act as Care Co-ordinator. This would be subject to inter-agency agreement, with the final decision on who acts as Care Co-ordinator resting with the LHB. A detailed description of the role is attached at **Annex 2**.

4.20 The individual and their carers must be fully involved in the assessment process from the outset. They should be provided with all the necessary information and support they need to participate effectively, taking into account specific requirements e.g. language needs or other needs such as sensory loss. Language need and preference must be recorded.

4.21 Many individuals can only communicate their care needs effectively through the medium of Welsh and the ability to use their language of choice has to be seen as a core component of care and not an optional extra.

4.22 Individuals and their carers must be made aware (through the giving of verbal and written information) of their right to be considered for CHC and also of the right to have the decision-making process reviewed. Information should also make it clear that the assessment of eligibility for CHC is subject to reassessment, that people may move in and out of eligibility, depending on their changing health care needs, and that this can impact on how care is funded. The involvement of the patient/carer/family does not mean that they can veto a decision.

4.23 Public information leaflets, including bilingual and easy-read versions to support this dialogue are available on the Welsh Government website (www.wales.gov.uk) and the CCISS site www.cciss.org.uk. Individuals being assessed for CHC, and their carers, should routinely be offered access to independent advocacy services.

4.24 Involving social services colleagues as well as health professionals in the assessment process is essential and will make decision-making more effective, informed and consistent.

4.25 The assessment must include the input of the consultant or GP who has responsibility for the patient, so that the clinical facts and medical needs are considered alongside all other care needs.

4.26 The assessment should, where appropriate, involve other agencies who work with the individual and form part of their existing support mechanisms. This could include for example, third sector agencies and housing associations.

The Multi-disciplinary Team ("MDT")

4.27 Discussions about an individual's needs, along with any consideration of eligibility, including use of the Decision Support Tool (DST), must be undertaken in a formal Multi-disciplinary Team ("MDT") meeting. The individual and if they wish, their family, carer or advocate, must be invited to attend this meeting.

4.28 It is important that those contributing to this process have the relevant skills and knowledge. While as a minimum requirement an MDT can comprise two professionals from different healthcare professions, the MDT should include both health and social care professionals (unless there are exceptional circumstances), who are knowledgeable about the individual's health and social care needs and, where possible, have recently been involved in the assessment, treatment or care of the individual.

4.29 The individual or their representatives cannot be members of the MDT. However, they should be fully involved in the process and be given every opportunity to contribute and opportunity to attend the MDT discussions which will inform the recommendation. The Care Co-ordinator must ensure that the individual and their family/carer(s) have been provided with the leaflet 'Preparing You for a CHC Eligibility Meeting' (see www.wales.gov.uk & www.cciss.org.uk). The Chair of the MDT is responsible for ensuring that they appear to know what to expect, are actively included in the discussion and subsequently understand the rationale for the decision made. The Care Co-ordinator should make contact to answer any queries arising from the meeting. As a minimum, the individual and/or their representative should be provided with copies of the matrix and the summary record/rationale.

4.30 The Care Co-ordinator must ensure that the assessments undertaken by the MDT are robust and provide the evidence required to enable reasoned decision-making on CHC eligibility. Whilst the benefit of MDT meetings is recognised, they should not result in delay that could negatively impact on the outcome for the person. Co-ordination of assessment can, and should, continue in a timely manner, beyond the confines of a formal meeting.

4.31 The Care Co-ordinator and/or the MDT may decide that additional information is required to provide robust expert advice to the LHB concerning the individual's eligibility for CHC. If this is the case the information required must be identified together with the most appropriate professional to supplement the assessment. Decision-making should not be delayed because of repeated requests for further information.

4.32 As far as is reasonably practicable, the LHB should consult with the relevant LA before making any decision about an individual’s eligibility for CHC. In doing so it should cooperate with the relevant local authority to arrange for individuals to participate in an MDT for that purpose. LHBs may use a number of approaches (e.g. face-to-face, video/tele-conferencing etc.) to arrange these MDT assessments in order to ensure active participation of all members as far as is possible.

4.33 If an LA is consulted, it is **expected** to provide advice and assistance to the LHB, as far as is reasonably practicable. It should, if requested by an LHB, co-operate in arranging for persons to participate in an MDT. The involvement of both LA and NHS professionals in the assessment process should streamline the process of care planning and will make decision-making more effective and consistent. As with any assessments that they carry out, LAs should not allow an individual’s financial circumstances to affect its participation in a joint assessment.

4.34 Once all the information has been gathered (and depending on agreed local protocols) it is acceptable for the MDT to have a discussion without the individual. MDTs should be aware that the DST contains a section at the end of the domain tables for the individual and/or the representative to give their views on the completion of the DST that have not already been recorded elsewhere in the document, including whether they agree with the domain levels selected. It also asks for reasons for any disagreement to be recorded. Therefore, the MDT meeting should be arranged in a way that enables that individual to give their views on the completed domain levels before they leave the meeting.

4.35 Once eligibility has been considered and discussed with the individual and/or their representatives, and the DST completed, MDT members will immediately make their recommendation on whether a primary health need is present, based on the four key indicators (**see para 4.45**). This recommendation will be made separately from any discussions with the individual and/or their representative but even if they are not present on the day it should be communicated to them as soon as possible.

Identifying an Individual’s Needs

4.36 Establishing whether an individual has a primary health need requires a clear, reasoned decision, based on evidence of needs from a comprehensive range of assessments relating to the individual. A good-quality multi-disciplinary assessment of needs that looks at all of the individual’s needs ‘in the round’ – including the ways in which they interact with one another – is crucial both to addressing these needs and to determining eligibility for CHC. The individual and any representative should be enabled to play a central role in the assessment process.

4.37 It is important that the individual’s own view of their needs, including any supporting evidence, is given appropriate weight alongside professional views. Many people will find it easier to explain their view of their needs and preferred outcomes if the assessment is carried out as a conversation, dealing with key issues as the discussion naturally progresses, rather than working through an assessment document in a linear fashion.

4.38 The multi-disciplinary assessment of an individual’s needs informs the process for determining whether or not they are eligible for CHC. However, regardless of whether the individual is determined to be eligible for CHC, LHBs and LAs should always consider whether the multi-disciplinary assessment of needs has identified issues that require action to be taken. For example, if a multi-disciplinary assessment of needs indicates that the individual has significant communication difficulties, referral to a speech and language service should be considered.

4.39 If a needs assessment under the SSWB Act has already been carried out by the LA and is still relevant to an individual’s current care and support needs and the outcomes they wish to achieve the local authority may use this assessment as a source of information for the LHB. The LA should provide any other relevant information relating to the individual’s up-to-date needs, where appropriate.

4.40 Once an individual has been brought to the attention of the LA either through the provision of information advice and assistance or a referral, consideration must be given as to whether an assessment for care and support under the SSWB Act is required. The absence of a needs assessment for care and support should not delay an assessment of eligibility for CHC.

4.41 This Framework encourages a joint approach to the assessment of eligibility for CHC and it is important that all agencies respond in a timely manner. Local protocols should set how this is achieved, including in the absence of an existing LA needs assessment under the SSWB Act.

Determining Primary Health Need

Sole Criterion for Eligibility

4.42 The policy of Welsh Ministers on eligibility for CHC is based on whether an individual's primary need is a health need (this is known as the "primary health need approach"). The sole criterion for determining eligibility for CHC is whether an individual's primary need is a health need.

4.43 Where a person has been assessed to have a primary health need, they are eligible for CHC and the NHS will be responsible for providing for all of their assessed health and associated social care needs, including accommodation, if that is part of the overall need. Determining whether an individual has a primary health need involves looking at the totality of the relevant needs. This assessment is undertaken by the MDT **(see paragraphs 4.27 to 4.35).**

4.44 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. Having a primary health need is not about the reason why an individual requires care or support, nor is it based on their diagnosis; it is about the level and type of their overall actual day-to-day care needs taken in their totality, which must use the national Decision Support Tool (DST) **(see paragraphs 4.55 - 4.60).**

4.45 Each individual case has to be considered on its own facts in accordance with the principles outlined in this Framework. The following characteristics of need, and their impact on the care required to manage them, will determine whether an individual's primary need is a health need:

- **Nature**: This describes the particular characteristics of an individual's needs (which can include physical, mental health or psychological needs) and the type of those needs. This also describes the overall effect of those needs on the individual, including the type ('quality') of interventions required to manage them.

- **Intensity**: This relates both to the extent ('quantity') and severity ('degree') of the needs and to the support required to meet them, including the need for sustained/ongoing care ('continuity').

- **Complexity**: This is concerned with how the needs present and interact to increase the skill required to monitor the symptoms, treat the condition(s) and/ or manage the care. This may arise with a single condition, or it could include the presence of multiple conditions or the interaction between two or more conditions. It may also include situations where an individual's response to their own condition has an impact on their overall needs, such as where a physical health need results in the individual developing a mental health need.

- **Unpredictability**: This describes the degree to which needs fluctuate and thereby create challenges in managing them. It also relates to the level of risk to the individual's health if adequate and timely care is not provided. Someone with an unpredictable healthcare need is likely to have either a fluctuating, unstable or rapidly deteriorating condition.

4.46 Each of these characteristics may alone or in combination, demonstrate a primary health need, because of the quality and/or quantity of care required to meet the individual's needs. The totality of the overall needs and effects of the interaction of needs should be carefully considered.

4.47 The diagnosis of a particular disease or condition does not, of itself, determine eligibility. The determination of a primary health need should take into account all the relevant health care needs.

4.48 That said there should be no gap in the provision of care. The primary health need test should be applied so ineligibility should only be determined where, taken as a whole, the nursing or other health services required:

- are no more than incidental or ancillary to the provision of accommodation which local authority social services are (or would be but for a person's means) be under a duty to provide; or

- are not of a nature beyond which a local authority whose primary responsibility it is to provide social services could be expected to provide.

4.49 In applying the primary health need test, LHBs should take into account that provisions in the Social Services and Well-being (Wales) Act, which requires LA's to apply the incidental and ancillary tests in all situations. Health boards should therefore consider these tests when determining eligibility.

Well-managed Needs

4.50 The decision-making rationale should not marginalise a need just because it is successfully managed; well-managed needs are still needs. Only where successful management of a healthcare need has permanently reduced or removed an ongoing need, such that the active management of this need is reduced or no longer required, will this have a bearing on CHC eligibility. The MDT should therefore give due regard to well-controlled conditions when considering the four characteristics of need and making an eligibility recommendation on primary health need.

4.51 Care should be taken when applying this principle. 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. If they move to a different environment and their needs reduce this does not necessarily mean that the need is now ‘well-managed’; the need may actually be reduced or no longer exist.

4.53 It is also important that deterioration and disease progression are taken into account when considering eligibility. The assessment should anticipate circumstances where deterioration or a material change in condition might reasonably be regarded as likely in the near future. In these circumstances, although the individual may not have a primary health need at the time of assessment, an earlier review should be considered.

4.54 The MDT should also advise commissioners of services, such as care homes, if, in their professional opinion, any stabilisation of a progressive condition, and potential withdrawal of CHC funding, is likely to be short-term. In such cases, commissioners should balance the contribution of well-managed need to the current assessment and the benefits to the individual of continuity of care provision, alongside financial considerations.

Using the Decision Support Tool (DST)

4.55 The Decision Support Tool (DST) **{DN: Insert Link in published version of Framework here}**} that accompanies this Framework is designed to support the decision-making process. The tool must only be used following a comprehensive assessment of an individual's care needs. It is not an assessment in itself and it does not replace professional judgement in determining eligibility. It is simply a means of recording the rationale and facilitating logical and consistent decision-making.

4.56 The MDT should use this tool to support consideration of not just the overall needs, but also the interaction between the needs, and evidence from relevant risk assessments. Conversely, the DST should not be completed without a multi-disciplinary assessment of needs.

4.57 If any assessments relating to the individual's health and wellbeing have recently been completed by practitioners, they may be used to complete the DST. For example, if the integrated assessment and care plan are sufficiently robust there is no requirement to duplicate paperwork by copying information into the DST document. It will be acceptable in these circumstances to only complete:

- the DST Summary Sheet (matrix)
- the summary record of the MDT decision on eligibility and the rationale
- the Equality Monitoring Form.

4.58 Nevertheless, care should be taken to ensure that such assessments provide an accurate reflection of current need. The evidence concerning eligibility and the decision-making process should be accurately and fully recorded. The documentation should be organised e.g. collated into a single folder or section of the patient notes, to ensure the CHC process and the outcomes can be easily identified via a clear audit trail. The focus must be on a rounded and holistic assessment of the individual rather than DST scores.

4.58 The DST is designed to ensure that the full range of factors that have a bearing on an individual's eligibility are taken into account in reaching the decision, irrespective of client group or diagnosis. The tool provides practitioners with a method of bringing together and recording the various needs in 12 'care domains', or generic areas of need. Each domain is broken down into a number of levels. The levels represent a hierarchy from the lowest to the highest possible level of need (and support required) such that, whatever the extent of the need within a given domain, it should be possible to locate this within the descriptors provided.

4.59 The care domains are:

- Breathing
- Nutrition
- Continence
- Skin Integrity
- Mobility
- Communication
- Psychological & Emotional Needs
- Cognition
- Behaviour
- Drug Therapies and Medication
- Altered States of Consciousness
- Other Significant Care Needs.

4.60 Completion of the tool should result in a comprehensive picture of the individual's needs that captures their nature, and their complexity, intensity and/or unpredictability – and thus the quality and/or quantity (including continuity) of care required to meet the individual's needs. Figure 1 in the Decision Support Tool indicates how the domains in it can illustrate (both individually and through their interaction) the complexity, intensity and/or unpredictability of needs. The overall picture, and the descriptors within the domains themselves, also relate to the nature of needs.

Pandemic and Other Emergency Situations

4.61 There is an appreciation that completing a full CHC assessment in hospital during a declared emergency, such as pandemic influenza, would be problematic. As CHC is an assessment of long-term needs, decisions on CHC eligibility should not take priority in these situations. The priority instead should be the safety of the patient, and ensuring they receive the care they need.

4.62 In these situations, LHBs should be able to choose not to undertake a CHC assessment until after the emergency period. The intention of this is not to withdraw a duty of care over the patient. The LHB will retain responsibility for organising, funding and providing care for them. This may happen in various ways and does not mean a continued presence in hospital; it may mean discharge to a care or nursing home with appropriate support or discharge to their own home with appropriate support. In some cases this will mean a situation not too dissimilar to finding someone eligible for CHC and arranging a care package for them.

4.63 There is nothing which would prevent LA and NHS teams from working together to discharge to home, as necessary. During the pandemic response, or in guidance beforehand, local teams should be required to utilise their ‘discharge to assess arrangements’ to ease pressure on hospital beds if possible.

Section 5: Making and Undertaking a Decision on Eligibility for CHC

Making the Recommendation on Eligibility

5.1 The MDT is required to make a recommendation to the LHB as to whether or not the individual has a primary health need, bearing in mind that where the LHB decides that the individual has a primary health need they are eligible for CHC. In coming to this recommendation, the MDT should work collectively using professional judgement.

5.2 The written recommendation needs to be clear and concise whilst providing sufficient detail to enable the LHB and the individual to understand the underlying rationale for the recommendation. In doing so, it should;

- provide a summary of the individual’s needs in the light of the identified domain levels and the information underlying these. This should include the individual’s own view of their needs.

- provide statements about the nature, intensity, complexity and unpredictability of the individual’s needs, bearing in mind the explanation of these characteristics provided in **para 4.45.**

- give an explanation of how the needs in any one domain may interrelate with another to create additional complexity, intensity or unpredictability.

- in the light of the above, give a recommendation as to whether or not the individual has a primary health need. It should be remembered that, 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.

5.3 Where an individual and/or their representative expresses concern about any aspect of the MDT or DST process, the Care Coordinator should discuss this matter with them and seek to resolve their concerns. Where the concerns remain unresolved, these should be noted within the DST so that they can be brought to the attention of the LHB making the final decision.

5.4 Where an MDT recommends an individual is not eligible for CHC, a clear rationale is needed that considers their circumstances under the four key characteristics of the primary health need test. Care planning for those individuals with ongoing needs, including any consideration for NHS Funded Nursing Care (FNC), will still be necessary.

Lack of clear recommendation

5.5 If an MDT is unable to reach agreement on the recommendation this should be clearly recorded.

5.6 The DST advises practitioners to move to the higher level of a domain where agreement cannot be reached but there should be clear reasoned evidence to support this. If practitioners find themselves in this situation they should review the evidence provided around that specific area of need and carefully examine the wording of the relevant DST levels to cross-match the information and see if this provides further clarity. Additional evidence may be sought, although this should not prolong the process unduly. If this does not resolve the situation, the disagreement about the level should be recorded on the DST along with the reasons for choosing each level and by which practitioner. This information should also be summarised within the recommendation so that the LHB can note this when verifying recommendations.

5.7 The practice of moving to the higher level where there is disagreement should not be used by practitioners to artificially steer individuals towards a decision that they have a primary health need where this is not justified. It is important that this is monitored during the LHB audits of recommendations and processes so that individual practitioners found to be using the ‘higher level’ practice incorrectly can be identified. Discussion may need to take place with these practitioners and further training may be offered.

Quality Assurance

5.8 It is the responsibility of the MDT to:

- undertake robust needs assessment;
- provide the LHB with consistent expert advice on CHC eligibility;
- develop the care plan to meet the individual's needs, and
- make recommendations regarding the setting and skill set required to most effectively deliver the care plan.

5.9 LHBs and their partners have a responsibility to ensure that MDT members have the knowledge, skills and competency to undertake these functions effectively. LHBs must identify, through their quality assurance system, teams or individuals who fail to follow the CHC process to the expected standard and take the responsive action required to support service improvement.

5.10 Determination of eligibility must be based on assessed need and must be independent of budgetary constraint. LHBs must ensure therefore that there is a clear split between the MDT function and confirmation of their conclusions, and the commissioning of the services required to deliver the care plan.

5.11 There will be occasional circumstances, when for clearly articulated reasons, the LHB does not accept the MDT's advice on CHC eligibility and therefore may request additional evidence to support the MDT's recommendations. The LHB may also request that the MDT reconsider the recommended eligibility based on the available evidence presented.

5.12 LHBs must have robust quality assurance (QA) mechanisms in place to ensure consistency of decision-making. This should be in the form of a panel and include peer review by another MDT where consensus has not been achieved. LHBs are also encouraged to incorporate peer review of CHC eligibility decisions into their audit and continuous service improvement programmes.

5.13 Quality assurance processes should not however lead to delay in providing the individual with the support they need and LHBs should consider employing a stream-lined process for non-contentious cases.

Communicating the Decision on Eligibility to the Individual

5.14 Once the eligibility decision is made by the LHBs following the QA Panel, the individual should be informed in writing as soon as possible (although this could be preceded by verbal confirmation where appropriate). This written confirmation should follow the requirements under Principle 7 (**see paras 3.10 to 3.17**) and consider an individual's specific language requirements. It should include:

- the decision on primary health need **(see para 4.45)**, and therefore whether or not the individual is eligible for CHC
- the reasons for the decision
- a copy of the completed DST, if requested and dependent on authority to share information
- details of who to contact if they wish to seek further clarification
- how to request a review of the eligibility decision.

5.15 Where an individual is not eligible for CHC, the outcome letter may also include, where applicable and appropriate, information regarding FNC or a joint package of care.

5.16 Where an individual is eligible for CHC, an indication of the proposed care package, if known, could be included within this communication, or if not known at that stage, information on what the next steps are. Eligibility for CHC is not indefinite, as needs could change. This should be made clear to the individual and/or their representative.

Timescales and Commencement of CHC Funding

5.17 The care planning process is central to the commissioning and provision of care to meet an individual's needs. Responsibility for this rests with the LHB.

5.18 An individual may require services from the LHB and/or LA. Both have responsibilities, therefore, to ensure assessments of eligibility for CHC takes place in a timely and consistent fashion. The consideration for CHC must always be made first.

5.19 The legal responsibility for the LHB to fund commences at the point at which it confirms that the MDT's advice is consistent and fair. However, the principles of good public administration dictate that, if an individual has paid for their care in the interim, they should be reimbursed.

5.20 Reimbursement would normally commence from the date on which the MDT met and made its determination of eligibility. However, the MDT should advise the LHB if they can, in their reasoned professional judgement, identify a date at which the primary health need became evident and the individual should be reimbursed accordingly.

5.21 The time taken for assessments informing CHC decision-making and agreeing a care package may vary but should generally be completed **in no longer than eight weeks**, from initial trigger to agreeing a care package. This includes the period of reablement and assessment at home or in step-down facility. Extension of this timeframe is acceptable where the individual needs a longer period of rehabilitation or reablement, but not in relation to delays in determining CHC eligibility.

5.22 In some cases much speedier decisions should be taken in the individual's best interests: for example in terminal illness, or where there has been a catastrophic event from which point it is clear that the individual has a primary health need (see 'Fast Track Assessments').

Planning

5.23 The timescale for the provision of care following assessment can vary; people may move in and out of eligibility for CHC. Individuals, their families and carers, and other care purchasers and providers, must be made fully aware of the financial and practical implications of this as part of the information provided to support the assessment process.

5.24 In exceptional circumstances timescales may be more protracted, though as an underpinning principle the professionals involved must ensure that the individual is in the most appropriate environment and, wherever possible, re-abled, during this period. The Care Co-ordinator should ensure that timescales, decisions and rationales relating to eligibility are transparent from the outset for individuals, carers, family and staff.

5.25 Any exceptions to the 8-week timescale should be monitored locally as part of the performance framework and actioned as appropriate.

5.26 Where a person qualifies for CHC, the package to be provided is that which the LHB assesses is appropriate to meet all of the individual's assessed health and associated care and support needs. The LHB has responsibility for ensuring this is the case, and determining what the appropriate package should be. In doing so, the LHB should have due regard to the individual's wishes and preferred outcomes. Although the LHB is not bound by the views of the LA on what services the individual requires, any LA assessment will be important in identifying the individual's needs and in some cases the options for meeting them. Whichever mechanism is used for meeting an individual's assessed needs, the approach taken should be in line with the principles of personalisation.

5.27 Care planning for needs to be met under CHC should not be carried out in isolation from care planning to meet other needs, and, wherever possible, a single, integrated and personalised care plan should be developed.

Fast Track Assessments

5.28 Occasionally, it will be necessary to safeguard an individual's well-being by 'fast tracking' people for immediate provision of CHC. An example of this may be individuals who arerapidly deteriorating In such circumstances, people can be supported in their preferred place of care without waiting for the full CHC eligibility process to be completed. In such cases LHBs should aim to complete the process within two days. There will also be cases, other than end-of-life care e.g. a catastrophic event where professional judgement indicates that the individual has evidently developed a primary health need, where LHBs should also consider applying fast track assessment.

5.29 LHBs should consider and put in place a fast track process that reduces the amount of information required, the time taken to gather information and reduce timescales for making a decision for those individuals who require 'fast tracking'. However, streamlined processes should still ensure that the individual and their carers are fully involved, provide enough information to support the need for fast tracking and for the decision makers to agree a package of care**.** An example policy can be accessed via the Complex Care Information & Support site www.cciss.org.uk.

5.30 Fast track assessments should be completed by an appropriate clinician who should give the reasons why the individual meets the conditions requiring a fast track decision to be made. 'Appropriate clinicians' are those who are, pursuant to the National Health Service (Wales) Act 2006, responsible for an individual's diagnosis, treatment or care who are registered nurses or medical practitioners. The clinician should have an appropriate level of knowledge and experience of the type of health needs to decide on whether the individual has a rapidly deteriorating condition that may be entering a terminal phase.

5.31 Although an NHS professional must co-ordinate the fast track assessment, appropriate clinicians contributing to that assessment can include professionals employed in the voluntary and independent sector organisations that have a specialist role in end of life care e.g. hospice nurses, providing they are offering services pursuant to the National Health Service (Wales) Act 2006. Others involved in supporting those with end of life needs, including wider voluntary and independent sector organisations may identify the fact that the individual has needs for which the fast track process should be considered. In these cases, they should contact the care Co-ordinator.

5.32 The completed fast track assessment should be supported by a prognosis. However, strict time limits that base eligibility on some specified expected length of life remaining should not be imposed. It is the responsibility of the assessor to make a decision based on the relevant facts of the case.

5.33 Where a recommendation is made for an urgent package of care by an appropriate clinician through the fast track process, this should be accepted and actioned immediately by the LHB. Disputes about the fast track process should be resolved outside of the care delivery

5.34 No individual who has been identified through the fast track process should have their care package removed without their eligibility being reviewed in accordance with the review process set out in **Section 4**. The review should include completion of the DST by the MDT, including a recommendation on future eligibility. This overall process should be carefully and sensitively explained to the individual and, where appropriate, their representatives. Sensitive decision-making is essential in order to avoid the undue distress that may result from an individual moving in and out of CHC eligibility within a very short period of time.

5.35 CHC fast track assessments, care planning and commissioning for those with end of life needs should be carried out in an integrated manner in line with the individual's overall end of life care pathway, with full account being taken of the individual's preferences. An Advance Care Plan should be developed in accordance with Welsh Government policy[10].

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[10] Together for Health: End of Life Delivery Plan 2013

Section 6: Service Provision and Review

Care Provision and Monitoring

6.1 Local authorities and local health boards are required to follow statutory arrangements to undertake jointly, an assessment of the needs of the local population for care and support, support for carers and preventative services.

6.2 This means identifying and utilising information about people's well-being and the barriers they experience, to inform and evidence the range and level of services that are required to meet and prevent the development of care and support needs of those living within their boundaries.

6.3 The commissioning of services to meet the needs of individuals with continuing care needs cannot be undertaken in isolation to the commissioning of other similar services. LHBs and LAs should have an integrated approach to the commissioning of residential and nursing home care to exercise maximum influence over the development of provision. They will also need to work closely with providers to ensure that an appropriate range of services are in place to respond to the needs of their population. The Social Services and Well-being (Wales) Act also requires regional partnership boards to establish pooled budgets from April 2018 in relation to the provision of care home accommodation for older people. These pooled budgets will support integrated commissioning allowing local authorities and health boards to focus on improved quality as well as securing better value for money. The pooled budget may include funds to cover local authority FNC and CHC commitments.

6.4 All service provision must demonstrably respond to assessed need and the care plan. The Multi-disciplinary Team (MDT), in hospital or community, is responsible for undertaking a thorough and objective assessment in partnership with the individual and/or their representative. It is also responsible for providing expert advice on eligibility for CHC and for developing a detailed care plan (collated by the Care Co-ordinator) which responds to the assessed need and maximises independence wherever possible, taking into consideration the preferences of the individual. The MDT is responsible for making recommendations on the skills and interventions that need to be commissioned in order to deliver the care plan.

6.5 Support for carers is a health and social care responsibility and must be considered and provided. These are defined under **Section 2** of this Framework.

6.6 The Social Services and Well-being (Wales) Act 2014 Code of Practice relating to Part 4 Meeting Needs[11], the Unified Assessment Process for other user groups and Integrated Assessment Framework provide guidance on the arrangements for ongoing monitoring and management of care for adults. In particular, the Code of Practice:

- emphasises the importance of monitoring and reviewing the care and support needs and the personal outcomes the person wishes to achieve, the effectiveness of provision put in place to meet those needs /services, in order to confirm, amend or close personal plans of care;

- indicates the necessity to review continued eligibility for CHC as their needs change.

Where a person is eligible for CHC

6.7 When it has been determined that an individual is eligible for CHC, it is the responsibility of the health service to make the necessary arrangements for the care of the patient irrespective of setting. The NHS will take the lead role in working with the other organisations to establish an appropriate package of care, accommodation and support. While the overall responsibility for the care provision for those individuals who are eligible for CHC will lie with the LHB there will be ways in which other agencies, such as (but not only) social services may become involved, for example through:

- ongoing social work services

- agreed delegated responsibility, under formal partnership arrangements, for purchasing or providing care

- agreed delegated or shared responsibility for providing ongoing assessment and/or care management

- locally developed joint service provision

- their housing, education and leisure services responsibilities, local authorities have a corporate role in enabling people to have fulfilling lifestyles and to participate in and contribute to the wider community

- the provision of equipment via the integrated community equipment service

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[11] http://gov.wales/docs/phhs/publications/160106pt4en.pdf

6.8 The CHC package to be provided is that which the LHB assesses is appropriate for the individual’s health and personal care needs. LHBs are encouraged to consider the LAs assessment or its contribution to a joint assessment as these will be important in identifying the individual’s needs and, in some cases, the options available for meeting them.

6.9 It is the responsibility of the LHB to plan, specify outcomes, procure services, and manage demand and provider performance for all services that are required to meet the health and personal care needs of individuals who are eligible for CHC. Regional partners are expected to develop an integrated approach to the commissioning of care home services, including in relation to negotiating contracts, service specifications, fee negotiations and quality assurance. Partners must establish a pooled fund in relation to care home accommodation functions to support these integrated arrangements.

6.10 Unless the function is formally delegated LHBs continue to have responsibility for the case management/care co-ordination role for those entitled to CHC as well as for the NHS component of a joint care package, including an assessment and review of individual patient needs.

6.11 The LHB will have arrangements in place for brokering and commissioning the services required to deliver the detailed care plan. The MDT recommendations and the individual’s preferences need to be balanced in accordance with the Sustainable Care Planning Policy (see www.cciss.org.uk).

6.12 The LHB must demonstrate a clear rationale for its decision on the CHC package to be commissioned, and should reflect the principles detailed above. This rationale and the care package arrangements must be clearly explained to the individual and/or their representatives and confirmed in writing.

6.13 Clear contract arrangements must be established with the service provider. The contract must be outcomes-focussed and include arrangements for regular review.

6.14 As with all service contracts, LHBs are responsible for monitoring quality, safety, access and patient experiences within the context of provider performance. The ultimate responsibility for arranging and monitoring the services required to meet the needs of those with CHC rests with the LHB. LHBs should ensure that there is clarity on the respective responsibilities of the LHB and providers for CHC.

6.15 LHBs will have in place service specifications and contracts for registered settings which cover health and social care and take into account relevant regulations, Standards for Health Services and other relevant guidance and best practice.

6.18 Where individuals eligible for CHC are cared for in a care home, escalating concerns will be managed in accordance with the Welsh Government's '*Escalating Concerns With, and Closures of, Care Homes Providing Services for Adults*' Guidance (May 2009). In accordance with this guidance, LHBs and social care agencies should have in place systems and processes which enable registered providers, contract managers, care managers and other professionals to clearly understand what is expected and required from each setting and how such requirements will be delivered and monitored. These systems will frame how agencies contract and work with providers to shape quality services.

6.20 LHBs should develop operational procedures to ensure its responsibility for commissioned services are effectively secured and monitored where care is provided by external agencies.

6.21 LHBs have a statutory duty under the Health and Safety at Work Act (HSWA) 1974 to ensure the health and safety of NHS patients is maintained where a provider is providing services on behalf of the NHS. This duty is owed to residents both by the provider and the NHS commissioning body.

6.22 The individual should be advised that welfare benefits available to support the person's living costs may be affected by eligibility for CHC, and should be signposted to appropriate advice.

6.23 The location of the delivery of the CHC care package will be determined in response to the care plan and in accordance with the Sustainable Care Planning Policy (see www.cciss.org.uk).

6.24 The choice of location for those individuals who meet eligibility for CHC will have differing implications for the involvement of other agencies. Where a person receives their CHC care package in a hospital or care home, the NHS will arrange and fully fund the care, including the accommodation, board costs and personal care. Where a person returns to their own home (or that of a carer) the LHB fully funds the cost of their health and personal care needs but not the accommodation, food or general household support.

6.25 LHBs and LAs must work together to identify gaps in current and future service provision. There is an expectation that partner organisations will share intelligence to inform future workforce planning and to develop market position statements, working with a range of independent and not-for-profit organisations to develop the required provision.

Additional personal contributions from an individual who is eligible for CHC

6.26 The NHS provides a comprehensive service available to all. Access to NHS services is based on clinical need and not on an individual's ability to pay. Public funds for healthcare will be devoted solely to the benefit of people that the NHS serves. As overriding principles, it is essential that: the NHS should never subsidise private care with public money (which would breach core NHS principles) and patients should never be charged for their NHS care, or be allowed to pay towards NHS care (except where specific legislation is in place to allow this) as this would contravene the founding principles and legislation of the NHS. To avoid these risks, there should be as clear a separation as possible between private and NHS care. LHBs should seek to ensure that providers are aware of the above principles.

6.27 The care plan should set out the services to be funded and/or provided by the NHS. It may also identify services to be provided by other organisations such as local authorities and third sector providers. Where such non-NHS funded support is provided as part of a total package, the individual and their carers should be signposted by the local authority to clear information on charging arrangements and by the voluntary sector to potential alternative funding sources e.g. benefits and charitable organisations.

6.28 In addition to such arrangements, there may be circumstances, as described below, where individuals and/or their representative may choose to access additional services or premium accommodation by making, and paying for, separate arrangements themselves.

6.29 Queries regarding additional personal contributions ('top ups') to CHC packages usually fall into three categories:

- Additional services;
- Higher cost 'premium' accommodation;
- Retaining an existing (more expensive) provider.

Additional Services.

6.30 Where a provider receives a request for privately funded additional services from an individual who is funded by CHC, they should refer the matter to the LHB for consideration.

6.31 ‘Additional services’ are defined as those which are over and above those detailed in the care plan developed to address assessed need. Such personal contribution arrangements must never be utilised as a mechanism for subsidising the service provision for which the LHB is responsible.

6.32 Any decision to purchase additional private services must be borne purely through personal choice and not through a lack of appropriate NHS or LA provision to meet assessed need. It is the responsibility of the LHB to engage with the individual and/or their representatives to assure them that this is not the case, and that individuals are not at risk of financial exploitation. If the individual advises that they have concerns that the existing care package is not sufficient or not appropriate to meet their needs, the LHB should offer to review the care package in order to identify whether a different package would more appropriately meet the individual’s assessed needs.

6.33 The following examples of where individuals may choose to purchase private services may be helpful:

Example 1:

An individual who is assessed as requiring, and is provided with, one NHS physiotherapy session a week but wishes to purchase an additional session privately. In such circumstances the financial arrangements for the privately funded service will be entirely a matter between the individual and the relevant provider and it should not form part of any service agreement between the LHB and the provider.

Example 2:

An individual may wish to purchase an additional visit each day from the care provider. The LHB must firstly consider whether it should meet the full costs of the care package. If after review, the LHB is satisfied that the services it has commissioned are appropriate to meet the individual’s identified needs, the person may choose to initiate a private arrangement with the care provider. In such a case the LHB will need to liaise with the individual and the care provider to ensure that all parties are clear as to the additional support to be provided in the privately funded visits.

6.34 Although NHS funded services must never be reduced or downgraded to take account of privately-funded care, the LHB and the organisations delivering NHS funded care should, wherever clinically appropriate, liaise with those delivering privately-funded care in order to ensure safe and effective coordination between the services provided. The care plan should detail effective risk management, appropriate sharing of information, continuity of care and co-ordination between NHS funded and privately funded care.

Higher Cost ‘Premium’ Accommodation

6.35 As stated above, the funding provided by LHBs in CHC packages should be sufficient to meet the needs identified by the MDT in the care plan. Unless it is possible to separately identify and deliver the NHS funded elements of the service, it will not usually be permissible for individuals to pay for higher-cost accommodation.

6.36 There may be exceptional circumstances, to be considered on a case-by-case basis, where a LHB should consider the case for a higher than usual cost, for example, where an individual and/or their representative requests a larger room or a new placement in a care home which charges a rate significantly above that which the LHB would normally pay.

6.37 The LHB must liaise with the individual and/or their representative(s) to identify the reasons for the preference. Where the need is for identified clinical reasons (for example, an individual with challenging behaviour who requires a larger room because it is identified that the behaviour is linked to feeling confined, or an individual considers that they would benefit from a care provider with specialist skills rather than a generic care provider), consideration should be given as to whether it would be appropriate for the LHB to meet this.

6.38 If no clinical need is established the LHB will need to make a decision which balances the needs and preferences of the individual with the requirement for probity with public funds. See the All Wales Policy for Sustainable Care Planning.

6.39 In some circumstances, providers may offer ‘extras’ such as flower arrangements, daily newspapers etc. as part of their package. In the interests of public probity, it is reasonable to expect individuals and/or their representatives to make separate arrangements to purchase such items directly from the provider as detailed above.

Retaining an existing (higher cost) provider.

6.40 In some circumstances, individuals become eligible for CHC when they are already resident in care home accommodation for which the fees are higher than the relevant LHB would usually meet for someone with their needs. This may be where the individual was previously funding their own care or where they were previously funded by a local authority and a third party had ‘topped up’ the fees payable.

6.41 “Topping up” is legally permissible under legislation governing local authority social care but it is not permissible under NHS legislation. In such situations, LHB should consider whether there are reasons why they should meet the full cost of the care package, notwithstanding that it is at a higher rate. Such reasons could include for example the frailty, mental health needs or other relevant needs of the individual which mean that a move to other accommodation could involve significant risk to their health and well-being.

6.42 There may also be circumstances where an individual in an existing out of area placement becomes entitled to CHC and where, although the care package is of a higher cost than the responsible LHB would usually meet for the individual’s needs, the cost is reasonable taking into account the market rates in the locality of the placement. LHBs should establish this by liaison with the LHB where the placement is located.

6.43 LHBs should also consider whether there are particular circumstances that make it reasonable to fund the higher rate. This could be because the location of the placement is close to family members who play an active role in the life of the individual or because the individual has resided in the placement for many years so that they have strong social links with the area and it would be significantly detrimental to the individual to move them.

6.44 LHBs should deal with the above situations with sensitivity and in close liaison with the individuals affected and, where appropriate, their families, the existing service provider and the local authority if they have up to this point been funding the care package. Where a local health board determines, following the recommendations from the MDT, that circumstances do not justify their funding an existing higher cost placement or services for which they have inherited responsibility, the LHB does have the authority to move accommodation or change provider. Any decisions should be taken in full consultation with the individual concerned and confirmed in writing with reasons given. Advocacy support should be provided where this is appropriate.

6.45 Where an individual becomes entitled to CHC and has an existing high-cost care package, LHBs should consider funding the full cost of the existing higher-cost package until a decision is made on whether to meet the higher cost package on an ongoing basis or to arrange an alternative placement.

6.46 Where an individual wishes to dispute a decision not to pay for higher-cost accommodation, they should do so via the NHS Complaints Procedure. The letter from the LHB advising them of the decision should also include details of the complaints process and who to contact if the individual wishes to make a complaint.

6.47 In cases of transition, a care plan should be developed by the existing commissioners with the new providers that identifies health and social care needs, and addresses how any specific clinical needs and risks should be addressed. The LHB is responsible for monitoring and reviewing the placement. It should keep in regular liaison with the new provider and with the individual during the initial weeks of the new services to ensure that the transition has proceeded successfully and to ensure that any issues that have arisen are being appropriately addressed.

Supporting individuals eligible for CHC in their own home

6.48 Where an individual is eligible for CHC and chooses to live in their own home, the LHB is financially responsible for meeting all assessed health and associated social care needs. This could include: equipment provision, routine and incontinence laundry, daily domestic tasks such as food preparation, shopping, washing up, bed-making and support to access community facilities, etc. (including additional support needs for the individual whilst the carer has a break). However, there is a range of everyday household costs that are expected to be covered by personal income or welfare benefits, including food, rent/mortgage interest, fuel and water, clothing and other normal household items.

6.49 Whilst LHBs can take comparative costs and value for money into account, they must not set arbitrary limits on care at home packages based purely on the notional costs of caring for an individual in a home. Such arbitrary limits are incompatible with personal health budgets which have been developed to enable people to live independently, work or participate in society.

6.50 People who are eligible for CHC and who choose to live in their own home may have additional support needs which it may be appropriate for the local authority to address subject to SSWB Act provisions and eligibility guidance, e.g. assistance and advice regarding property adaptation, support with essential parenting activities, deputyship or appointeeship services, safeguarding concerns, carer support or services required to enable the carer to maintain his/her caring responsibilities.

Direct Payments[12] and CHC

6.51 It is currently unlawful for Direct Payments to be used to purchase health care which the NHS is responsible for providing, however it is not unlawful for local authorities and health boards to work together to provide individuals with voice and control in respect of their health and social care needs. This includes the pooling of budgets and other mechanisms to ensure people experience seamless care.

6.52 As a matter of principle, if an individual has existing Direct Payment arrangements, these should continue wherever and for as long as possible within a tailored joint package of care.

6.53 Where an individual whose care was arranged utilising Direct Payments becomes eligible for CHC funding, the LHB must work with them in a spirit of co-production. Although Direct Payments will no longer be applicable where an individual has a primary health need, this should not mean that the individual loses their voice, choice and control over their daily lives. Every effort should be made to maintain continuity of the personnel delivering the care, where the individual wishes this to be the case.

6.54 There may be circumstances where it is possible for an individual to retain some Direct Payment for the elements of their care for which the local authority is still responsible, e.g. opportunities for social inclusion. Partner organisations must work together to explore all the options available to maximise an individual’s independence.

6.55 An individual in receipt of Direct Payments retains the right to refuse to consent to CHC assessment and /or care package, as detailed in **Section 3**. In such cases, partner agencies must work together with the individual and their family/carers to ensure that the risks are fully understood and mitigated as far as possible. It cannot automatically be assumed, however, that LAs will continue to provide those services, as this may mean that they are acting outside of their legal authority.

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[12] Code of Practice on Part 4 of the Social Services and Well-being (Wales) Act 2014.

Where a person is not eligible for CHC

6.56 Where it has been determined that a person is not eligible for CHC and an alternative package of care is required (e.g. FNC in a care home, or a joint package of care in the community), the lead role will normally lie with the local authority, or, as agreed between agencies, in their local care management arrangements. The NHS will work alongside the local authority to develop and implement an appropriate care plan.

6.57 This care plan must not require an LA to provide services which are beyond its powers to provide. However, neither the LHB nor the local authority can dictate what the other organisation can provide.

6.58 There should be no gap in the provision of care. People should not find themselves in a situation where neither the NHS nor the relevant local authority (subject to the person meeting the relevant means test and having needs that fall within the appropriate Fair Access to Care eligibility criteria) will fund care, either separately or together.

6.59 A written agreement should also be established with the individual and/or their representative, clearly setting out what is covered by NHS funding, what may be accessed via the local authority subject to its eligibility criteria, and what the individual will be responsible for.

6.60 Clarity of responsibility for funding and implementation should inform, rather than prevent, any joint arrangements that may be established e.g. lead commissioning, pooled budgets.

Joint packages of health and social care

6.61 Increasing numbers of people with complex care needs are being supported in the community. If services are to be truly outcome-focussed, person-centred, supporting independence and not diagnosis-led, then it is logical that, where sustainable, individuals will be supported for longer at home with joint packages of care.

6.62 If an individual is not entitled to CHC but has some healthcare and social care needs, they should receive a package of health and social care that is tailored to their individual needs. There will be some individuals who, although they are not entitled to CHC, have needs identified through the DST that are not of a nature that a local authority can solely meet or are beyond the powers of a local authority to solely meet. LHBs should therefore work in partnership with the LA to agree their respective responsibilities in joint care packages and ensure seamless provision of care.

Joint funding in care home placements.

6.63 Where an individual is not eligible for CHC but has health needs which are different from, or additional to, those supported by FNC, the NHS may still have a responsibility to meet those needs as part of a joint package in so far as these health needs are beyond the powers of the local authority to provide.

6.64 There may be some individuals in care home placements who do not have a primary health need indicating eligibility for CHC but are acknowledged to have nursing needs greater than would normally be expected to be covered by the FNC rate and what can be reasonably expected for an LA to commission. Along with this Framework, Welsh Health Circular (2004) 024 (NHS Funded Nursing Care in Care Homes) states that there should be no gap between local authority and NHS provision.

6.65 Options available to LHBs to meet their responsibility in providing this additional level of health care include NHS in-reach from core services or additional financial contribution to the total funding package. LHBs and local authorities will need to work together to ensure that neither body is operating outside of its statutory duty. The funding arrangements and the local authority contribution for which the individual may be charged must be confirmed in writing by the lead agency and shared with commissioners, providers and the service user and/or representative.

6.66 Examples of additional services to funded nursing care, which may also be provided by the NHS if these are agreed as part of an assessment and individual care plan include (but are not limited to):

- primary healthcare
- assessments involving doctors and registered nurses.
- rehabilitation and recovery (where this forms part of an overall package of NHS care as distinct from intermediate care).
- community health services.
- community mental health services.
- specialist support for healthcare needs.
- additional support for episodic higher needs in joint care packages e.g. additional registered nurse input into behaviour management assessment/care planning.
- palliative care and end of life care.
- specialist transport (i.e. ambulances).

Joint funding of packages of care delivered in an individual’s own home.

6.67 More, and increasingly complex, packages of care are being delivered in an individuals’ own homes. Where an individual is not eligible for NHS CHC, a comprehensive joint health and social care package must be developed and agreed co-productively which meets the person’s assessed care and support needs and achieve personal outcomes. This must be detailed in a clear inter-agency care plan, with a named care co-ordinator/lead professional, which is jointly owned by commissioners, providers and the individual and/or their representative.

6.68 LAs have a responsibility to meet people’s needs for care and support in accordance with the Social Services and Well-being (Wales) Act 2014.

6.69 The joint funding arrangements will be determined locally and in accordance with the needs and outcomes of the individual. Options available include the use of a joint funding matrix or formalised pooled budget arrangements. The individual should not experience delay in receiving their care package whilst funding arrangements are negotiated.

6.70 A written agreement should also be established with the individual and/or their representative, clearly setting out what is funded by the LHB, what may be accessed via the local authority subject to its eligibility criteria and charging, and for what the individual will be responsible.

Reviews

Purpose and frequency of reviews

6.71 An individual’s eligibility for CHC is subject to review. Reviews should follow the format of an assessment, consider all the services received and be tailored to the individual.

6.72 These reviews should primarily focus on whether the care plan or arrangements remain appropriate to meet the individual’s needs. It is expected that in the majority of cases there will be no need to reassess for eligibility.

6.73 As a minimum there should be an initial review of the care plan within 3 months of services first being provided, unless this is triggered earlier by the individual, their family/representative or the provider.

6.74 Thereafter, reviews should be at least annually. Where an individual’s condition is anticipated to deteriorate, more regular review may be necessary. The frequency of such reviews will be determined by professional judgement based on the individual’s assessed needs or if there is a change in circumstances. They should be proportionate to the situation in question in order to ensure that time and resources are used effectively. Where there is an obvious deterioration in circumstances, reviews should also be held within 2 weeks and acted upon appropriately.

6.75 The individual and/or their representative and the service provider must be provided with the contact details of a named care co-ordinator, so that any changes in the individual’s condition or circumstances can be promptly addressed.

6.76 Review timescales should be identified and communicated to the individual and their relatives verbally and in writing. For those receiving secondary mental heath services there is a legal requirement to review their care at least every 12 months and in line with the Code of Practice to Part 2 and 3 of the Mental Health (Wales) Measure 2010.

6.77 The individual should be central to the review process. Prior to the review, they should be offered the opportunity to re-assess their own needs and be offered appropriate support to do so. It will also be necessary to consider whether a further carer’s assessment should be undertaken at this time.

6.78 It is expected that the most recently completed DST will normally be available at the review. It should be used as a point of reference to identify any potential change in needs. Where there is clear evidence of a change in needs to such an extent that it may impact on the individual's eligibility for CHC, the LHB should arrange a full reassessment of eligibility for CHC.

6.79 Where reassessment of eligibility for CHC is required, a new DST must be completed by a properly constituted Multi-disciplinary Team (MDT), as set out in this Framework. Where appropriate, comparison should be made to the information provided in the previous DST. LHBs are reminded that they must (in so far as is reasonably practicable) consult with the LA before making an eligibility decision, including any re-assessment of eligibility. This duty is normally discharged by the involvement of the LA in the MDT process, as set out in the Assessment of Eligibility section of this Framework **(Section 4).** LHBs should ensure an individual's needs continue to be met during this reassessment of eligibility process.

6.80 If the LA is also responsible for any part of the care, both the LHB and the LA will have a requirement to review care and support needs and ensure that personal outcomes are being met by the provisions in place. In such circumstances, it would be beneficial to conduct a joint review. Even if all the services are the responsibility of the NHS, it would be beneficial for the review to be held jointly by the NHS and the local authority especially as any decision affecting CHC will require input from both sectors. Some cases will require a more frequent case review, in line with clinical judgement and changing needs.

6.81 Individuals who are in receipt of FNC in a care home must also be reviewed at least annually. The LHB must ensure that the individual, their family/representative and care home provider have the information and contacts available to enable them to identify changes in need which indicate a timely review is required. Care home checklist can be found at **Annex 4**.

6.82 When reviewing the need for FNC, potential eligibility for CHC must always be considered and a full assessment should be carried out, where necessary.

6.83 Care providers who monitor their own service effectiveness should contribute this information to the review of the whole plan of care. The review should be recorded and set out:

- who was involved
- those individuals not involved and reasons why
- the location
- the method of review
- issues that the individual (or carer/advocate) raised.

6.84 The LHB's responsibility to provide or commission care (including CHC) is not indefinite as needs might change. This should be made clear to the individual and their family or carer at the time of the initial assessment and at each subsequent review and confirmed in writing. The individual and the carer or representative should be provided with the '*What receiving CHC-funded services means for you'* leaflet at the commencement of their CHC care package.

Outcomes of a review

6.85 The review will determine whether:

- the individual's needs are being met appropriately,
- whether eligibility should be reconsidered through reassessment for CHC.
- whether the individual's needs have changed, which then determines
- whether the package of care needs to be revised or the funding responsibilities altered.

6.86 The outcome of a review does not necessarily indicate the same outcome should have been reached with a previous assessment, provided that the previous assessment was properly carried out and the decision taken was based on sound reasoning.

6.87 The review information should be used to inform the individual's care plan. A copy of the review and care plan should be drafted, agreed and given to the service user. Subject to the constraints of confidentiality, the findings of the review and changes to the care plan should also be shared with those involved in the individual's care.

6.88 If the individual/relative or their carer is not satisfied with the care plan which has been developed, they will need to raise this with the person responsible for it in the first instance. They may request a re-assessment of their needs and review of the care plan. If they continue to be dissatisfied, they will need to consider making use of the complaints process.

6.89 The CHC Independent Review Panel (see **Section 8**) is not designated to review the content of care plans, only the decision-making process relating to the application of the primary health need approach.

6.90 Where, following a review, services are to be discontinued, the review report should clearly state the reasons for this withdrawal. There should be an evaluation and record of the extent to which the objectives and outcomes were achieved and the name of the professional that the individual can contact if needs and circumstances change.

6.91 Providers must be made aware, within the contract documentation, of their responsibilities to notify the funding body of any marked deterioration or any other issues affecting the delivery of care.

6.92 Neither the LHB nor the LA should unilaterally withdraw from an existing funding arrangement without a joint reassessment of the individual and without first consulting one another and the individual about the proposed change of arrangement. Therefore, in order to ensure continuity of care, if there is a change in eligibility, it is essential that alternative funding arrangements are agreed and put into effect before any withdrawal of existing funding. Any proposed change should be put in writing to the individual by the organisation that is proposing to make such a change. If joint agreement cannot be reached upon the proposed change, the local disputes procedures **(see Section 8)** should be invoked and current funding arrangements should remain in place until the dispute has been resolved.

6.93 The risks and benefits to the individual of a change of location or support (including funding) should be considered carefully before any move or change is confirmed. Neither the LHB nor the local authority should unilaterally withdraw from funding of an existing package until there has been appropriate reassessment and agreement on future funding responsibilities and any alternative funding arrangements have been put into effect. Further details on responsibilities during changes (including approaches to disputes) are set out in **Section 8.**

Section 7: Links to Other Policies and Specialist Areas of Practice

Links to Mental Health Act 1983 - Aftercare Services

7.1 Under Section 117 of the Mental Health Act 1983 (the 1983 Act), health and social services authorities have a duty to provide or arrange after care services for individuals who have been detained under certain provisions of the 1983 Act, until they are satisfied that the person is no longer in need of such services. It should be borne in mind, however, that some people may be eligible for care and support under both CHC and Section 117.

7.2 Section 117 is a free-standing joint duty. Local health boards (LHBs) and local authorities (LAs) should develop protocols to help determine their respective responsibilities for the delivery of Section 117 aftercare (see for example Mental Health Act 1983 Code of Practice for Wales, chapter 31). This Framework does not therefore attempt to provide additional guidance on this issue, but focusses on the interface between Section 117 and eligibility for Continuing NHS Healthcare.

7.3 Responsibility for the provision of Section 117 is shared between LAs and LHBs, although this does not necessarily mean there should be a 50/50 split in all cases. Where a patient is eligible for services under Section 117 these should be provided under Section 117 and not under CHC.

7.4 All those subject to Section 117 are considered to be in receipt of secondary mental health services, as defined under the Mental Health (Wales) Measure 2010 (the Measure) and will therefore have a Care Co-ordinator and an outcome-focussed prescribed Care and Treatment Plan (CTP) that is reviewed at least annually. Detailed guidance regarding care and treatment planning is given in the Code of Practice to Parts 2 and 3 of the Measure.

7.5 There are no powers to charge for services provided under Section 117 of the 1983 Act, regardless of whether those services are provided by LHBs or LAs. Accordingly, the question of whether services should be ‘free’ NHS services rather than potentially charged-for services does not arise. It is not appropriate to assess eligibility for CHC if all the services in question are to be provided as after-care under Section 117.

7.6 However, an individual in receipt of after-care services under Section 117 may also have additional needs which are not related to their mental disorder. For example, an individual may be receiving services under Section 117 and develop separate physical needs, for example following a stroke, which may then mean they are eligible for CHC or FNC.

7.7 In such cases, the general approach set out in this Framework of considering the totality of need in assessing eligibility for CHC still applies. The individual may as a result, have the services required to meet their total care needs funded by the NHS, but this does not necessarily remove the shared *duty* under Section 117. The Section 117 shared duty remains unless a joint assessment and agreement by both the LA and the LHB determines that those arrangements are no longer needed.

7.8 Where an individual in receipt of Section 117 services develops physical care needs resulting in a rapidly deteriorating condition which may be entering a terminal phase (or a catastrophic health event which clearly requires CHC), consideration should be given to the use of the Fast Track Pathway Tool.

7.9 Where an individual is to be discharged from Section 117, eligibility for CHC or FNC will need to be considered where the transition assessment and plan indicates that new or other services may be required.

7.10 Information should be provided to the individual or their representative on the effect that discharge from Section 117 may have on their financial circumstances.

7.11 Example local Section 117 local policies, Section 117 pack and case scenarios can be accessed via the CCISS site www.cciss.org.uk.

Deprivation of Liberty

7.12 The Mental Capacity Act 2005 contains provisions that apply to a person who lacks capacity and where care arrangements amount to a deprivation of their liberty. The fact that a legal authorisation is being sought or is in place in relation to a deprivation of liberty of capacity does not affect the consideration of whether that person is eligible for CHC.

7.13 Where an individual is in receipt of CHC, and they lack mental capacity to consent to their accommodation, or care and support arrangements, the LHB must ensure that the arrangements they commission are lawful and compliant with provisions under the Mental Capacity Act.

The Transition from Child and Young Person's to Adult Services

7.14 This Framework should be used to determine eligibility for CHC and what services people aged 18 years or over should receive from the NHS. The Framework should be used in conjunction with the Welsh Government's Children's and Young People's Continuing Care Guidance (2012) and the Sustainable Care Planning in Continuous NHS Health Care operational policy for local health boards (2012) and the Social Services and Well-being (Wales) Act (2014). These documents can be accessed via the CCISS site www.cciss.org.uk. Key principles for transition from children's to adult's services for young people using health or social services are outlined in National Institute for Health and Care Excellence (NICE) guidance (2016) and support best practice which equally applies to young people with continuing care needs.

7.15 The legislation and the respective responsibilities of the NHS, social services and other services are different in children and young persons (CYP) and adult services. The term 'continuing care' also has different meanings in CYP and adult services. The Children and Young People's Continuing Care Guidance was issued in November 2012. That guidance applies to children and young people whose health needs cause them to require a bespoke multi-agency package of continuing care that cannot be met by existing universal or specialist services alone. Although the main reason for such a package will derive from the child or young person's health needs, they are likely to require multi-agency service provision involving input from education, social services and sometimes others. CHC for adults refers to a package of care which is arranged and funded solely by the NHS for those individuals who have been assessed as having a primary health need. The LA will retain the responsibility for meeting any ongoing educational needs.

7.16 It is important that young people and their families are helped to understand this and its implications right from the start of transition planning. An example transition pack can be accessed via the CCISS site www.cciss.org.uk.

7.17 While service provision and the meaning of the term 'continuing healthcare' is different pre- and post-18 years, the needs of the individual will not automatically change because an individual has reached 18 years of age. Individuals with complex needs, regardless of their age, require continuous review and assessment to ensure that their needs are met in the most effective way. The assessment and review process should continue throughout transition.

7.18 Transition is an area that can cause anxiety for children, their parents and carers. When some young people move from CYP services to adult services they experience uncertainty about future care provision and support and also the loss of income due to changes in benefits. Each LHB must draw up a robust local transition policy with its partner agencies. A template document is provided in the CCISS site www.cciss.org.uk.

7.19 Transitional arrangements with key milestones must be identified in care plans and LHBs must work with their partners and with the young person and their family/carer to agree a process for transition from CYP services into adult services.

7.20 All of the partner agencies must ensure that practitioners with the appropriate skills and knowledge are available to contribute to the assessment and care planning process. Appropriateness of practitioners will be indicated by the child or young person's presenting needs.

7.21 Initial planning for transition to adult CHC services must commence when the young person is aged 14, where the need is already identified or as soon as possible, if problems emerge that will require ongoing care, after this age. A lead professional must be identified and supported by all the agencies involved. This person will act as the Transition Co-ordinator and key point of communication for the individual and their family. There is an expectation that partners will work together to define and agree the role and responsibilities of the Lead Professional/ Transition Co-ordinator. Support materials can be found on the Complex Care Information & Support site www.cciss.org.uk.

7.22 Support during transition should be routinely provided up to 19 years of age, though there will be cases where such support may be required up to the age of 25 years, for example, local authorities have the discretion to support a young person in the process of leaving care, who may need ongoing support with support living/emotional support.

7.23 Once the young person reaches 16 years of age there should be a formal referral for screening to the appropriate adult CHC team. At the age of 17, eligibility for adult CHC should be determined in principle by the relevant HB, bearing in mind that, in complex cases, needs can change in the course of a year. Local multi-disciplinary teams will need to use their professional judgement regarding the timing of assessment and review to ensure that effective packages of care can be planned and commissioned in time for the individual's 18th birthday. If needs are likely to change, it may be appropriate to make a provisional decision and then to recheck it be repeating the process as adulthood approaches.

7.24 Even if a young person is not entitled to adult CHC, provision of services for health needs is the responsibility of the NHS. In such circumstances, LHBs should continue to play a full role in transition planning for the young person and should ensure that services to meet these needs are provided. The focus should always be mutually agreed and take into account the individual preferences.

7.25 A key aim is to ensure that a consistent package of support, jointly designed and agreed by the young person and their carers, is provided based on assessed need. The nature of the package may change because the young person’s needs or circumstances change. However, it should not necessarily change simply because of the move from CYP to adult services or because of a switch in the organisation with commissioning or funding responsibilities. Where change is necessary, it should be carried out in a phased manner, in full consultation with the young person and their family. No services or funding should be withdrawn unless a full assessment has been carried out of the need for adult health and social services.

7.26 Service provision should be tailored for the individual and may be drawn from a combination of sources, including core (e.g. primary care, district nursing, social services), specialist services (e.g. mental health, learning disability, residential educational placements) as well as individually funded elements of the package. The potential complexity of the package means that effective care co-ordination by the designated lead professional is essential. The individual and their family must be provided with a detailed and co-produced multi-agency care plan which sets out which services will be provided by whom, including funding arrangements.

7.27 Financial implications for the young person and their family, including any changes to benefits or other funding sources such as Direct Payments, must be clearly explained at the earliest possible opportunity. Accommodation and independent living choices should be fully explored, and a clear explanation provided of entitlements and options. Support for carers must be included in the care plan, in accordance with the Social Services and Well-Being Act.

7.28 The young person and their family/carers should not experience any delay in receiving the services they require whilst funding sources are being negotiated. Partner agencies should consider joint/pooled resource, including budget arrangements to ensure that the right care is provided at the right time.

7.29 There is a risk that the tailoring of comprehensive packages of care (be they CHC or joint funded) for children and young people with complex needs can lead to families feeling overwhelmed by the numbers of people involved. Co-ordination of care, active involvement of a designated lead professional, and effective communication will do much to mitigate that risk.

7.30 In order to continue to provide effective support to the increasing numbers of young people with complex needs who move to adult service provision, there is an expectation that partner agencies and providers will share intelligence and work together to address any emerging skills and service gaps. Examples may include developing a workforce (registered and unregistered) which has a broad range of skills to support young people and adults with a combination of physical, mental health and learning needs, and developing market position statements to bring residential provision closer to home.

7.31 Compliance with the guidance on transition will be assessed via the Performance Management Framework.

Applying the CHC Framework to adults with a learning disability

7.32 'The Statement on Policy and Practice for Adults with a Learning Disability, published in 2007, sets out the key principles, aims, responses and outcomes the Welsh Government believes are desirable. This is the Welsh Government's latest guidance and is still relevant today.

7.33 In 2017 a review of learning disability services was undertaken to identify areas where action could potentially be taken to build on good practice in Wales taking a lifespan approach and considering all main service areas. This review resulted in the Learning Disability Improving Lives Programme of work which contains 24 recommendations focusing on improving services in five key areas: Early Years; Housing; Social Care; Health; and Education, Skills and Employment (June 2018)'.

7.34 It is expected that partnerships will work in collaboration to ensure that evidenced need is appropriately met. Care packages should be developed in accordance with the Mental Capacity Act 2005 and the following long-established principles[13]:

a. Community Presence
b. Relationships & Partnerships
c. Choice
d. Competence
e. Respect & Status
f. Individuality & Continuity

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[13] O'Brien, J. (1984) A guide to personal futures planning. Lithonia, GA: Responsive Systems Associates.

7.35 Many individuals with a learning disability already live in supported living environments. In order to maintain continuity and stability for the individual, joint care packages which utilise staff with whom they are familiar, supplemented by flexible health and social care responses, must be the preferred option wherever it is safe to do so from a clinical and social perspective. Funding arrangements will change once an individual has been assessed as having a primary health need (**see para 4.45**) but disruption to the individual should be minimised as far as possible.

7.36 In all cases, eligibility for CHC should be informed by good quality multi-disciplinary assessment. It will be important to involve all professionals who know and are involved with the individual. The question is not whether learning disability is a health need, but rather whether the individual concerned, whatever client group he or she may come from, has a 'primary health need'.

7.37 NHS and social care service providers have a responsibility to ensure that their staff have the inclusive skills required to assess and support people with a learning disability. Access to care should not be restricted to specialist learning disability services.

7.38 Where an individual is presenting with behaviours that challenge, there is an expectation that the MDT will have undertaken the appropriate assessment to attempt to determine the cause. See 'Frequently Asked Questions' at www.cciss.org.uk.

Entitlement to other NHS funded care

7.39 Those in receipt of CHC continue to be entitled to access the full range of primary, community, secondary and other health care services regardless of care setting.

7.40 LHBs should ensure that their contracting arrangements with care homes that provide nursing care clarify the responsibilities of nurses within the care home and of community nursing services respectively. There should be no gap in service provision between these two sectors (**see Section 6**).

Community equipment

7.41 Where individuals are in receipt of CHC and they require equipment to meet their care needs, there are a number of routes by which this may be provided.

7.42 If the individual is, or will be, supported in a care home setting, the care home may be expected to provide certain equipment as part of regulatory standards or as part of the contract with the LHB. The care home should normally provide equipment which can or is used by a number of residents i.e. it is not prescribed for an individual. Equipment which is specifically prescribed for an individual and should not be used by other residents should be provided by the LHB.

7.43 LHBs have the option to contribute to the existing formal partnership and pooled fund arrangements for community equipment services to purchase and manage CHC equipment to benefit from existing procurement arrangements. Alternatively, where LHBs purchase CHC equipment separately they should consider an agreement with the joint store to manage this equipment to ensure that appropriate servicing and maintenance are in place. Where the LHB maintains completely separate arrangements for CHC equipment it must have in place systems to keep track of equipment, maintain and service it and recall and refurbish when no longer required.

7.44 LHBs should ensure that there is clarity about which of the above arrangements is applicable in each individual case.

Section 8: Disputes and Appeals

Disputes Between Organisations

Principles

8.1 It should be remembered that decisions regarding eligibility for CHC are the responsibility of the LHB, who may choose to make their decision before an inter-agency disagreement has been resolved. In such cases it is possible that the formal dispute resolution process will have to be concluded after the individual has been given a decision by the LHB.

8.2 The Welsh Government expects LHBs and their partners to work together to deliver the best possible outcomes for the citizens of Wales.

8.3 The fundamental principle is for LHBs and LA's to minimise the need to invoke formal inter-agency dispute resolution procedures through effective partnership working, integration and implementation of this Framework.

8.4 In the first instance, where the MDT is unable to reach a consensus view on CHC eligibility, they should escalate the dispute to the appropriate managers and access peer review from within, or outside of, their LHB. Normally, this should be within 48 hours.

8.5 If mature partnership discussion, including objective managerial/clinical expertise and peer review, has failed to achieve a consensus view, the formal dispute process will need to be initiated.

8.6 Where disputes relate to LAs and LHBs in different geographical areas, the dispute resolution process of the responsible LHB should normally be used in order to ensure resolution in a robust and timely manner

Protocols

8.7 LHBs and LAs should have in place locally agreed procedures/protocols for dealing with any formal disputes about

- eligibility for CHC and/or about the apportionment of funding in jointly funded care packages.
- where an individual is not eligible for CHC:
    - the contribution of either party to a joint package of care
    - the operation of refunds guidance

8.8 These protocols should make clear how the LHB discharges its duty to consult with the local authority and how the LA discharges its duty to co-operate with the LHB. **See paragraphs 2.15 - 2.21).**

8.9 LHBs and LAs must maintain a culture of genuine partnership working in all aspects of CHC. They should ensure eligibility decisions are based on thorough, accurate and evidence-based assessments of the individuals' needs. Individuals must never be left without appropriate support while disputes between statutory bodies about funding responsibilities are resolved. They should be kept at the heart of the process and there should be a person-centred approach to decision-making.

8.10 If there is an opportunity to resolve inter-agency disagreements this should be explored and undertaken at the earliest opportunity and preferably at an informal stage. Any genuine disagreements between practitioners in a professional manner without drawing the individual concerned into the debate in order to gain support for one professional's position or the other.

8.11 Practitioners in health and social care receive high-quality joint training (i.e. health and social care) which gives consistent messages about the correct application of the Framework.

8.12 Disputes must not delay the provision of care and the protocol should make clear how funding will be provided pending the resolution of the dispute. Where disputes relate to the NHS and LAs in different geographical areas, the relevant NHS body and LA should agree a dispute resolution process to ensure resolution in a timely manner. This should include agreement on how funding will be provided during the dispute and arrangements for reimbursement to the relevant organisations once the dispute is resolved.

8.13 All stages of disputes procedures will normally be completed within four weeks of raising the dispute. All stages will be appropriately documented. An example of a dispute process can be accessed via the CCISS site www.cciss.org.uk.

What should a protocol contain?

8.14 When developing and agreeing local inter-agency disagreement and dispute resolution protocols, LHBs and LAs should both encompass the following elements:

- A brief summary of principles, including a commitment to work in partnership and in a person-centred way.

- The LHB's and the LA's various duties to consult with each other. This should include arrangements for situations where the local authority has not been involved in the MDT and in formulating the recommendation.

- An 'informal' stage at operational level whereby disagreements regarding the correct eligibility recommendation can be resolved – this might, for example, involve consultation with relevant managers immediately following the MDT meeting to see whether agreement can be reached. This stage might include seeking further information/clarification on the facts of the case or on the correct interpretation of this Framework.

- A formal stage of resolving disagreements regarding eligibility recommendations, involving managers and/or practitioners who have delegated authority to attempt resolution of the disagreement and can make eligibility decisions. This stage could involve referral to an inter-agency CHC panel.

- If the dispute remains unresolved, the dispute resolution agreement may provide further stages of escalation to more senior managers within the respective organisations.

- A final stage involving independent arbitration. This stage should only be invoked as a last resort and should rarely, if ever, be required. It can only be triggered by senior managers within the respective organisations who must agree how the independent arbitration is to be sourced, organised and funded.

- Clear timelines for each stage.

- Agreement as to how the placement and/or package for the individual is to be funded, pending the outcome of dispute resolution and arrangements for reimbursement to the agencies involved once the dispute is resolved. Individuals must never be left without appropriate support whilst disputes between statutory bodies about funding responsibility are resolved.

- Arrangements to keep the individual and/or their representative informed throughout the dispute resolution process.

- Arrangements in the event of an individual requesting a review of the eligibility decision made by the LHB.

Appeals Against Eligibility Decisions from Individuals

8.15 The formal responsibility for informing individuals of the decision about eligibility for CHC and of their right to request a review lies with the LHB. Whether or not it is considered that an individual has a primary health need, the LHB must give clear reasons for its decisions, setting out the basis on which the decision was made, and explain the arrangements and timescales for dealing with a review of the eligibility decision in the event that the individual or someone acting on their behalf disagrees with it.

8.16 A request to review a decision about eligibility for either CHC or NHS Funded Nursing Care must be made within **28 days** of the individual and/or their representative being informed of that decision. Requests made after this time period will only be considered in exceptional circumstances

8.17 Where the individual and/or their representative disputes the clinical assessment of the MDT, external (from another directorate or LHB) peer review should be offered as a matter of course. This may avoid escalation to the formal appeals or complaints procedure and applications for retrospective reviews.

8.18 LHBs should deal promptly with any request to review decisions about eligibility. A clear and written response should be given including the individual's rights to complain under the NHS Complaints Procedure.

8.19 Each LHB should agree local review processes, including timescales. These should be available publicly and set out the stages involved in dealing with any requests for a review.

8.20 Once local procedures have been exhausted, the case should be referred to the Independent Review Panel(See below).

8.21 If the original decision is upheld by the Independent Review Panel and the individual still wishes to challenge the decision, the individual has access to the Public Services Ombudsman for Wales.

8.22 The individual's rights under the existing NHS Complaints Procedure and their existing right to refer their case to the Ombudsman remains unaltered by the panel arrangements. In particular, where an individual is dissatisfied with issues other than the points outlined above, the matter should be considered through the appropriate complaints procedure.

8.23 LHBs are accountable for ensuring that processes are in place and their staff have the skills and resources required to determine CHC eligibility correctly first time.

8.24 LHBs should deal promptly with any request to reconsider decisions about eligibility for CHC. They should, in the first instance, work closely with the individual to resolve the situation informally, as detailed above. They should ensure that appropriate assessments have been undertaken, applied, recorded and peer reviewed. Where the patient still wishes to contest the decision, the LHB will consider whether it is appropriate to convene the review panel.

8.25 An individual may apply to the relevant LHB for a review of the decision if they are dissatisfied with:

- the procedure followed by the LHB in reaching its decision on the individual’s eligibility for CHC, or
- how the primary health need was considered.

8.26 LHBs must give this request due consideration, taking into account all the information available, including any additional information from the individual and/or their representative.

Promoting Consistency in the Operation of Independent Review Panels

Independent Review Panel

8.27 The Independent Review Panel (IRP) process **(see Annex 5)** is intended as an additional safeguard for individuals who require ongoing support from health and/or social services and who consider that the eligibility criterion for CHC (the primary health need) has not been correctly applied in their case, or that appropriate procedures have not been followed.

8.28 If the local review process, including peer review, indicates that there is an element of doubt then recourse to the IRP process should be granted.

8.29 There should be recourse to the IRP process if the individual or their representative has significant additional information to present or exceptional circumstances apply.

8.30 Before taking a decision, the LHB will seek the advice of the chair of the review panel. In all cases where a decision not to convene a panel is made, a full written explanation of the basis of its decision should be provided to the individual and/or their representative, together with a reminder of their rights under the NHS Complaints Procedure.

8.31 The Independent Review Panel is not designated to review the content of care plans, only the decision-making process relating to the determination of whether a person is eligible for CHC.

8.32 The LHB will administer the procedure on behalf of all persons residing within the area for which it is responsible. The procedure is also available for reviewing decisions FNC. See www.cciss.org.uk for a template policy.

8.33 When reviewing the need for FNC, potential eligibility for CHC should always be considered and a full assessment carried out where necessary.

8.34 LHBs must ensure that arrangements are in place for:

- the establishment and operation of independent panels (**see Annex 5**)
- providing any additional translation or communication services so that individual and/or their representatives may fully engage with the process.

- access to independent clinical advice where needed, taking into account the range of medical, nursing and therapy needs in each case. Advisers will provide an opinion on judgements as to whether the primary health need approach and this Framework have been followed, and will not have a role in providing a second opinion on diagnosis, management or prognosis of the individual. Arrangements should avoid conflicts of interest between clinicians giving advice and organisations from which the patient has been receiving care.

- allocation of responsibility for review panels to a designated officer, who will ensure efficient operation of the process, check that appropriate steps have been taken to resolve the case informally and collect the factual evidence for the review panel.

8.35 In order to avoid delay and to maximise available expertise LHBs should implement a regional panel process as described in **Annex 5**. Each LHB will, however, ensure that it has allocated responsibility for overview of the proper and efficient operation of the process in their area to a designated officer.

8.36 LHBs are responsible for ensuring that the regional Independent Review Panels operate to a consistent standard and must make arrangements for the appropriate training and mentorship of all panel members.

8.37 There is an expectation that the partner agencies will allocate sufficient time within normal working hours for panel members to prepare sufficiently for the Panel proceedings. The importance of the role of a member of the Independent Review Panel should be reflected in their employing organisations through their job description and personal objectives.

8.38 The Panel's deliberations must be unanimous and properly recorded and communicated, with a clear rationale provided for their decision. This must be in line with the provisions under Principle 7 (**para 3.10 to 3.17**). A template format is available from www.cciss.org.uk.

Complaints

8.39 If an individual is dissatisfied with the decision at this stage (or the decision-making process at any stage) they may make use of the NHS Complaints Procedure, ‘Putting Things Right’, which is the appropriate mechanism for lodging such a complaint.

8.40 If an individual wishes to make a complaint about NHS funded services, they should initially speak to the service provider, if possible, or to the LHB. Under the Regulation and Inspection of Social Care (Wales) Act 2016, individual complaints about the provision of care will be considered by regulated establishments via their own procedures; local authorities will consider complaints relating to the commissioning process (such as the appropriateness of a type of placement); and the Care Inspectorate Wales (CIW) has discretionary powers to investigate complaints where that complaint may inform its role as a regulator of care homes. Any agency receiving a complaint needs to consider whether a referral should be made in line with procedures for protecting adults at risk.

8.41 It is good practice for LHBs and LAs to make each other aware of complaints received to speed up their resolution, and to pinpoint the main issue to be addressed to improve services.

8.42 Information on all relevant complaints procedures should be available in all service provision settings. The need for advocacy should be considered where appropriate.

8.43 Individuals who are dissatisfied with the way in which the NHS, an LHB or CIW investigates their complaint may complain to the Public Services Ombudsman for Wales. However, the Ombudsman will normally expect complainants to have tried to resolve their concerns through the relevant procedure before he considers taking a case. The Ombudsman does not have to investigate every complaint submitted, but will normally do so if there is evidence of hardship or injustice and that an investigation may be of benefit.

8.44 Further information on the NHS Complaints Procedure is contained in: Putting Things Right: raising a concern about the NHS (Welsh Government, 2011). The procedure can also be accessed via www.cciss.org.uk

Section 9: Retrospective Claims for Reimbursement.

9.1 An individual and/or their representative may request a retrospective review where they contributed to the cost of their care but have reason to believe that they may have met the eligibility for CHC due to the nature, intensity, complexity and/or unpredictability of their healthcare needs. A retrospective review claim is different from an appeal against a current CHC assessment and decision on eligibility. The appeals process is outlined in **Section 8**.

9.2 If eligibility is demonstrated for either the full or part period of the claim, the principles of good public administration demand that timely restitution be made.

9.3 As with the process of determining CHC eligibility, the retrospective claim process is not a legal process. Consideration of an individuals eligibility for a retrospective claim involve the use of distinct processes such as the All Wales Retrospective CHC Review to analyse the chronology of need over the entire period of the claim, as opposed to the Decision Support Tool, which provides indications of need over a snapshot in time. It is delivered by the LHB and therefore no charge will be made to the individual.

9.4 The process for making a claim is set out in **Figure 2**, below. If the individual and /or their representative wish to access support in following the process they may seek advice from the LHB itself, from voluntary sector advocacy or they may choose to engage a solicitor to act on their behalf. If eligibility is found, reimbursement will not cover the costs of any legal fees incurred.

9.5 Each LHB should publish a point of contact to which retrospective claims may be submitted. The all Wales Public Information Leaflet on retrospective claims and the Frequently Asked Questions leaflet are available via the CCISS site www.cciss.org.uk.

9.6 The claim may be submitted by either:

- the individual who is the subject of the claim.

- a person authorised by the individual to receive reimbursement on his/her behalf.

- a person holding a registered Enduring or Lasting Power of Attorney or who is a Court-appointed deputy for an individual who lacks mental capacity.

- in the case of a deceased individual, an executor named in the Grant of Probate in respect of the deceased's estate or an administrator named in the Grant of Letters of Administration of the estate.

9.7 Reimbursement, should eligibility be found, will only be paid to the above.

9.8 The process for considering the claim period for a retrospective review is as follows.

- the end of the claim period to be considered will be **no longer than 12 months** before the date of application.

- if the claim period is after a MDT/Independent Review Panel (IRP) decision of no eligibility, the period to be reviewed may go back to the date of the decision as long as it is no longer than 12 months.

- if the claim period is prior to a MDT/IRP decision, no longer than a 12 month period will be reviewed.

- **within 5 months** of registering the claim, claimants will be required to provide evidence of:

    - proof of fees paid to care home or domiciliary agency (see **Annex 6**)

    - where the claimant is not the patient, their right to make the claim on the individual's behalf (i.e Enduring/Lasting Power of Attorney or Grant of Probate).

9.9 LHBs need to balance their requirement to provide timely restitution with that of demonstrating probity with the public purse. Making an application does not mean that reimbursement is guaranteed; LHBs must satisfy themselves that the application is genuine and that the person was indeed eligible for CHC during the disputed period.

9.10 Applications outside of the stated claim period may be considered in exceptional circumstances where there is justification. Such circumstances can include for example, the claimant suffering critical illness, serving with the armed forces or living abroad. This is not an exhaustive list and other circumstances may apply.

The process for considering retrospective claims is as follows:

i. Evidence of legal authority to make the application and proof of payment of care fees will be provided by the claimant.

ii. A claim form (including a request for the claimant's views) and Information/Frequently Asked Questions booklets are sent to the claimant.

iii. On receipt of the proof of payment and legal authority to make the claim, requests are made to the appropriate care providers for records. In accordance with the all-Wales protocol for obtaining records, all agencies are allowed a maximum of 3 months to provide the records or to inform LHBs that they have been destroyed, lost or are unavailable for any other reason. A copy of the protocol and template letters can be found in www.cciss.org.uk

iv. A chronology of need is produced from the records available and the claimant's views. See www.cciss.org.uk for template.

v. The guidance in this Framework must be applied to the claim. The guidance and Checklist are based on the Decision Support Tool and must be used as part of a two-stage process.

vi. Stage 1 Review – the Checklist is applied to the chronology in order to identify triggers for full consideration of eligibility for CHC. A trigger date may be identified at the start of the claim period or part way through. If there are no triggers for consideration of eligibility, the case is closed at this point.

vii. In order to comply with the ethos of this Framework, the use of the Checklist must not replace professional judgement. Claimants should be sent a written explanation of the outcome of the application of the Checklist to their claim.

viii. Stage 2 Review - where triggers for CHC consideration are found, the All Wales Retrospective CHC Review (see www.cciss.org.uk) will be used by the reviewer to analyse the information in the chronology using the 4 key indicators of Nature, Intensity, Complexity and Unpredictability, applying the primary health need approach for the claim period by application of the Checklist.

ix. On completion of the analysis, the document will be peer reviewed by a different clinician to ensure the recommendation is robust, based on the evidence available and that the criteria have been consistently applied. If the clinicians do not agree, the case will be referred to the Independent Review Panel (IRP), (**see 9.12)**.

x. In cases where no eligibility is found, the document will be peer reviewed by at least one further different clinician to ensure that the evidence supports the recommendation made.

xi. The recommendation on eligibility will be made on the evidence available. It can be 1 of 4 possibilities:

- **matching**- the period of eligibility found matches the claim period in totality from the trigger date

- **partial**- eligibility is found for part of the claim period from the trigger date

- **no eligibility** found for any part of the claim period from the trigger date

- **Panel** - the reviewer has been unable to make a decision as the information available is complex or the clinicians are unable to agree on the period of eligibility.

xii. Dependant on the recommendation made, the case will go along 1 of 3 pathways:

- **matched** cases will go directly for ratification

- **partial** and **no eligibility** cases will be forwarded to claimants with the opportunity to discuss the findings

- **Panel** cases- an Independent Review Panel will be convened.

9.11 The claimant and/or their representative will be invited to discuss cases where partial or no eligibility has been found:

- Partial eligibility- the discussion will aim to reach a mutually acceptable period of eligibility based on the evidence available and/or new evidence that has not previously been available. If agreement is reached at this stage, the case will be forwarded for scrutiny and ratification. If no agreement is reached, the case will be forwarded for IRP consideration.

- No eligibility- the discussion will provide opportunity for further explanation of the CHC criteria and to check that the claimant/representative has understood the lack of evidence on eligibility.

Independent Review Panel

9.12 If the peer review indicates that there is an element of doubt then recourse to the IRP process should be granted.

9.13 There should be recourse to the IRP process if the individual or their representative has significant additional information to present or exceptional circumstances apply.

9.14 Before taking a decision, the LHB will seek the advice of the Chair of the review panel. The Chair provides the lay perspective in the review process. In all cases, where a decision not to convene a panel is made, a full written explanation of the basis of its decision should be provided to the individual and/or their representative, together with a reminder of their rights under the NHS Complaints Procedure and access to the Public Services Ombudsman for Wales.

9.15 The following principles and processes should be followed for all IRP cases:

- all decisions of the IRP must be unanimous.
- an All-Wales Decision Document will be completed by the person scrutinising and ratifying the recommendation made/Chair of the IRP.
- a copy of the completed Decision Document is provided to the claimant/representative and the LHB Finance Department.
- in cases of no eligibility, if a claimant does not wish to attend a negotiation meeting in person, the recommendation should be discussed over the telephone or in writing as far as possible.
- in cases of partial eligibility, a claimant not wishing to attend the negotiation should be able to discuss the recommendation over the phone. An IRP should then be convened.

Responsibility for the management of claims

9.16 A significant number of applications received by Health Boards after 16th August 2010 were transferred to the National CHC Retrospective Claims (Powys) Project. These claims relate to the period 12 April 1996 to 31 March 2003 and 1 April 2003 to 31 July 2013. Both the Powys Project and individual LHBs will follow the process detailed above.

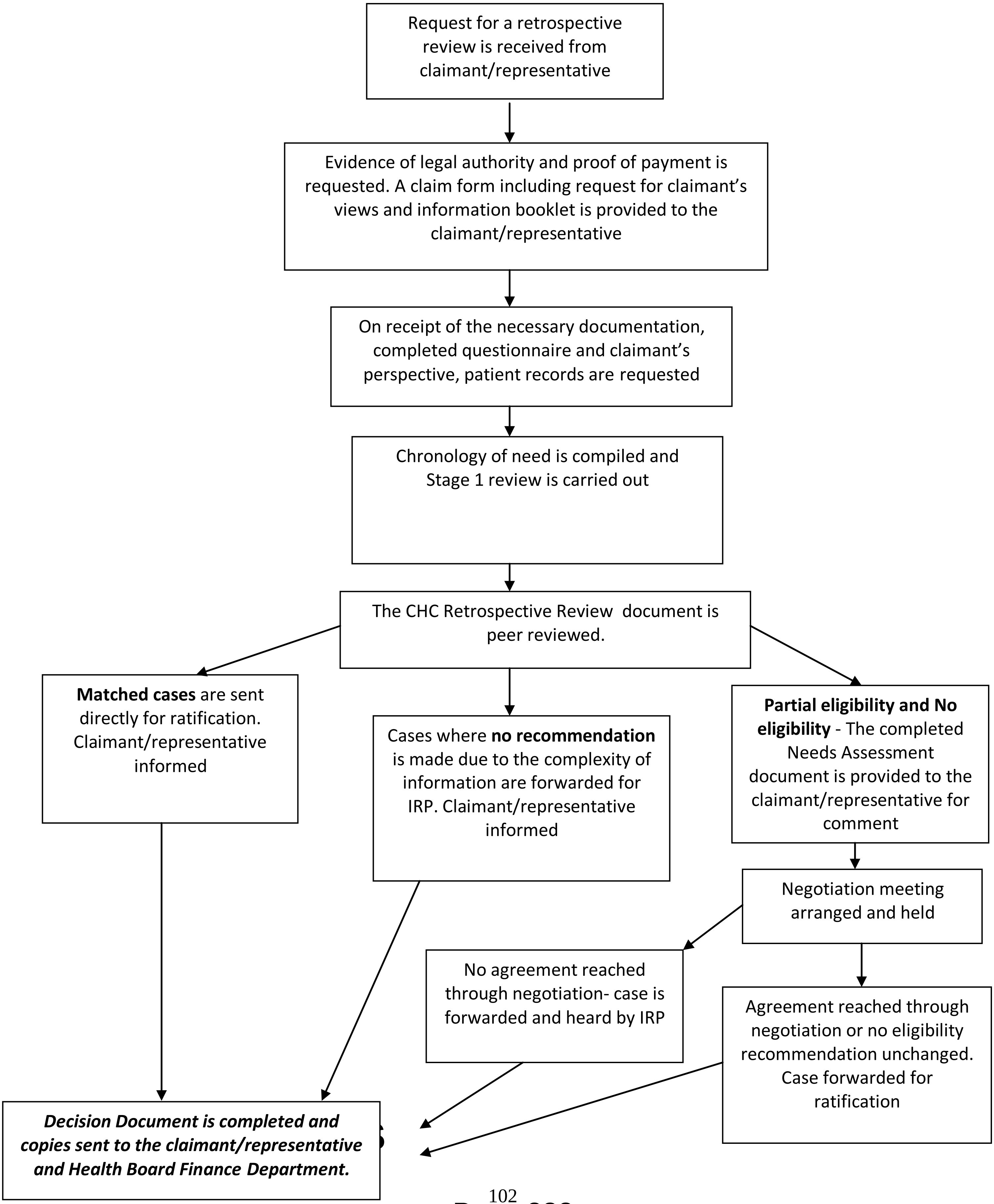
9.17 In January 2014 a national NHS Executive Task and Finish Group was established, with the support of Welsh Government, to assume responsibility for the oversight of the management of all retrospective claims and compliance with this guidance. The LHBs have agreed joint arrangements with the national (Powys) project to ensure completion of claims within the stipulated timescales and will submit monthly performance information to Welsh Government.

9.18 In July 2015 the Welsh Government issued additional guidance in respect of proof of payment for reimbursement of retrospective claims (WHC(2015)039).

9.19 The All Wales Retrospective CHC Reviews Project will close down on 31 March 2019. From April 1, 2019 the responsibility for the management of all retrospective claims will fall to local health boards.

9.20 Claimants who are dissatisfied with the review process are able to access the NHS Complaints Procedure and have recourse to the Public Services Ombudsman for Wales, as outlined in **paragraph 8.21.**

Figure 2: Process for undertaking a Retrospective Review



Glossary of Terms

All Wales Retrospective CHC Review Document
There are different arrangements concerning the administration of ongoing or contemporary CHC cases and those of backdated, or retrospective ones. DST is used in contemporaneous assessments and provides a picture of the needs at one point in time. A retrospective covers a long period of time and it is necessary to identify changes in need over that period that may indicate eligibility /no eligibility at different times based on identified need. The All Wales Needs Assessment doc (formerly the All Wales Needs Assessment doc) is based on the DST but facilitates the identification of needs over an extended period of time which may be divided in to a number of periods depending on the length of the whole claim period.

Assessment
Assessment involves a balanced analysis of the individual's needs, resources and capacities and the outcomes they want to achieve, in order to identify how they can best be supported to achieve them.

Behaviours that challenge

Behaviours that challenge are defined as "culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities.

Care Home

An establishment registered under the Regulation and Inspection of Social Care Act 2016 to provide accommodation, together with nursing or personal care.

Care Planning and Review

Care Planning and Review is a dynamic process, bringing together the individual, their carers and professionals to agree how their needs can best be met, the actions needed and who will do them.

Care and Support Package
A combination of support and services designed to meet individual's assessed health and social care needs, as detailed in the Care and Support Plan.

Care and Support Plan
A Care Plan must contain:

- plans and actions to be undertaken to help achieve the desired outcomes;

- the roles and responsibilities of the individual, carers and family members and practitioners (including for example GP, Nurse), and the frequency of contact with those;

- the resources (including financial resources) required from each party; and

- the review and contingency arrangements and how progress will be measured.

Carer
The Social Services and Well-being (Wales) Act 2014 defines a carer as a person who provides or intends to provide care for an adult or disabled child. The definition excludes those who provide or intend to provide care under, or by virtue of, a contract or as voluntary work.

Care Worker
Care workers provide paid support to help people manage the day-to-day activities of living. Support may be of a practical, social care nature or to meet a person's healthcare needs.

Complex Care Information & Support site www.cciss.org.uk
This is a web-based resource hosted by Welsh Government to support implementation of this Framework.

Cognition
The higher mental processes of the brain and the mind including memory, thinking, judgement, calculation, visual spatial skills etc.

Cognitive impairment
Cognitive impairment applies to disturbances of any of the higher mental processes, many of which can be measured by suitable psychological tests. Cognitive impairment, especially memory impairment, is the hallmark and often the earliest feature of dementia.

Commissioning
Commissioning involves a set of activities by which local health boards and local authorities ensure that services are planned and organised to best meet the health and social care outcomes of people in Wales. It involves understanding the need of their populations, best practice and local resources and using these to plan, implement and review changes in services. It encompasses both planning and procurement.

Commissioning requires a whole systems perspective and applies to services across all sectors. Commissioning services to respond to the needs of people with continuing health care should not be undertaken in isolation to commissioning other closely related services.

Local health boards can delegate the function of commissioning to local authorities and local authorities can delegate the function of commissioning to local health boards whilst still retaining their statutory responsibilities. This facilitates the development of a coherent approach to commissioning services such as, for example, residential and nursing home care or reablement and intermediate care services with one approach to developing contracts, service specifications, fee settings and quality assurance.

Continuing NHS Healthcare (CHC)
A complete package of ongoing care arranged and funded solely by the NHS, where it has been assessed that the individual's primary need is a health need. Continuing NHS healthcare can be provided in any setting. In a person's own home, it means that the NHS funds all the care that is required to meet their assessed health and social care needs to the extent that this is considered appropriate as part of the health service. This does not include the cost of accommodation, food or general household support. In care homes, it means that the NHS also makes a contract with the care home and pays the full fees for the person's accommodation as well as their care.

Decision Support Tool
The Decision Support Tool (DST is designed to support the decision-making process. The tool must only be used following a comprehensive assessment of an individual's care needs. It is not an assessment in itself and it does not replace professional judgement in determining eligibility. It is simply a means of recording the rationale and facilitating logical and consistent decision-making.

The DST is designed to ensure that the full range of factors that have a bearing on an individual's eligibility are taken into account in reaching the decision, irrespective of client group or diagnosis. It provides practitioners with a method of bringing together and recording the various needs in 12 'care domains' (see below), or generic areas of need. Each domain is broken down into a number of levels of severity.

Domain
One of 12 key areas of consideration within the integrated assessment and the Decision Support Tool. These are breathing, nutrition, continence skin integrity, mobility, communication, psychological & emotional needs, cognition, behaviour, drug therapies and medication, altered states of consciousness and other significant care needs.

End-of-Life Care
Care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes the management of pain and other symptoms, and the provision of psychological, social, spiritual and practical support.

Funded Nursing Care – see NHS Funded Nursing Care

General Household Support
Such services as cleaning, laundry, meal preparation, shopping, cooking, collecting benefits, sitting with or accompanying on social outings.

IRP
Independent Review Panel

Intermediate Care
A range of integrated services to promote faster recovery from illness, prevent unnecessary acute hospital admission, support timely discharge and maximise independent living. This type of service is usually provided on a short-term basis at home or in a residential setting (usually about 6 weeks) for people who need some degree of rehabilitation and recuperation. Its aims are to prevent unnecessary admission to hospital, facilitate early hospital discharge and prevent premature admission to residential care.

Lead Professional/Care Co-ordinator

This is the person who:

- co-ordinates the assessment process, and draws in additional specialists as required;
- acts as a focus for communication for different professionals and the individual to make sure that information is recorded correctly; and,
- ensures that any problems or difficulties in the co-ordination or completion of an assessment are resolved.

For people with mental health needs the Mental Health Measure makes specific requirements regarding who the Care Co-ordinator should be.

LA
Local authority

LHB
Local Health Board.

Long-term Care
This is a general term that describes the care which people need over an extended period of time, as the result of disability, accident or illness in order to address both physical and mental health needs. It may require services from the NHS and/or social care, and can be provided in a range of settings, such as a NHS hospital, a care home (providing either residential or nursing care), hospice, and in people's own homes. Long-term care is distinct from intermediate/transitional/interim care which has specific time limited outcomes for rehabilitation, reablement or recuperation.

Long-term Conditions
Those conditions that cannot, at present, be cured, but can be controlled by medication and other therapies.

Mental Capacity
The ability to make a decision about a particular matter at the time the decision needs to be made. The legal definition of a person who lacks capacity is explained in Section 2 of the Mental Capacity Act 2005: ‘ a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or disturbance in the functioning of, the mind or brain’.

Mental Disorder
Mental disorder is defined in Section 1(2) of the Mental Health Act 1983 (as amended by the Mental Health Act 2007) as meaning ‘any disorder or disability of the mind’.

Multi-disciplinary or Multi-agency
These terms refer to professionals across health and social care and the third sector who work together to address the holistic needs of their patients/clients in order to improve delivery of care and reduce fragmentation.

National Integrated Assessment Framework
This is the Welsh Government Framework that applies to promoting wellbeing, assessment, care planning and review arrangements for services for people aged 65+ irrespective of presenting need, disability or condition and supports access to care and support in the community. (**See Annex 1**)

NHS
National Health Service

NHS Funded Nursing Care (FNC)

The provision of NHS Funded Nursing Care derives from Section 49 of the Health and Social Care Act, 2001 (now replaced, in relation to Wales, by Section 47(4) and (5) of the Social Services and Well-being (Wales) Act 2014), which excludes nursing care by a registered nurse from the services which can be provided by local authorities. NHS Funded Nursing Care applies to all those persons currently assessed as requiring care by a registered nurse in care homes. The decision on eligibility for NHS Funded Nursing Care should only be taken when it is considered that the person does not fall within the eligibility criteria for CHC.

Palliative Care

The active holistic care of patients with advanced, progressive illness. This includes the management of pain and other symptoms and provision of psychological, social, spiritual and practical support. The goal of palliative care is the achievement of the best quality of life for patients and their families.

Personal Information

The term "personal information" should be taken to include, where appropriate, "special category information" (e.g. health information). Those terms have the same meaning as "personal data" and "special category data" in the Data Protection Act 2018.

Power of Attorney

an applicant with an Enduring or Lasting Power of Attorney registered with the Court of Protection may, in general, exercise the patient's rights of access to records on behalf of that patient, but only to the extent that the information is necessary for them to be able to carry out their duties as an attorney or deputy. There is an important distinction between:

a) Someone acting as Lasting Power of Attorney (health and welfare) who will generally be able to exercise the patient's rights of access to health and social care records in order to make informed decisions about their health and welfare. This includes being able to consent (or refuse consent) to the NHS CHC process and to sharing information with relevant professionals involved in the process. The Power of Attorney (POA) has to be registered and this type of POA can only be used if the individual has lost the capacity to make the relevant decision about their health and welfare.

b) Someone with Enduring Power of Attorney (EPA) or someone acting as Lasting Power of Attorney (property and finance). Again the EPA or LPA has to be registered but can be used with the donor's permission to help them make decisions about property and finance even if they still have capacity to make such decisions themselves. More usually, the POA (property and finance) or EPA is used once the individual has lost capacity. Because CHC can have a significant impact on an individual's finances someone with this type of LPA or an EPA may well have legitimate reason for having access to health and social care records but **only** in so far as these are necessary for them to make a particular decision at a particular time regarding property and finance. An obvious example would be for them to have sufficient information to decide whether or not they agree with the eligibility decision made and whether or not to seek a review of that decision. Any health or welfare records which are not directly relevant should not be shared as they may contain sensitive information which the individual would not have wanted shared with the person to whom they gave the right to manage their financial affairs. Generally speaking the information that they are likely to need should be contained within the Decision Support Tool and the assessments which underlie it.

Primary Health Need
An individual is deemed to be eligible for CHC when their primary need is a health need: ‘’the primary health need approach’. This is determined by consideration of the four key characteristics of need: nature, intensity, complexity and unpredictability – see **Section 3**.

Reablement

The term 'reablement' refers to the active process of regaining skills, confidence and independence. This may be required following an acute medical episode or to reverse or halt a gradual decline in functioning in the community. It is intended to be a short-term intensive input.

Registered Nurse
A nurse registered with the Nursing and Midwifery Council. Within the UK all nurses, midwives and specialist community public health nurses must be registered with the Nursing and Midwifery Council and renew their registration every three years to be able to practise.

Rehabilitation
A programme of therapy and reablement designed to maximise independence and minimise the effects of disability

Social Care
Social care is care provided to support an individual’s social needs. It refers to the wide range of services designed to support people to maintain their independence, enable them to play a fuller part in society, protect them in vulnerable situations and manage complex relationships. Social care services are provided for people who need help/assistance to live their lives as independently as possible in the community (either at home or in a care setting), people who are vulnerable and people who may need protection. Local authorities, the voluntary sector and the independent sector can provide social care. This definition should be viewed in the context of the policy of the Welsh Government to move to a more integrated approach. The Social Services and Well-being (Wales) Act 2014 emphasises the duty

of local authorities and local health boards to work together to develop integrated primary, community and well-being services that are focussed on the holistic needs of people.

5.5 Social services and Wellbeing (Wales) Act 2014

The Social Services and Well-being (Wales) Act (SSWBA) came into force on 6 April 2016.

The SSWBA 2014 provides the legal framework for improving the well-being of people who need care and support, and carers who need support, and for transforming social services in Wales. It transforms the way social services are delivered, promoting people's independence to give them stronger voice and control.

The fundamental principles of the SSWBA 2014 are:

- Voice and control – putting the individual and their needs, at the centre of their care, and giving them a voice in, and control over reaching the outcomes that help them achieve well-being.
- Prevention and early intervention – increasing preventative services within the community to minimise the escalation of critical need.
- Well-being – supporting people to achieve their own well-being and measuring the success of care and support.
- Co-production – encouraging individuals to become more involved in the design and delivery of services.

Social Work

Social work is a professional activity/service provided by a Registered Social Worker. It is an activity that can enable individuals, families and groups to identify personal, social and environmental difficulties adversely affecting them. It is a range of activities that can provide supportive, rehabilitative protective or corrective action. This can include care management, social care assessment and planning and counselling.

Sustainable Care Planning Policy

This is a policy which has been developed and adopted by all local health boards in Wales for use when considering care planning options appropriate to meet the assessed need for people eligible for CHC. It describes the approach to fair and sustainable care planning within CHC and to the management of a fair allocation of resources within the wider context of care planning considerations.

Annex 1: Legal Judgments

The Coughlan judgment

(R v. North and East Devon Health Authority ex parte Pamela Coughlan)

A 1.1 Deciding on the balance between local authority and health service responsibilities with respect to long-term care has been the subject of key court judgments.

A 1.2 The decision of the Court of Appeal in R v North and East Devon Health Authority ex parte Coughlan [1999] considered the responsibilities of Health Authorities and local authority social service provision.

A 1.3 The Court examined the language of the relevant sections of the National Assistance Act 1948 (“the Care Act”) and the National Health Service Act 1977 (“the Health Act”) and acknowledged that the Health Act is the dominant act. The Court noted that the Secretary of State’s duty under Section 3 of the Health Act is limited to providing the services identified to the extent that he or she considers necessary to meet all reasonable requirements: in exercising his or her judgement the Secretary of State is entitled to take into account the resources available to him or her and the demands on those resources.

A 1.4 The Court went on to consider the limits on the provision of nursing care by local authorities (in a broad sense, i.e. not just registered nursing). The Court referred to a very general indication of the limit of local authorities provision in the context of a person living in residential accommodation, saying that if the nursing services are: -

i. merely incidental or ancillary to the provision of the accommodation which a local authority is under a duty to provide pursuant to Section 21; 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, then such nursing services can be provided under Section 21 of the National Assistance Act 1948.

A 1.5 This case was decided before the enactment of Section 49 of the Health and Social Care Act 2001. However, since the enactment of the Health and Social Care Act 2001, care from a registered nurse cannot be provided by the local authority as part of community care services. Such care is now provided within NHS Funded Nursing

Care. Persons who have been assessed as not having a primary health need, and therefore as not eligible for continuing NHS healthcare may be assessed as requiring care which can now be provided within NHS Funded Nursing Care.

A 1.6 Eligibility for CHC must always be considered prior to any consideration of eligibility for NHS Funded Nursing Care. The interaction between CHC and NHS funded Nursing Care was further considered by the High Court in R v. Bexley NHS Trust, ex parte Grogan [2006]12. The Court also acknowledged that the extent of the Secretary of State's duties to provide health services is governed by the health legislation and not by the limits of the duties of local authorities.

A1.7 Pamela Coughlan was seriously injured in a road traffic accident in 1971. Until 1993 she received NHS care in Newcourt Hospital. When the Exeter Health Authority wished to close that hospital and to move Miss Coughlan and other individuals to a new NHS facility at Mardon House the individuals were promised that Mardon House would be their home for life. In October 1998, the successor Health Authority (North and East Devon Health Authority) decided to withdraw services from Mardon House, to close that facility, and to transfer the care of Miss Coughlan and other disabled individuals to social services. Miss Coughlan and the other residents did not wish to move out of Mardon House and argued that the decision to close it was a breach of the promise that it would be their home for life and was therefore unlawful.

A1.8 The arguments on the closure of Mardon House raised other legal points about the respective responsibilities of the Health Service and of Social Services for nursing care. The Court of Appeal's judgment on this aspect has heavily influenced the development of continuing care policies and the National Framework. The key points in this regard are as follows:-

1. The NHS does not have sole responsibility for all nursing care. Local authorities can provide nursing services under section 21 of the National Assistance Act as long as the nursing care services are capable of being properly classified as part of the social services' responsibilities

2. No precise legal line can be drawn between those nursing services which are and those which are not capable of being provided by a local authority: the distinction between those services which can and cannot be provided by a local authority is one of degree which will depend on a careful appraisal of the facts of an individual case

3. As a very general indication as to the limit of local authority provision, if the nursing services are:-

i. merely incidental or ancillary to the provision of the accommodation which a local authority is under a duty to provide pursuant to Section 21; 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,

they can be provided under Section 21 of the National Assistance Act 1948.

1. By virtue of Section 21(8) of the National Assistance Act a local authority is also excluded from providing services where the NHS has in fact decided to provide those services

2. The services that can appropriately be treated as responsibilities of a local authority under Section 21 may evolve with the changing standards of society

3. Where an individual's primary need is a health need, the responsibility is that of the NHS, even when the individual has been placed in a home by a local authority

4. An assessment of whether an individual has a primary health need should involve consideration not only the nature and quality of the services required but also the quantity or continuity of such services

5. The Secretary of State's duty under Section 3 of (what is now) the National Health Service Act 2006 is limited to providing the services identified to the extent that he or she considers necessary to meet all reasonable requirements: in exercising his or her judgement the Secretary of State is entitled to take into account the resources available to him or her and the demands on those resources. (NB the Welsh Ministers have similar duties under the National Health Service (Wales) Act 2006)

6. In respect of Ms Coughlan, her needs were clearly of a scale beyond the scope of local authority services.

The Grogan Judgment

(R v. Bexley NHS Care Trust ex parte Grogan)

A1.9 Maureen Grogan had multiple sclerosis, dependent oedema with the risk of ulcers breaking out, was doubly incontinent, a wheelchair user requiring two people for transfer, and had some cognitive impairment. After the death of her husband her health deteriorated, she had a number of falls and, following an admission to hospital with a dislocated shoulder, it was decided that she was unable to live independently and she was transferred directly to a care home providing nursing care. Subsequent assessments indicated that Mrs Grogan's condition was such that she did not qualify for fully funded Continuing NHS Healthcare.

A1.10 She was initially determined to be in the medium band of NHS-funded nursing care, and remained in this band with the exception of one determination which placed her in the high band from April to October 2004. Mrs Grogan argued that the decision to deny her full NHS funding was unlawful, since the eligibility criteria put in place by South East London SHA were contrary to the judgment in the *Coughlan* case. She also submitted that the level of nursing needs identified in the RNCC medium and high bandings (in which she had been placed) indicated a primary need for health care which should be met by the NHS.

A1.11 The Court concluded that in assessing whether Mrs Grogan was entitled to Continuing NHS Healthcare, the Care Trust did not have in place or apply criteria which properly identified the test or approach to be followed in deciding whether her primary need was a health need. The Trust's decision that Mrs Grogan did not qualify for Continuing NHS Healthcare was set aside and the question of her entitlement to Continuing NHS Healthcare was remitted to the Trust for further consideration. There was no finding, or other indication, that Mrs Grogan in fact met the criteria for Continuing NHS Healthcare.

Annex 2: The Role of the Care Co-ordinator in Assessment for Longer-term Care and CHC Eligibility.

A 2.1 The ‘Care Co-ordinator’ role is also referred to in some documents e.g. the Integrated Assessment Framework[14], as the Lead Professional. We use the term ‘Care Co-ordinator’ in this document but it reads across to the Lead Professional function.

A 2.2 We note that the term ‘Care Co-ordinator’ has specific meaning in relation to Care and Treatment Planning for people with mental health needs. Whilst the same professional may also co-ordinate the CHC assessment, they are different functions.

Why do we need a Care Co-ordinator?

A 2.3 Evidence tells us that the assessment process for longer-term care, particularly where eligibility for Continuing NHS Healthcare is being considered, can often be fragmented, inefficient and stressful for the individual and their family/representative(s).

A 2.4 The purpose of having a named Care Co-ordinator is to address those challenges by having a key professional who is accountable for ensuring that the assessment process is co-produced, robust, and timely.

Who should be the Care Co-ordinator?

A 2.5 The Care Co-ordinator is the named individual responsible for co-ordinating the whole process of assessment for longer-term care, including gathering evidence to inform the decision on CHC eligibility.

A 2.6 The Care Co-ordinator is most likely to be a health professional and it will be important to maintain continuity where, for example, the individual has a progressive disease and specialist key professional. This person-centred approach would suggest that it may also be acceptable for a social worker with a long-standing relationship with the individual and the family to act as care co-ordinator. This would be subject to inter-agency agreement, with the final decision on who acts as Care Co-ordinator resting with the local health board.

A 2.7 It is acknowledged that the role of Care Co-ordinator can be complex and challenging. Whilst they that may not have sufficient capacity to undertake the role themselves, the expertise of specialist discharge liaison nurses and nurse assessors will be invaluable in providing guidance and support to those undertaking this function.

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[14] ‘Integrated Assessment, Planning and Review Arrangements for Older People – Guidance for Professionals in supporting in the Health, Care and Wellbeing of Older People: aged 65+’. Welsh Government 2013

A 2.8 In order to ensure that continuity is not lost, should the Care Co-ordinator be unavailable for example due to sickness and annual leave, a second (back-up) key contact should be identified who is closely involved with the case.

A 2.9 Ideally, the Care Co-ordinator should remain with the patient during the assessment process, irrespective of whether the patient moves in order to reduce miscommunication due to hand-offs. Where this is not possible and the Care Co-ordinator changes, there must be a formal handover of relevant information and (if possible and appropriate) introduction to the individual and their family/representative(s).

What is the Care Co-ordinator expected to do?

A 2.10 As the lead professional and key point of contact for the individual being assessed, the Care Co-ordinator is responsible for ensuring that all the appropriate people are involved in a timely manner and for pulling together their contributions to the assessment and care planning process. This does not mean however, that the Care Co-ordinator does all the work.

A 2.11 They must ensure that the individual and/or their representative is kept informed of the process and fully involved in discussions about their care.

A2.12 The Care Co-ordinator role includes:

- identifying and securing the involvement of all the appropriate MDT members
- ensuring that MDT members understand their role in the comprehensive assessment and their contribution to the decision-making process;
- ensuring that the individual and their family/representative(s) have all the information they need to understand and fully contribute to the assessment and decision-making process. This will include securing access to advocacy support if required.
- ensuring that all assessments are collated in one place and are of sufficient quality to provide the evidence required to support fair and rational decision-making
- ensuring that there is a clear timetable for the decision-making process and that the process complies with the requirements of this Framework
- ensuring that the MDT's expert advice to the LHB on eligibility and the rationale is clearly recorded and communicated to the necessary parties, including the individual and their family/carer

- liaising with individual and/or their family/representative(s) within 48 hours of the MDT meeting at which CHC eligibility was determined. This is to ensure that the outcome is fully understood and to answer any questions they may have on reflection.
- Ensuring compliance with local protocols including quality assurance arrangements and, if required, disputes resolution and appeals processes, prior to escalation to the next level of management

A2.13 Specific responsibilities regarding keeping the individual and/or their family/representatives informed include:

- providing the standard information leaflets:
    - ‘Continuing NHS Healthcare Public Information Leaflet’
    - ‘Preparing You for a CHC Eligibility Meeting’
    - ‘What Receiving CHC Services Means for You’ (if applicable);

- explaining timescales and key milestones, including timescales for review
- making the person aware of other individuals likely to be involved
- informing them of any potential delays
- providing a clear channel of communication between the individual and their family/representative(s) and the MDT

Annex 3: Overview of Standard Assessment & CHC Eligibility Decision-Making Process

TIMEFRAME

PROCESS

Up to 8 weeks

(extension of the timeframe is acceptable where further rehabilitation is required. but should not be due to the CHC eligibility process.)

Comprehensive assessment for longer-term care needs triggered.

Identify the Care Co-ordinator/Lead Professional

Obtain valid consent to comprehensive assessment.

Transfer individual (if required) to the most appropriate environment for assessment.

Deliver rehabilitation/reablement programme (unless clinically contra-indicated)

Collate co-produced comprehensive assessment.

Arrange the MDT meeting at which CHC eligibility will be considered.

Ensure the individual and/or their representatives have the information and support they need to fully participate.

At the meeting, review the comprehensive assessment and determine whether the individual has a primary health need.

Ensure that a clear and agreed rationale is documented and shared with the individual and/or their representatives.

Contact with individual and/or their representatives within 48 hours to answer queries etc.

1 week max.

Complete the quality assurance process

2 weeks

Arrange the care package

ANNEX 4:

NHS Continuing Healthcare Checklist

for current and retrospective cases

NHS Continuing Healthcare Checklist

Section 1: Current Cases

Section 2: Retrospective Reviews

Process

NHS CONTINUING HEALTHCARE CHECKLIST

Introduction

1. This Checklist is a tool to help practitioners identify people who need a full assessment for Continuing NHS Healthcare (CHC), either for current or retrospective cases. Please note that referral for assessment for CHC is not an indication of the outcome of the eligibility decision. This fact should also be communicated to the individual and, where appropriate, their representative.

2. The Checklist is based on the Decision Support Tool for NHS Continuing Healthcare (DST). The notes to the DST and *Continuing NHS Healthcare – The* National Framework for Implementation in Wales (the National Framework) will aid understanding of this tool. Practitioners who use this tool should have received suitable training.

3. The Checklist is the same for current or retrospective cases, however, the processes around its use differ. This document sets out separate notes for these different circumstances as follows:

    - Section 1: Current cases
    - Section 2: Retrospective reviews

SECTION 1: CURRENT CASES

Introduction

4. The aim is to allow a variety of people, in a variety of settings, to refer individuals for a full assessment for CHC. For example, the tool could form part of the discharge pathway from hospital; a GP or nurse could use it in an individual's home; and social services workers could use it when carrying out a community care assessment. This list is not exhaustive, and in some cases it may be appropriate for more than one person to be involved. It is for each organisation to decide for itself which are the most appropriate staff to participate in the completion of a Checklist. However, it must be borne in mind that the intention is for the Checklist to be completed as part of the wider process of assessing or reviewing an individual's needs. Therefore, it is expected that all staff in roles where they are likely to be involved in assessing or reviewing needs should have completion of Checklists identified as part of their role and receive appropriate training.

5. Individuals may request an assessment for CHC. In these circumstances, the organisation receiving the request should make the appropriate arrangements for a Checklist to be completed if this option is chosen.

6. All staff who apply the Checklist will need to be familiar with the principles of the National Framework and with the DST.

How to use the Checklist

7. Before applying the Checklist, it is necessary to ensure that the individual and (where appropriate) their representative understand that completing the Checklist is not an indication of the likelihood that the individual will necessarily be determined as being eligible for CHC.

8. The individual should be informed that the Checklist is to be completed and should have the process for completion explained to them. The individual and (where appropriate) their representative should be supported to play a full role in the process and should be given an opportunity to contribute their views about their needs. Decisions and rationales should be transparent from the outset.

9. As with any examination or treatment, the individual's informed consent should be obtained before the process of completing the Checklist commences.

10. It should be made explicit to the individual whether their consent is being sought for a specific aspect of the eligibility process (e.g. completion of the Checklist) or for the full process. It should also be noted that individuals may withdraw their consent at any time in the process.

11. If there is a concern that the individual may not have capacity to give their consent, this should be determined in accordance with the Mental Capacity Act 2005 and the associated code of practice. Anyone who completes a Checklist should be particularly aware of the five principles of the Act:

    - **A presumption of capacity:** A person must be assumed to have capacity unless it is established that they lack capacity.
    - **Individuals being supported to make their own decisions:** A person is not to be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success.
    - **Unwise decisions:** A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
    - **Best interests:** An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his or her best interests.
    - **Least restrictive option:** Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

12. It must also be borne in mind that consideration of capacity is specific to both the decision to be made and the time when it is made – i.e. the fact that a person may be considered to lack capacity to make a particular decision should not be used as a reason to consider that they cannot make any decisions. Equally, the fact that a person was considered to lack capacity to make a specific decision on a given date should not be a reason for assuming that they lack capacity to make a similar decision on another date.

13. If the person lacks the mental capacity to either give or refuse consent to the use of the Checklist, a 'best interests' decision, taking the individual's previously expressed views into account, should be taken (and recorded) as to whether or not to proceed. Those making the decision should bear in mind the expectation that everyone who might meet the Checklist threshold should have this opportunity. A third party cannot give or refuse consent for an assessment of eligibility for CHC on behalf of a person who lacks capacity, unless they have a valid and applicable Lasting Power of Attorney (Welfare) or they have been appointed a Welfare Deputy by the Court of Protection. Before making a best interest decision as to whether or not to proceed with the completion of the Checklist the assessor should be mindful of their duty to consult with appropriate third parties. This is particularly important if the decision is not to complete a Checklist.

14. Further information on consent and mental capacity can be found in points 3.57 – 3.76 of the National Framework.

Completion of the Checklist

15. In an acute hospital setting, the Checklist should not be completed until the individual's needs on discharge are clear.

16. Please compare the descriptions of need to the needs of the individual and select level A, B or C, as appropriate, for each domain. Consider all the descriptions and select the one that most closely matches the individual. If the needs of the individual are the same or greater than anything in the A column, then 'A' should be selected. For each domain, please also give a brief reference, stating where the evidence that supports the decision can be accessed, if necessary.

17. Where it can reasonably be anticipated that the individual's needs are likely to increase in the next three months (e.g. because of an expected deterioration in their condition), this should be reflected in the columns selected. Where the extent of a need may appear to be less because good care and treatment is reducing the effect of a condition, the need should be recorded in the Checklist as if that care and treatment was not being provided.

18. A full assessment for CHC is required if there are:

    - two or more domains selected in column A;
    - five or more domains selected in column B, or one selected in A and four in B; or
    - one domain selected in column A in one of the boxes marked with an asterisk (i.e. those domains that carry a priority level in the DST), with any number of selections in the other two columns.

19. There may also be circumstances where a full assessment for CHC is considered necessary, even though the individual does not apparently meet the indicated threshold.

20. Whatever the outcome, assessors should record written reasons for the decision and should sign and date the Checklist. Assessors should inform the individual and/or their representative of the decision, providing a clear explanation of the basis for the decision. The individual should be given a copy of the completed Checklist. The rationale contained within the completed Checklist should give enough detail for the individual and their representative to be able to understand why the decision was made.

21. Individuals and their representatives should be advised that, if they disagree with the decision not to proceed to a full assessment for CHC, they may ask the Local Health Board (LHB) to reconsider it. This should include a review of the original Checklist and any new information available, and might include the completion of a second Checklist. If they remain dissatisfied they can pursue the matter through the normal complaints process.

22. Each LHB should have clear local processes that identify where a completed Checklist should be sent, in order for the appropriate next steps to be taken. Completed Checklists should be forwarded in accordance with these local processes.

23. The Equality Monitoring Form should be completed by the patient who is the subject of the Checklist. Where the patient needs support to complete the form, this should be offered by the practitioner completing the Checklist. The practitioner should forward the completed data form to the appropriate location, in accordance with the relevant LHB’s processes for processing equality data.

Checklist Record Form – Current Cases

Date of completion of the Checklist _______

Date of birth _______

Name _____________________

NHS number ________________ GP practice ___________________

Permanent address and current location (e.g. telephone number, hospital ward etc.)

Gender _______

Please ensure that the Equality Monitoring Form at the end of the Checklist is completed.

Was the individual involved in the completion of the Checklist? **Yes/No** (please delete as appropriate)

Was the individual offered the opportunity to have a representative such as a family member or other advocate present when the Checklist was completed? **Yes/No**

If yes, did the representative attend the completion of the Checklist? **Yes/No**

Please give the contact details of the representative (name, address and telephone number).

Did you explain to the individual how their personal information will be shared with the different organisations involved in their care, and did they consent to this information sharing? **Yes/No**

Please highlight the outcome indicated by the Checklist:

- Referral for full assessment for NHS continuing healthcare is necessary ***or***

- No referral for full assessment for NHS continuing healthcare is necessary.

(*There may be circumstances where you consider that a full assessment for NHS continuing healthcare is necessary, even though the individual does not apparently meet the indicated threshold. If so, a full explanation should be given*.)

Rationale for decision

Name(s) and signature(s) of assessor(s)	**Date**

Contact details of assessors (name, role, organisation, telephone number, email address)

SECTION 2: RETROSPECTIVE REVIEWS

Introduction

24. An individual and/or their representative may request a retrospective CHC review where they contributed to the cost of their care, but have reason to believe that they may have met the eligibility criteria for CHC which were applicable at that time.

25. Local Health Boards (LHBs) need to balance their requirement to provide timely restitution with that of demonstrating probity with the public purse. Making an application does not mean that reimbursement is guaranteed; LHBs must satisfy themselves that the application is genuine and that the person was indeed eligible for CHC during the disputed period.

26. The data generated from Phases 1, 2 & 3 of the All Wales Retrospective CHC Reviews Project, which operated until April 2019, indicates that eligibility was found for 31% and no eligibility for 69%. This data supports the rationale for applying a Checklist to all applications to identify if there are triggers for CHC consideration and if so, for what period. This will facilitate focus on cases where there are triggers identified and will be a more effective and efficient use of the public purse.

27. The Checklist is based on the DST and is advocated for use in the National Framework.

28. This Checklist should be applied to all retrospective CHC cases in Wales, in line with the guidance set out in the National Framework.

Explanation of Review Stage

29. Stage 1 Review - A chronology of need comprising of care plans and risk assessments from the care provider, the GP records and the claimant's statement is considered by a Panel to identify if there are any triggers for retrospective CHC to be considered in Stage 2 Review.

30. Stage 2 Review - Triggers have been identified and the chronology of need is completed using any other records available. The case is then reviewed through the normal process as detailed in the National Framework.

Process

Stage 1 Review

i. This Checklist will be utilised as a tool to aid a virtual Independent Scrutiny Panel (ISP) decide if cases where a retrospective CHC review has been requested should proceed to full review.

ii. The ISP will be comprised of an Independent Chair appointed by Welsh Government through the Public Appointments process and a Clinical Adviser. A senior investigator nominated by the Health Board will be responsible for co-ordinating this part of the process.

iii. The ISP members who will be applying the Checklist will be familiar with the principles of the National Framework and with the DST.

iv. The ISP will apply this Checklist to a chronology of need comprised of general practitioner records, risk assessments and care plans from care providers and the claimant's statement. If any of these records are unavailable then the records that are available will be used.

v. The ISP will identify if there are triggers for retrospective CHC to be considered in Stage 2 Review for all, some or none of the claim period requested by the claimant/representative.

vi. The ISP will complete as many Checklist documents as necessary to ensure that the whole claim period is considered along with any changes in level of need throughout the claim period or until a trigger date is identified.

vii. If the ISP do not find any triggers for retrospective CHC to be considered in Stage 2 Review, then a completed Checklist will be provided to the claimant/representative to explain why the case will not be forwarded for Stage 2 Review and the case will be closed at this stage.

viii. If the ISP do find triggers for retrospective CHC to be considered in Stage 2 Review for part of the claim period, then a completed Checklist will be provided to the claimant/representative to explain why the whole of the claim period will not be reviewed and will document the dates that will be reviewed in Stage 2 Review.

ix. If the ISP find triggers for retrospective CHC to be considered in Stage 2 Review at the outset of the claim period, then the whole claim period will be reviewed in Stage 2.

Notes:

- Progress to Stage 2 Review is not an indication of the outcome of the eligibility decision in that it is not guaranteed that eligibility for retrospective CHC funding will be evidenced.
- The Panel process is a closed process and no submissions or representations will be considered.

Stage 2 Review

i. If the ISP has identified triggers for CHC to be considered for all or part of the claim period then any additional evidence from available records will be added to the Chronology of Need.

ii. The case will then be reviewed by a Clinical Adviser encompassing either the whole of the claim period requested if triggers have been identified at the start of the claim period or part of the claim period requested with the start date being identified by the ISP using the Checklist to identify the start date based on triggers.

iii. The case will then go through the review process as detailed in the National Framework.

Complaints

31. If individuals have a concern regarding the process applied by the ISP, they may wish to raise a concern with the Public Services Ombudsman for Wales.

Completion of the Checklist

32. Please compare the descriptions of needs of the individual and select level A, B or C, as appropriate, for each domain. Consider all the descriptions and select the one that most closely matches the individual. If the needs of the individual are the same or greater than anything in the A column, then ‘A’ should be selected. For each domain, please also give a brief reference, stating where the evidence that supports the decision can be accessed, if necessary.

33. A case will be forwarded to Stage 2 Review if there are:

- two or more domains selected in column A;
- five or more domains selected in column B, or one selected in A and four in B; or
- one domain selected in column A in one of the boxes marked with an asterisk (i.e. those domains that carry a priority level in the DST), with any number of selections in the other two columns.

Checklist Record Form – Retrospective Cases

Stage 1 Review

Date of completion of the Checklist ________________________________

Name of subject of the claim ________________________________

Health Board ________________________________

Case Identifier ________________________________

Claim period requested **from:** ________________________________

to: ________________________________

Please highlight the outcome indicated by the Checklist:

- Referral for Stage 2 Review is necessary from (date) **or**

- No referral for Stage 2 Review is necessary as no triggers have been identified.

Rationale for decision

Clinical Adviser
Levels:

Based on the above levels of need:
- the evidence does not support any trigger for Stage 2 Review ***or***
- the evidence supports a trigger for Stage 2 Review from **(enter date)** ***or***
- the evidence supports the need for Stage 2 Review from the start of the Claim Period.

Name:

Signed:

Date:

Independent Chair

I agree with the recommendation made by the Clinical Adviser/s.

Or

I disagree with the recommendation made by the Clinical Adviser:
- The evidence supports a trigger for Stage 2 Review from (enter date) ***or***
- The evidence supports the need for Stage 2 Review from the start of the Claim Period.

The rationale for this decision is documented below:

Name:

Signed:

Date:

Section 3: CHC Checklist

Name of patient		**Date of completion**		
Please circle statement A, B or C in each domain. AN ASTERISK placed against each category indicates a PRIORITY domain				
LEVEL→ *CATEGORY↓*	**C**	**B**	**A**	**Recorded evidence to support level**
1. Breathing *	Normal breathing, no issues with shortness of breath. **OR** Shortness of breath, 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, which may require the use of inhalers or a nebuliser and limit some daily living activities. **OR** Episodes of breathlessness that do not 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)	

Section 3: CHC Checklist

LEVEL→ *CATEGORY↓*	**C**	**B**	**A**	**Recorded evidence to support level**
2. Nutrition, food and drink	Able to take adequate food and drink by mouth to meet all nutritional requirements. **OR** Needs supervision, prompting with meals, or may need feeding and/or a special diet. **OR** Able to take food and drink by mouth but requires additional/supplementary feeding.	Needs feeding to ensure adequate intake of food and takes a long time (half an hour or more), including liquidised feed. **OR** Unable to take any food and drink by mouth, but all nutritional requirements are being adequately maintained by artificial means, for example via a non-problematic PEG.	Dysphagia requiring skilled intervention to ensure adequate nutrition/hydration and minimise the risk of choking and aspiration to maintain airway. **OR** Subcutaneous fluids that are managed by the individual or specifically trained carers or care workers. **OR** Nutritional status 'at risk' and may be associated with unintended, significant weight loss. **OR** Significant weight loss or gain due to an identified eating disorder. **OR** Problems relating to a feeding device (e.g. PEG) that require skilled assessment and review.	

LEVEL→ *CATEGORY↓*	**C**	**B**	**A**	**Recorded evidence to support level**
3. Continence	Continent of urine and faeces. **OR** Continence care is routine on a day-to-day basis. **OR** Incontinence of urine managed through, for example, medication, regular toileting, use of penile sheaths, etc. **AND** Is able to maintain full control over bowel movements or has a stable stoma, or may have occasional faecal incontinence/constipation.	Continence care is routine but requires monitoring to minimise risks, for example those associated with urinary catheters, double incontinence, chronic urinary tract infections and/or the management of constipation.	Continence care is problematic and requires timely and skilled intervention, beyond routine care. (for example frequent bladder wash outs, manual evacuations, frequent re-catheterisation).	

Section 3: CHC Checklist

LEVEL→ *CATEGORY↓*	**C**	**B**	**A**	**Recorded evidence to support level**
4. Skin and Tissue Viability	No risk of pressure damage or skin condition. **OR** Risk of skin breakdown which requires preventative intervention once a day or less than daily, without which skin integrity would break down. **OR** Evidence of pressure damage and/or pressure ulcer(s) either with ‘discolouration of intact skin’ or a minor wound. **OR** A skin condition that requires monitoring or reassessment less than daily and that is responding to treatment or does not currently require treatment.	Risk of skin breakdown which requires preventative intervention several times each day, without which skin integrity would break down. **OR** Pressure damage or open wound(s), pressure ulcer(s) with ‘partial thickness skin loss involving epidermis and/or dermis’, which is responding to treatment. **OR** A skin condition that requires a minimum of daily treatment, or daily monitoring/reassessment to ensure that it is responding to treatment.	Pressure damage or open wound(s), pressure ulcer(s) with ‘partial thickness skin loss involving epidermis and/or dermis’, which is not responding to treatment. **OR** Pressure damage or open wound(s), pressure ulcer(s) with ‘full thickness skin loss involving damage or necrosis to subcutaneous tissue, but not extending to underlying bone, tendon or joint capsule’, which is responding to treatment. **OR** Specialist dressing regime in place which is responding to treatment.	

LEVEL→ *CATEGORY↓*	**C**	**B**	**A**	**Recorded evidence to support level**
5. Mobility	Independently mobile. **OR** Able to bear weight but needs some assistance and/or requires mobility equipment for daily living.	Not able to consistently bear weight. **OR** Completely unable to bear weight but is able to assist or cooperate with transfers and/or repositioning. **OR** In one position (bed or chair) for majority of the time but is able to cooperate and assist carers or care workers. OR At moderate risk of falls (as evidenced in a falls history or risk assessment)	Completely unable to bear weight and is unable to assist or cooperate with transfers and/or repositioning. **OR** Due to risk of physical harm or loss of muscle tone or pain on movement needs careful positioning and is unable to cooperate. **OR** At a high risk of falls (as evidenced in a falls history and risk assessment). **OR** Involuntary spasms or contractures placing the individual or others at risk.	

Section 3: CHC Checklist

LEVEL→ *CATEGORY ↓*	**C**	**B**	**A**	**Recorded evidence to support level**
6. Communication	Able to communicate clearly, verbally or non-verbally. Has a good understanding of their primary language. May require translation if English is not their first language. **OR** Needs assistance to communicate their needs. Special effort may be needed to ensure accurate interpretation of needs or additional support may be needed either visually, through touch or with hearing.	Communication about needs is difficult to understand or interpret or the individual is sometimes unable to reliably communicate, even when assisted. Carers or care workers may be able to anticipate needs through nonverbal signs due to familiarity with the individual.	Unable to reliably communicate their needs at any time and in any way, even when all practicable steps to assist them have been taken. The person has to have most of their needs anticipated because of their inability to communicate them.	

Section 3: CHC Checklist

LEVEL→ *CATEGORY↓*	**C**	**B**	**A**	**Recorded evidence to support level**
7. Psychological and Emotional Needs	Psychological and emotional needs are not having an impact on their health and well-being. **OR** Mood disturbance or anxiety or periods of distress, which are having an impact on their health and/or well-being but respond to prompts and reassurance. **OR** Requires prompts to motivate self towards activity and to engage in care planning, support and/or daily activities.	Mood disturbance or anxiety symptoms or periods of distress which do not readily respond to prompts and reassurance and have an increasing impact on the individual's health and/or wellbeing. **OR** Due to their psychological or emotional state the individual has withdrawn from most attempts to engage them in support, care planning and/or daily activities.	Mood disturbance or anxiety symptoms or periods of distress that have a severe impact on the individual's health and/or well-being. **OR** Due to their psychological or emotional state the individual has withdrawn from any attempts to engage them in care planning, support and daily activities.	

Section 3: CHC Checklist

LEVEL→ *CATEGORY↓*	**C**	**B**	**A**	**Recorded evidence to support level**
8. Cognition	No evidence of impairment, confusion or disorientation. **OR** Cognitive impairment which requires some supervision, prompting or assistance with more complex activities of daily living, such as finance and medication, but awareness of basic risks that affect their safety is evident. **OR** Occasional difficulty with memory and decisions/choices requiring support, prompting or assistance. However, the individual has insight into their impairment.	Cognitive impairment (which may include some memory issues) that requires some supervision, prompting and/or assistance with basic care needs and daily living activities. Some awareness of needs and basic risks is evident. The individual is usually able to make choices appropriate to needs with assistance. However, the individual has limited ability even with supervision, prompting or assistance to make decisions about some aspects of their lives, which consequently puts them at some risk of harm, neglect or health deterioration.	Cognitive impairment that could include frequent short-term memory issues and maybe disorientation to time and place. The individual has awareness of only a limited range of needs and basic risks. Although they may be able to make some choices appropriate to need on a limited range of issues, they are unable to do so on most issues, even with supervision, prompting or assistance. The individual finds it difficult, even with supervision, prompting or assistance, to make decisions about key aspects of their lives, which consequently puts them at high risk of harm, neglect or health deterioration.	

Section 3: CHC Checklist

LEVEL→ *CATEGORY↓*	**C**	**B**	**A**	**Recorded evidence to support level**
9. Behaviour *	No evidence of ‘challenging’ behaviour. **OR** Some incidents of ‘challenging’ behaviour. A risk assessment indicates that the behaviour does not pose a risk to self, others or property or a barrier to intervention. The person is compliant with all aspects of their care.	‘Challenging’ behaviour that follows a predictable pattern. The risk assessment indicates a pattern of behaviour that can be managed by skilled carers or care workers who are able to maintain a level of behaviour that does not pose a risk to self, others or property. The person is nearly always compliant with care.	‘Challenging’ behaviour that poses a predictable risk to self, others or property. The risk assessment indicates that planned interventions are effective in minimising but not always eliminating risks. Compliance is variable but usually responsive to planned interventions.	

Section 3: CHC Checklist

LEVEL→ *CATEGORY↓*	C	B	A	Recorded evidence to support level
10. Drug therapies and medication symptom control *	Symptoms are managed effectively and without any problems, and medication is not resulting in any unmanageable side-effects. **OR** Requires supervision/administration of and/or prompting with medication but shows compliance with medication regime. **OR** Mild pain that is predictable and/or is associated with certain activities of daily living; pain and other symptoms do not have an impact on the provision of care.	Requires the administration of medication (by a registered nurse, carer or care worker) due to: • non-concordance or noncompliance, or • type of medication (for example insulin); or • route of medication (for example PEG). **OR** Moderate pain which follows a predictable pattern; or other symptoms which are having a moderate effect on other domains or on the provision of care.	Requires administration and monitoring of medication regime by a registered nurse, carer or care worker specifically trained for this task because there are risks associated with the potential fluctuation of the medical condition or mental state, or risks regarding the effectiveness of the medication or the potential nature or severity of side-effects. However, with such monitoring the condition is usually non-problematic to manage. **OR** Moderate pain or other symptoms which is/are having a significant effect on other domains or on the provision of care.	

Section 3: CHC Checklist

LEVEL→ *CATEGORY↓*	**C**	**B**	**A**	**Recorded evidence to support level**
11. Altered states of consciousness *	No evidence of altered states of consciousness (ASC). **OR** History of ASC but effectively managed and there is a low risk of harm.	Occasional (monthly or less frequently) episodes of ASC that require the supervision of a carer or care worker to minimise the risk of harm.	Frequent episodes of ASC that require the supervision of a carer or care worker to minimise the risk of harm. **OR** Occasional ASCs that require skilled intervention to reduce the risk of harm.	

Section 3: CHC Checklist

Name of patient		**Date of completion**		
TOTAL FROM ALL PAGES	**C**	**B**	**A**	
ADDITIONAL COMMENTS				
SINGED AND POSITION OF SIGNATORY				

EQUALITY MONITORING FORM

For use with current cases only

Please provide us with some information about yourself. This will help us to understand whether everyone is receiving fair and equal access to CHC. All the information you provide will be kept completely confidential by the NHS. No identifiable information about you will be passed on to any other bodies, members of the public or press.

Please tick only one box in each category.

1. SEX	
Male	
Female	
Transgender	

2. SEXUAL ORIENTATION

Only answer this question if you are aged **16 years** or over. Which applies to you? (*If 'Other', please highlight and write in box provided)

Heterosexual / Straight	Lesbian / Gay Woman	Gay Man	Bisexual	Prefer not to say	*Other

* Any other, write here

3. AGE GROUP –

Which applies to you?

0-15	16-24	25-34	35-44	45-54	55-64	65-74	75-84	85+

4. DISABILITY

Do you have a disability, as defined by the *Equality Act 2010?*		The Equality Act defines a person with a disability as someone who 'A physical or mental impairment which has a substantial and long term adverse effect on your ability to carry out normal day to day activities. https://www.gov.uk/definition-of-disability-under-equality-act-2010
Yes		
No		

5. ETHNIC GROUP –

Which applies to you? (*If ‘Other’, please highlight and write in box provided)

White		Mixed		Asian *or* Asian British		Black *or* Black British		Chinese or other group	
British		White and Black Caribbean		Indian		Caribbean		Chinese	
Irish		White and Black African		Pakistani		African		Other*	
Other*		White and Asian		Bangladeshi		Other*			
		Other*		Other*					

* Any other, write here

6. RELIGION

Which applies to you? (*If ‘Other’, please highlight and write in box provided)

Christian includes Church of Wales, Catholic, Protestant and all other Christian denominations

Christian	Buddhist	Hindu	Jewish	Muslim	Sikh

* Any other, write here

ANNEX 5: Setting up an Independent Review Panel

Establishment of review panels

A.5.1 Local health boards must have access to a standing panel, comprising as a minimum an independent chair, a representative of a LHB and a representative of a local authority. It will also have access to expert opinion. In order to avoid delays in the process and to maximise the available expertise, health boards must make use, wherever possible of regional chairs. In using them they should also not rely on any one figure for convenience or consistency and should make use of all operating in their area.

A.5.2 Independent chairs are appointed via the Public Appointments process and their services can be accessed via the CHC Lead in each LHB.

A.5.3 The appointment of representatives of the LHB(s) and LAs will be on the basis of nomination by those organisations. They should take account of the professional and other skills, which will be relevant to the work of the panel.

A.5.4 Each LHB should designate an individual to maintain the review procedure and collect information for the panel by interviewing patients, family members and any relevant carer.

A.5.5 Each LHB should aim to ensure that the review procedure is completed within four weeks of the request being received, where possible. This period starts once any action to resolve the case informally has been completed, and should be extended only where unavoidable because of exceptional circumstances. The review procedure must not delay the provision of care and the local protocol should make clear how funding will be provided pending the resolution.

A.5.6 Each LHB must ensure that arrangements are in place to support the work of the panel through the provision of relevant information and clinical advice.

The purpose and scope of review panels

A.5.7 The purpose of the review procedure is:

- to check that proper procedures have been followed in reaching decisions about the need for continuing NHS healthcare and NHS Funded Nursing Care
- to ensure that the primary health need approach in determining eligibility for continuing NHS healthcare and NHS Funded Nursing Care is properly and consistently applied

A.5.8 The review procedure does not apply where patients or their families and any carer wish to challenge:

- the content, rather than the application, of the local health board's eligibility criterion
- the type and location of any offer of NHS funded continuing NHS healthcare or NHS Funded Nursing Care services
- the content of any alternative care package which they have been offered
- their treatment or any other aspect of the services they are receiving or have received

These would more properly be dealt with through the complaints procedure

A.5.9 A review should not proceed until the LHB has, in the first instance, worked with the individual to resolve the situation informally. They should ensure that appropriate assessments have been undertaken, care plans produced, that the proper procedures and criteria have been applied, and that the patient has been provided with all relevant information.

A.5.10 If the case cannot be resolved by informal means, the patient, his or her family or any carer may ask the LHB where the patient is normally resident to review the decision that the patient is not eligible for continuing NHS healthcare. The expectation is that the LHB in reaching a view will seek advice from an independent panel (See paragraph 7). Before doing so it should ensure, having regard to paragraphs 5.7-5.8 above, that the decision is one to which the review procedure applies.

A.5.11 The LHB has the right to decide in any individual case not to convene a panel. It is expected that such decisions will be confined to those cases where the patient falls well outside the eligibility criteria or where the case is very clearly not appropriate for the panel to consider. Before taking a decision the LHB should seek the advice of the chair of the review panel. In all cases where a decision not to convene a panel is made, the LHB should give the patient and their family or carer a full written explanation of the basis of its decision, together with a reminder of their rights under the NHS Complaints Procedure.

A.5.12 While the review procedure is being conducted any existing care package, whether hospital care or community health services, should not be withdrawn until the outcome of the review is known.

Operation of the panel

A.5.13 The designated LHB is responsible for preparing information for the panel. The panel should have access to any existing documentation, which is relevant, including the details of the patient's original assessment. They should also have access to the views of key parties involved in the case including the patient, their family and any carer, health and social services staff, and any other relevant bodies or individuals. It will be open to key parties to put their views to the LHB officer. This will normally be managed by the production of written statements prepared by the LHB's designated responsible officer.

A.5.14 A patient may have a representative act on their behalf if they choose, or are unable or have difficulty in presenting their own views.

A.5.15 While the patient or their representative will normally provide information to the designated LHB officer, they may request direct representation at the panel hearing. This does not include a lawyer acting in a professional capacity.

A.5.16 The panel must maintain patient confidentiality.

A.5.17 The panel will require access to independent clinical advice, which should take account of the range of medical, nursing and therapy needs involved in each case.

A.5.18 The role of the panel is advisory. However, while its decisions will not be formally binding, the expectation is that its recommendations will be accepted. If a LHB decides to reject a panel's recommendation in an individual case, it must put in writing to the patient and to the chairman of the panel its reasons for doing so.

A.5.19 In all cases the LHB must communicate in writing to the patient the outcome of the review, with reasons. All relevant parties (NHS, consultant, GP and other clinician(s), LA where appropriate) should also receive this information.

A.5.20 The patient's rights under the existing complaints procedures and their existing right to refer the case to the Public Services Ombudsman Wales, remain unaltered by the panel arrangements.

Annex 6: Retrospective Claim Proof of Payment

WELSH HEALTH CIRCULAR

Issue Date: 1 February

Llywodraeth Cymru
Welsh Government

STATUS: COMPLIANCE
CATEGORY: POLICY

Title:
Additional Guidance on Proof of Payment for Reimbursement of Retrospective Claims WHC/2016/003

Date of Expiry / Review
n/a

For Action by:

Health boards
NHS Trusts
Chief Executives
Directors of Primary Care

Action required by:
Immediate

Sender: Neil Jones

DHSS Welsh Government Contact(s) :
Neil Jones jones.neil@wales.gsi.gov.uk

Integration Policy and Delivery Division, Health and Social Services Group,

4th Floor Cathays Park 2, Cardiff. CF10 3NQ.

Enclosure(s): Annex 1

ANNEX 1 WELSH HEALTH CIRCULAR WHC/2016/003

Continuing NHS Healthcare (CHC) in Wales

Additional Guidance on Proof of Payment for Reimbursement of Retrospective Claims.

Background

1. On 16 December 2013, Welsh Government issued MD/ML/001/13. Supplementary Guidance (Proof of Payment) to Welsh Health Circular 015/2010. This guidance related specifically to cases reviewed by the Powys Project where further proof of payment had been requested by health boards (HBs) at the end of the process.

2. Additional guidance followed in WHC/2015/039 which extended the principles of the previous supplementary guidance and addressed the recommendations of the Continuing NHS Healthcare Follow up Report, published by the Wales Audit Office in January 2015. It related to:

   - those claims submitted to HBs since August 2010 but may relate to periods prior to that date;
   - those claims submitted in response to the 31 July 2014 cut off date, which may relate to any period between 1 April 2003 and 31 July 2013.

3. This guidance supersedes WHC/2015/039. It retains the same arrangements albeit no longer referring to the use of the County Court Rate (CCR) in calculating reimbursement in exceptional circumstances for claims still to be processed.

4. Redress is about placing individuals in the position they would have been in had CHC been awarded at the appropriate time and not about the NHS or the public profiting from public funds. The use of retail price index (RPI), without the deduction of historical benefits and allowances already received by the claimant, is considered to be the appropriate method of calculating a fair level of interest payable in addition to the claim settlement amount. It is also considered to be a relatively straight forward method of interest calculation.

5. A calculation using the CCR rate, with a deduction of benefits and allowances received, has proven to be impractical to determine in most cases and, therefore, is not considered an appropriate level of interest to be used in this scenario.

Claimants who have already requested that their settlement be considered using a CCR calculation may continue to pursue this with their Health Board, but all relevant information and evidence would need to be in place for that CCR calculation to be made and if this is not the case then RPI method should be applied as the default.

These arrangements have been agreed with the Public Service Ombudsman for Wales.

6. The new arrangements now relate to:

   - those claim periods set out above;
   - those claims submitted as a result of the 31 October 2015 cut-off date which may relate to any period between 1 August 2013 and 30 September 2014; and,
   - those claims submitted thereafter.

Principles of Good Public Administration

7. Health boards should ensure their undertakings are compliant with the Public Service Ombudsman's Principles of Good Public Administration. The full guidance of which is available via the following link:

   http://www.ombudsman-wales.org.uk/en/public-body-information/~/media/Files/Documents_en/Principles_of_Good_Administration.ashx

Implications for redress in CHC retrospective claims

8. HBs in Wales are independent decision-making bodies, and have agreed the arrangements for dealing with retrospective claims as set out in **Section 6** of Continuing NHS Healthcare: The National Framework for Implementation in Wales (2014).

9. The arrangements for dealing with retrospective claims, as set out in the 2014 Framework, are clear that proof of payment of care fees is required at the outset of the process. The claim will not be progressed if such evidence cannot be provided. The Framework also states that HBs need to balance their requirement to provide timely restitution with that of demonstrating probity with the public purse (para 6.10).

Prompt request for Proof of Payment and fair prioritisation of claims

10. It is the responsibility of the HB to request proof of payment and legal authority to submit a claim promptly on receipt of an application or of intent to claim (e.g. letter to the HB). The written request for Proof of Payment should be posted within 10 working days and recorded on the LHB database.

11. No claimant should be disadvantaged because the LHB has failed to request proof of payment in a timely manner. If the HB has not complied with the timescale as set out above, it should adjust the timescale for review accordingly.

12. As set out in the Framework, it is reasonable to expect the claimant to provide the required proof within 5 months, unless exceptional circumstances apply. The LHB should evidence that:

    - it has monitored progress with the claimant;
    - delays due to other agencies are evidenced; and
    - any exceptional circumstances have been considered.

13. The HB should provide feedback to the claimant and validate or reject the claim within 6 weeks (30 working days) of receipt of the proof of payment.
Reasoned and reasonable decisions on acceptable proof of payment.

14. HBs must make reasoned and reasonable decisions regarding acceptance of evidence of proof of payment, taking into account all available and relevant information. HBs should bear in mind that, owing to the passage of time, evidence may not be complete.

15. In order to demonstrate reasonableness, HBs will need to apply a degree of discretion to the level of evidence they deem acceptable, dependent on the period to which the claim relates. For cases relating to the claim period end date of 5 years or less, all evidence that is accessible, including bank statements, care home statements and invoices, must be provided. This will show there is no outstanding debt to the care provider if the subject of the claim is deceased unless there are extenuating circumstances.

16. As a minimum, HBs should satisfy themselves that:

    - The individual was resident in a care home for the period(s) of eligibility;
    - There is no evidence that any public body or agency paid all or part of the fees; and
    - There are no outstanding debts, e.g. unpaid fees to the care home.

Fair and transparent calculation of reimbursement

17. In arriving at the value for reimbursement, the HB should use a transparent rationale and clear calculations.

18. If evidence exists of proof of payment for part of the claim period, and is deemed robust, then this should be used as a basis for further calculations covering the whole claim period.

19. Where evidence of financial outlay by the claimant is not robust enough, LHBs may calculate reimbursement offers based on a different and well reasoned cost indicator; for example, the high dependency residential care home rate in operation by the Local Authority in the area during the period of eligibility.

20. If there is evidence that a public authority has paid a proportion of the claimants nursing home fees directly to the nursing home, an abatement of the reimbursement may be appropriate to abate that proportion.

21. It is deemed reasonable for HBs to continue to apply the Retail Prices Index (RPI) for the calculation of interest when considering recompense in continuing care reviews. Where RPI is used to calculate interest there will be no deduction for benefits received by the claimant during the claim period (and the Department for Work and Pensions has agreed that there will be no reclaim of those benefits).

22. On conclusion of the decision of eligibility, HBs should normally take no longer than 1 month (20 working days) to calculate reimbursement and send the indemnity letter to the claimant.

Ex-gratia payments

23. In addition to the reimbursement principles stated above, there may be occasions where HBs also wish to consider making ex-gratia payments in line with the existing guidance on Losses and Special Payments in the IFRS NHS Wales Manual for Accounts. HBs are encouraged to seek legal advice about individual cases where necessary, and make ex-gratia payments if appropriate.

Disputes

24. If the claimant is dissatisfied with the approach taken they may raise a concern with the relevant HB. Their concern will be handled in accordance with the NHS (Concerns, Complaints & Redress Arrangements) (Wales) Regulations 2011. Claimants may also contact the Public Service Ombudsman for Wales.

Decision Support Tool for Continuing NHS Healthcare

2019

Contents

Foreword

1. The Decision Support Tool (DST) is a national tool to support practitioners in the application of the *National Framework for the Implementation of Continuing NHS Healthcare in Wales (2018) (The Framework).* It is split into two parts; the first section (User Notes, pages 4-13), set out guidance around the application of the DST. The DST itself begins at page 14 and it is this section that should be issued to the individual.
2. The DST must only be used in conjunction with the guidance in the Framework. It brings together information from the assessment of needs and applying evidence in a single practical format to facilitate consistent evidence-based recommendations and decision making regarding eligibility for Continuing NHS Healthcare (CHC) in Wales. All staff using the DST should be familiar with Frameworks principles and have received appropriate training.
3. No assessment tool will be perfect and for that reason it is important that the DST is used in context. It cannot and should not replace professional judgement on whether the totality of a person's needs demonstrate the four key characteristics of a primary health need. It simply supports multi-disciplinary teams (MDTs) to demonstrate that they have implemented a rational and consistent approach to their decision-making.

Note: *This document is intended to be as clear and accessible as possible for people having an assessment for CHC, and their families and carers. However, in order to be medically accurate some words are used that may not be immediately understandable to someone who is not professionally trained. The Care Co-ordinator must make sure that persons and carers or representatives (where consent is given), understand and agree to what has been written and that advocacy support is offered. In order to assist this, a range of leaflets have been developed that aim to provide advice and information about the CHC assessment process in a format that may be more easily understood by those undergoing assessment and their families/representatives. Local Health Boards (LHBs) are required by the Welsh Government to provide these leaflets at appropriate stages of the assessment process. Links to these leaflets are provided on the following sites:*

https://gov.wales/topics/health/nhswales/healthservice/chc-framework/?lang=en
http://www.cciss.org.uk/home

The DST is also available on the sites (as a Word document) and pages or boxes can be expanded as necessary.

It is important to note, however, that the DST is a national tool. Content should not be changed, added to or abbreviated in any way. However, Local Health Boards may attach their logo and additional patient identification details if necessary (e.g. adding NHS number, etc).

User Notes

UNDERPINNING PRINCIPLES

(From the National Framework for the Implementation of Continuing NHS Healthcare in Wales, 2019)

Principle 1: People first.
Individuals who turn to health and social care providers when they have complex needs have to know that their best interests are the primary focus of the people assessing and supporting them. The focus will be manifested in the dignity and respect shown to them as individuals. Individuals who have a primary health need are entitled to CHC funding. They should therefore feel supported throughout the process of determination of eligibility and be confident that they will receive the quality of care required to meet their needs.

Principle 2: Integrity of decision-making
Members of the Multi-disciplinary Team (MDT) are responsible for the integrity of their assessments, expert professional advice and decisions which should be underpinned with a rationale. Assessments can only be challenged on the basis of their quality. They cannot be challenged on financial grounds.

Principle 3: No decisions about me without me.
Individuals are the experts in their own lives. Including them and/or their carers (be they paid or unpaid) as empowered co-producers in the assessment and care planning process is not an optional extra. Where the available care options carry financial or emotional consequences, professionals must not avoid honest and mature conversations with the individual and/or their representative. Professionals must be mindful that some individuals may need support or advocacy to express their wishes, feelings and aspirations.

Principle 4: No delays in meeting a persons needs due to funding discussions.
The individual must not experience delay in having their needs met because agencies are not working effectively together. Joint funding and pooled budget options must be considered wherever these can promote more agile, and as a consequence, more efficient responses to individual needs and preferences. Commissioners have a responsibility to resolve concerns/disputes at the earliest opportunity.

Principle 5: Understand diagnosis; focus on need.
Individuals do not define themselves by their medical diagnosis and nor should the professionals who are supporting them. Health and social care providers must work together to gain a holistic understanding of need and the impact on the individual's daily life. The aim of assessment, treatment and the planning and commissioning of longer-term care should be to deliver quality and tailored support which maximises independence and focuses on what is most important from the perspective of the individual and their carers.

Principle 6: Co-ordinated care & continuity.
Fragmented care is distressing, unsafe and costly. It can result in unnecessary change to living arrangements, which in turn creates instability and insecurity. Every effort must be made to avoid disruption to care arrangements wherever possible, or to provide smooth and safe transition where change is required in the best interests of the individual. Where an individual whose care was arranged through Direct Payments becomes eligible for CHC

funding, the health board must work with them in a spirit of co-production and make every effort to maintain continuity of the personnel delivering the care, where the individual wishes this to be the case.

The individual and their carers must have a named contact for advice and support, who can co-ordinate a prompt response to any change in need.

Principle 7: Communicate.
The vast majority of complaints, concerns and disputes have poor communication at their core. It is unacceptable for professionals to claim not to have time to communicate – it will take longer to put the situation right later and trust will have been broken. The individuals seeking our help and their carers will, by the nature of the interaction, require clear communication and support.

Extra care must be taken to communicate carefully and using the preferred means of communication with the individual. Information also needs to be provided in the most appropriate formats, including copies of relevant assessment and care planning documentation.

Where possible, the professional should attempt to establish the preferred means of communication of any individual prior to undertaking any assessment. Assessments together with any provision of care and support services have to be linguistically sensitive.

Users and carers will be empowered if they are able to speak with staff in their first language. It is important to recognise the concept of language need. For many Welsh speakers, language is an integral element of their care. Many people can only communicate and participate in their care as equal partners effectively through the medium of Welsh. Effective communication is a key requirement of assessment and the provision of any support required.

The same considerations apply to British Sign Language (BSL) users. The evidence suggests that BSL users prefer to communicate directly with professionals who can communicate fluently in BSL when discussing care and support needs. Many local authorities employ special social workers who work with deaf people and can communicate in BSL. Most local authorities employ specialist social workers for deaf people and can assist with assessments.

In cases where professionals cannot communicate directly in BSL, interpreters will have to be used either directly or via video computer link.

All professionals involved in an assessment of the needs of people with severe speech and communication difficulties will need to establish the preferred means of communication before starting the assessment. Assessment specifically concerned with communication may require the assistance of the 'National Centre for Electronic Assistive Technology'.

Any decision on eligibility must be clearly and professionally explained to an individual. See Communicating the Decision on Eligibility (see paragraphs 3.97 to 3.99 in the 2018 Framework).

PROCESS

4. The process for the assessment and determination of eligibility for CHC is described in detail in **Section 4** of the National Framework for the Implementation of Continuing NHS Healthcare in Wales (2019). Multi-disciplinary teams should refer to that document directly; the contents **are not** repeated in this Decision Support Tool ("DST").
5. The DST is not an assessment in itself and it does not replace professional judgement in determining eligibility. It is simply a means of recording the rationale and facilitating logical and consistent decision-making.
6. It must only be used following a comprehensive multi-disciplinary assessment of a person's health and social care needs and their desired outcomes. The Multi-disciplinary Team should use this tool to support consideration of not just the overall needs, but also the interaction between the needs, and evidence from relevant risk assessments.

How should consent be approached within the DST?

7. This area is covered in greater detail in **Section 3** of the Framework. Where the individual concerned has capacity, their informed consent should be obtained before the completion of the DST (if consent was not already obtained through a checklist). This consent needs to cover both the completion of the tool and the sharing of relevant information between the professionals involved.
8. If there is a concern the individual does not have the capacity to consent to the assessment process or to the sharing of information, this should be determined in accordance with the Mental Capacity Act 2005 and the associated code of practice. It may be necessary for 'best interest' decisions to be made, bearing in mind the exception that all who are permanently eligible for CHC should have the opportunity to be considered for eligibility. Guidance in such situations is set out in **Section 3** of the Framework.
9. The fact that an individual may have significant difficulties in expressing their views does not itself mean they lack capacity to make a decision. Appropriate support and adjustments should be made available in compliance with the Mental Capacity Act and with equalities legislation.
10. Robust data-sharing protocols, within and between organisations, will help to ensure confidentiality is respected whilst all necessary information is available to complete the DST. (See **Communicating the Decision/ Sharing of Information** later in this document)

The role of the individual in the process

11. The individual should be invited to be present or represented wherever practicable. The assessment of needs that informs completion of the DST should be carried out with the knowledge and consent of the individual and with a full opportunity to participate. They should be given the opportunity to be supported or represented by a carer, family member, friend or advocate if they so wish. The eligibility assessment process should draw on those who have direct knowledge of the individual and their needs.
12. This means the individual or their representative(s) should be given reasonable notice of completion of the DST to enable them to arrange for a family member or other person to be present, taking into account their personal circumstances. If it is not practicable for the individual (or their representative) to be present, their views should be obtained and actively considered in the completion of the DST. Those completing the DST should record how the individuals (or their representative) contributed to the assessment of their needs and if they were not involved, why this was.
13. Even where an individual has not chosen someone else to support or represent them, where consent has been given the views and knowledge of family members should be taken into account.
14. Completion of the DST should be organised so that the individual understand the process and receives advice and information to enable them to participate in informed decisions about their future care and support. The reasons for any decisions should be transparent and clearly documented.

Who can complete the DST?

15. Multi-disciplinary Team (MDT) members are responsible for working with the individual and/or their representatives to undertake a thorough and objective assessment of the person’s needs, for providing expert advice to the LHB regarding eligibility for CHC and for making recommendations as to the setting and skill set required to deliver the co-produced care plan.

16. The MDT works together to collate and review the relevant information on the individual’s health and social care needs. The MDT uses this information to help clarify individual needs, through the completion of the Decision Support Tool (“DST”), and then works collectively to make a professional judgement about the eligibility for CHC, which will be reflected in its recommendation. This process is known as a multi-disciplinary assessment for eligibility for CHC. The Multi-disciplinary Team should use this tool to support consideration of not just the overall needs, but also the interaction between the needs, and evidence from relevant risk assessments. Conversely, the DST should **<u>not</u>** be completed without a multi-disciplinary assessment of needs.

17. The DST provides practitioners with a needs-led approach by portraying need based on 12 ‘care domains’ (including an open domain for needs that do not readily fit into the other 11). The tool is in four sections:

- Section 1 – Personal information.
- Section 2 – Care domains.
- Section 3 – Recommendations.
- Section 4 – Equality Monitoring Form.

18. The documentation should be organised e.g. collated into a single folder or section of the patient notes, to ensure the CHC process and the outcomes can be easily identified via a clear audit trail. Where an LHB uses electronic records, the same principles must apply, i.e. the information must be organised and collated into a single folder to ensure it is possible to make appropriate checks that the process is being followed and that outcomes are easily identifiable.

19. If the collated integrated assessment and care plan are sufficiently robust there is no requirement to duplicate paperwork by copying information into the DST document. It will be acceptable in these circumstances to only complete:

- the DST Summary Sheet (matrix)
- the summary record of the MDT recommendation and rationale on eligibility
- the Equality Monitoring Form

The Use of “Care Domains”

20. The DST is designed to ensure that the full range of factors that have a bearing on an individual’s eligibility are taken into account in reaching the decision, irrespective of client group or diagnosis. The tool provides practitioners with a method of bringing together and recording the various needs in 12 ‘care domains’, or generic areas of need. Each domain is broken down into a number of levels. The levels represent a hierarchy from the lowest to the highest possible level of need (and support required) such that, whatever the extent of the need within a given domain, it should be possible to locate this within the descriptors provided. The domains are:

- Breathing
- Nutrition
- Continence
- Skin Integrity
- Mobility
- Communication
- Cognition
- Psychological & Emotional Needs
- Behaviour
- Drug Therapies and Medication
- Altered States of Consciousness
- Other Significant Care Needs.

21. Completion of the tool should result in a comprehensive picture of the individual's needs that captures their nature, and their complexity, intensity and/or unpredictability – and thus the quality and/or quantity (including continuity) of care required to meet the individual's needs. Figure 1 indicates how the domains in the Decision Support Tool can illustrate (both individually and through their interaction) the complexity, intensity and/or unpredictability of needs. The overall picture, and the descriptors within the domains themselves, also relate to the nature of needs.

The focus must be on a rounded and holistic assessment of the person rather than DST scores in isolation.

Scoring of domains – Levels of Need

22. Each domain is subdivided into statements of need representing no needs ('N' in the table below), low (L), moderate (M), high (H), severe (S) or priority (P) levels of need, depending on the domain (see Figure 1). The detailed descriptors of them are set out in the 12 domain tables for completion later in this document.

23. The descriptions in the DST are examples of the types of need that may be present. They should be carefully considered but may not always adequately describe every person's circumstances. There is an expectation that the MDT will be able to collectively reach a conclusion about the level of need within each of the domains and therefore eligibility.

24. If, however, 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, and by which practitioner. This information should be summarised within the overall recommendation. A person must not be recorded as having needs between levels. It is important that differences of opinion on the appropriate level are based on the evidence available and not on presuppositions about a person's need or generalised assumptions about the effects of a particular condition.

25. It is important that the wording of domain levels is carefully considered and assumptions are not made. The fact that a person has a condition that is described as 'severe' does not necessarily mean that they should be placed on the 'severe' level of the relevant domain. Similarly the fact that a risk assessment indicates a 'high' risk does not necessarily mean that an individual should be placed on the 'high' level of the relevant domain. It is the domain level whose description most closely fits their needs that should be selected (for example, the fact that a person is described as having 'severe' learning disabilities does not automatically mean that they should be placed on the 'severe' level of the Cognition domain).

26. The fast-track process should always be used for any person with a rapidly deteriorating condition that may be entering a terminal phase. For other persons who have a more slowly deteriorating condition and for whom it can reasonably be anticipated that their needs are therefore likely to increase in the near future, the domain levels selected should be based on current needs but the likely change in needs should be recorded in the evidence box for that domain and taken into account in the recommendation made. This could mean that a decision is made that they should be eligible for Continuing NHS Healthcare immediately (i.e. before the deterioration has actually taken place) or, if not, that a date is given for an early review of their needs and possible eligibility. Professional judgement based on knowledge of the likely progression of the condition should determine which option is followed.

27. It should be remembered that a single condition might give rise to separate needs in a number of domains. For example someone with cognitive impairment will have a weighting in the cognition domain and as a result may have associated needs in other domains, all of which should be recorded and weighted in their own right.

28. Some domains include levels of need that are so great that they could reach the 'priority' level (which would indicate a primary health need), but others do not. This is because the needs in some care domains are considered never to reach a level at which they on their own should trigger eligibility; rather they would form part of a range of needs which together could constitute a primary health need.

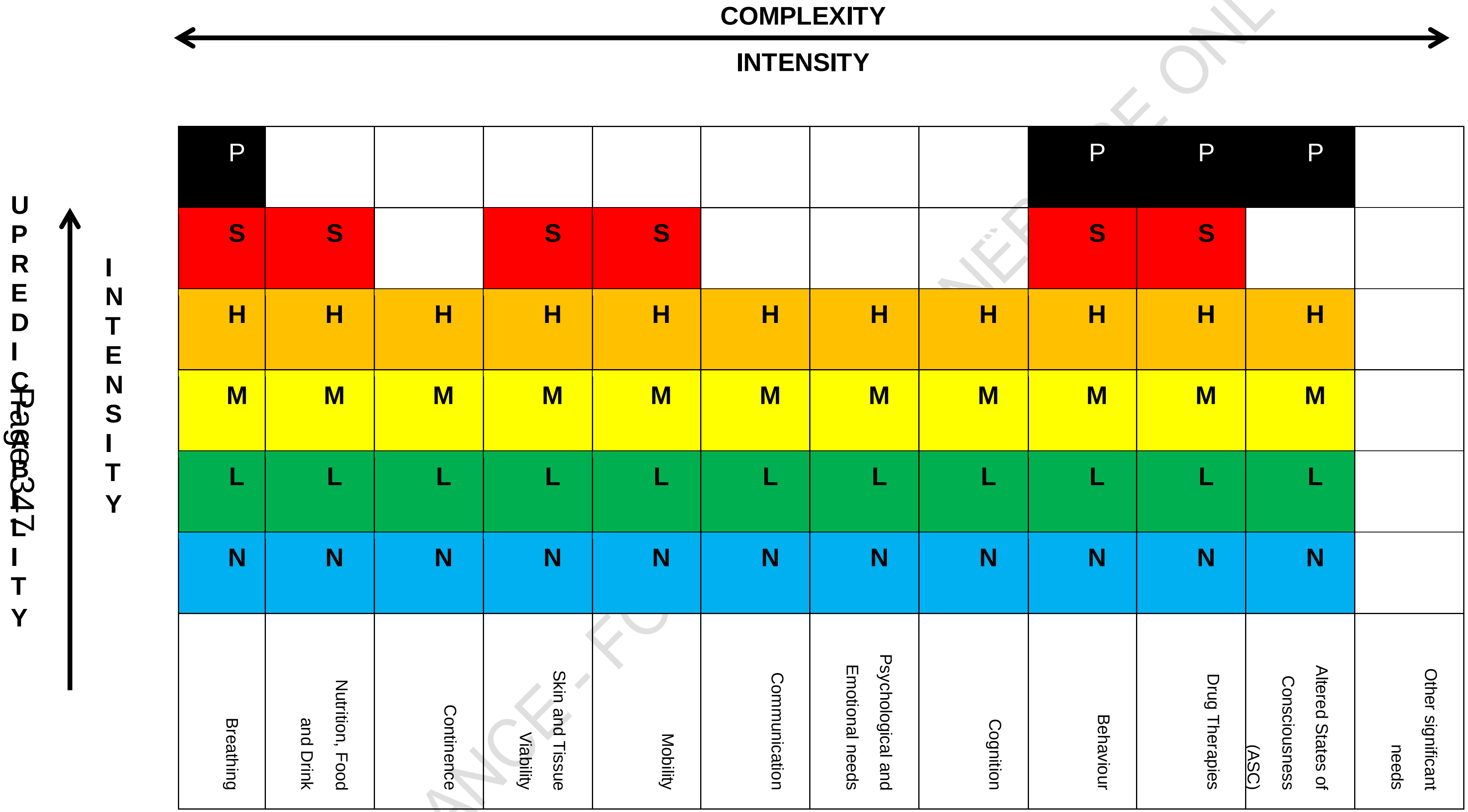
29. Within each domain there is space to justify why a particular level is appropriate, based on the available evidence about the assessed needs. It is important that needs are described in measurable terms, using clinical expertise, and supported with the results from appropriate and validated assessment tools where relevant.

30. Needs should not be marginalised because they are successfully managed. Well-managed needs are still needs. Only where the successful management of a healthcare need has permanently reduced or removed an ongoing need will this have a bearing on Continuing NHS Healthcare eligibility. However, there are different ways of reflecting this principle when completing the DST. 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.

31. It is not intended that this principle should be applied in such a way that well-controlled physical health conditions should be recorded as if medication or other routine care or support was not present. For example, where needs are being managed via medication (whether for behaviour or for physical health needs), it may be more appropriate to reflect this in the Drug Therapies and Medication domain. Similarly, where someone's skin condition is not aggravated by their incontinence because they are receiving good continence care, it would not be appropriate to weight the skin domain as if the continence care was not being provided.

32. There may be circumstances where a person may have particular needs that are not covered by the first 11 defined care domains within the DST. In this situation, it is the responsibility of the assessors to determine and record the extent and type of the needs in the "additional" 12th domain provided entitled 'Other Significant Health Care Needs' and take this into account when deciding whether a person has a primary health need. The availability of this domain should not be used to inappropriately affect the overall decision on eligibility.

Figure 1: How the different care domains are divided into levels of need.



Breathing	Nutrition, Food and Drink	Continence	Skin and Tissue Viability	Mobility	Communication	Psychological and Emotional needs	Cognition	Behaviour	Drug Therapies	Altered States of Consciousness (ASC)	Other significant needs
P								P	P	P	
S	S		S	S				S	S		
H	H	H	H	H	H	H	H	H	H	H	
M	M	M	M	M	M	M	M	M	M	M	
L	L	L	L	L	L	L	L	L	L	L	
N	N	N	N	N	N	N	N	N	N	N	

Key: N = No needs L = Low M = Moderate H = High S = Severe P = Priority

COMPLETING THE DST AND ESTABLISHING A PRIMARY HEALTH NEED

33. At the end of the DST, there is a summary sheet to provide an overview of the levels chosen and a summary of the person's needs, along with the MDT's recommendation about eligibility or ineligibility. A clear recommendation of eligibility for CHC would be expected in the following two circumstances:

    - 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.

    Where the following occur, this may also indicate a primary health need, requiring further consideration:

    - one domain recorded as severe, together with needs in a number of other domains, or
    - a number of domains with high and/or moderate needs.

34. Under these circumstances, clear reasons need to be recorded for the decision whether or not a person has a primary health need. In all cases, the overall need, the interactions between needs in different care domains, and the evidence from risk assessments should be taken into account in deciding whether a recommendation of eligibility for CHC should be made. MDTs are nevertheless reminded that, as emphasised throughout the Framework, the decision on eligibility should not be based on 'tick box scores' in isolation.

35. It is not possible to equate a number of incidences of one level with a number of incidences of another level, as in, for example 'two moderates equals one high'. The judgement whether someone has a primary health need must be based on what the evidence indicates about the nature and/or complexity and/or intensity and/or unpredictability of the person's needs.

36. If needs in all domains are recorded as **'no need'**, this would indicate ineligibility. Where all domains are recorded as **'low need'**, this would be unlikely to indicate eligibility. However, because low needs can add to the overall picture, influence the continuity of care necessary, and alter the impact that other needs have on the person, all domains should be completed.

37. The Care Co-ordinator should ensure that all parts of the DST have been considered. The MDT's recommendation on eligibility must be completed (agreed/signed by MDT members), and forwarded to the LHB for quality assurance and commissioning of the care package. The Care Co-ordinator should also advise the person of the timescales for confirmation of the MDT recommendation and arrangement of the CHC care package (i.e. no more than 21 days unless there are exceptional circumstances). (See Sections 3 & 4 of the National Framework.).

38. The Equality Monitoring Form should be completed by the person who is the subject of the DST, if the person agrees to this. Where the person needs support to complete the form, this should be arranged by the Care Co-ordinator. The Care Co-ordinator should forward the form to the appropriate location, in accordance with the relevant LHB's processes for processing equality data.

COMMUNICATING THE DECISION/ SHARING OF INFORMATION

39. In line with requirements set out in the Framework, a copy of the completed DST (including the recommendation) should be forwarded to the person (or, where appropriate, their representative) if requested and dependent on authority to share and receive information. This should include the final decision made by the LHLHB, along with the reasons for the decision.

40. If someone is acting as the person's representative they are entitled to receive a copy of the DST, provided that the correct basis for sharing such information has been established. This basis could be any one of the following:

a) consent from the person concerned (where they have capacity to give this).
b) consent from a court appointed deputy (health and welfare) or someone who holds Lasting Power of Attorney (health and welfare) for that person.
c) a "best interest" decision to share information made under the Mental Capacity Act (where the person lacks capacity to consent to the sharing of information).

41. Where a person lacks capacity but has an appointed Lasting Power of Attorney (property and finance), information (including a copy of the completed DST) should be shared in order for them to carry out their LPA duties, unless there are compelling and lawful reasons why this should not happen. If there is doubt, advice should be sought.

Decision Support Tool for Continuing NHS Healthcare

Section 1 – Personal Details

Date of completion of Decision Support Tool ________________________________

Name		**D.O.B.**	

NHS number and GP/Practice:	

Permanent Address and Telephone Number	**Current Location** **(i.e. where MDT assessment is taking place)**

Gender ________________________________

PLEASE ENSURE THAT THE EQUALITY MONITORING FORM AT THE END OF THE DST IS COMPLETED

Please delete answer as appropriate

Was the person involved in the completion of the DST?

Yes/No

Was the person offered the opportunity to have a representative such as a family member or other advocate present when the DST was completed?

Yes/No

If yes, did the representative attend the completion of the DST?

Yes/No

Decision Support Tool for Continuing NHS Healthcare

Section 1 – Personal Details

PLEASE GIVE THE CONTACT DETAILS OF THE REPRESENTATIVE (NAME, ADDRESS AND TELEPHONE NUMBER)

Summary

1. Summary pen portrait of the person’s situation, relevant history and current needs, including clinical summary and identified significant risks, drawn from the multi-disciplinary assessment**:**

2. Person’s view of their care needs and whether they consider that the multi-disciplinary assessment accurately reflects these:

3. Please note below whether and how the person (or their representative) contributed to the assessment of their needs. If they were not involved, please record whether they were not invited or whether they declined to participate.

Decision Support Tool for Continuing NHS Healthcare
Section 1 – Personal Details

4. Please list the assessments and other key evidence that were taken into account in completing the DST, including the dates of the assessments:

5. Assessors' (including MDT members) name/address/contact details noting lead coordinator:

Decision Support Tool for Continuing NHS Healthcare
Section 1 – Personal Details

6. Contact details of GP and other key professionals involved in the care of the person:

Decision Support Tool for Continuing NHS Healthcare

Section 2 – Care Domains

Please refer to the user notes

1. Breathing: As with all other domains, the breathing domain should be used to record needs rather than the underlying condition that may give rise to the needs For example, a person may have chronic obstructive pulmonary disease (COPD), emphysema or recurrent chest infections or another condition giving rise to breathing difficulties, and it is the needs arising from such conditions which should be recorded.

1. Describe below the actual needs of the person, providing the evidence that informs the decision overleaf on which level is appropriate, including the frequency and intensity of need, unpredictability, deterioration and any instability.
2. Circle the assessed level overleaf.

Decision Support Tool for Continuing NHS Healthcare

Section 2 – Care Domains

Please refer to the user notes

1. Breathing

Description	**Level of need**
Normal breathing, no issues with shortness of breath.	No needs
Shortness of breath 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.	Low
Shortness of breath which may require the use of inhalers or a nebuliser and limit some daily living activities. **OR** Episodes of breathlessness that do not respond to management and limit some daily living 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 person can still spontaneously breathe e.g. CPAP (Continuous Positive Airways Pressure) to manage obstructive apnoea during sleep.	Moderate
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 treatment and limits all daily living activities.	High
Difficulty in breathing, even through a tracheotomy, which requires suction to maintain airway. **OR** Demonstrates severe breathing difficulties at rest, in spite of maximum medical therapy **OR** A condition that requires management by a non-invasive device to both stimulate and maintain breathing (bilevel positive airway pressure, or non-invasive ventilation)	Severe
Unable to breathe independently, requires invasive mechanical ventilation.	Priority

Decision Support Tool for Continuing NHS Healthcare

Section 2 – Care Domains

Please refer to the user notes

2. Nutrition – Food and Drink: Persons at risk of malnutrition, dehydration and/or aspiration should either have an existing assessment of these needs or have had one carried out as part of the assessment process, with any management and risk factors supported by a management plan. Where a person has significant weight loss or gain, professional judgement should be used to consider what the trajectory of weight loss or gain is telling us about the person's nutritional status.

1. Describe the actual needs of the person, providing the evidence that informs the decision overleaf on which level is appropriate, including the frequency and intensity of need, unpredictability, deterioration and any instability.
2. Circle the assessed level overleaf.

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

Please refer to the user notes

2. Nutrition – Food and Drink

Description	Level of need
Able to take adequate food and drink by mouth to meet all nutritional requirements.	No needs
Needs supervision, prompting with meals, or may need feeding and/or a special diet. **OR** Able to take food and drink by mouth but additional risk assessment indicates additional/supplementary feeding is required.	Low
Needs feeding to ensure adequate intake of food and takes a long time (half an hour or more), including liquidised feed. **OR** Unable to take any food and drink by mouth, but all nutritional requirements are being adequately maintained by artificial means via an established feeding regime.	Moderate
Skilled intervention to ensure adequate nutrition/hydration and minimise the risk of choking and aspiration to maintain airway. **OR** Subcutaneous fluids that are managed by the person or specifically trained carers or care workers. **OR** Unintended, significant weight loss. **OR** Problems relating to a feeding device (for example PEG) that require skilled assessment and review.	High
Unable to take food and drink by mouth. All nutritional requirements taken by artificial means requiring ongoing skilled competent intervention and clinical decision making over a 24 hour period to ensure nutrition/hydration, for example I.V. fluids. **OR** Unable to take food and drink by mouth, intervention inappropriate or impossible.	Severe

Decision Support Tool for Continuing NHS Healthcare

Section 2 – Care Domains

Please refer to the user notes

3. Continence: Where continence problems are identified, a full continence assessment exists or has been undertaken as part of the assessment process, any underlying conditions identified, and the impact and likelihood of any risk factors evaluated.

1. Describe the actual needs of the person, providing the evidence that informs the decision overleaf on which level is appropriate, including the frequency and intensity of need, unpredictability, deterioration and any instability.
2. Take into account any aspect of continence care associated with behaviour in the Behaviour domain.
3. Circle the assessed level overleaf.

Decision Support Tool for Continuing NHS Healthcare

Section 2 – Care Domains

Please refer to the user notes

3. Continence

Description	**Level of need**
Continent of urine and faeces.	No needs
Continence care is routine on a day-to-day basis; Incontinence of urine managed through, for example, medication, regular toileting, use of penile sheaths, etc. **AND** is able to maintain full control over bowel movements or has a stable stoma, or may have occasional faecal incontinence/constipation.	Low
Continence care is routine but requires monitoring to minimise risks, for example those associated with urinary catheters, double incontinence, chronic urinary tract infections and/or the management of constipation.	Moderate
Continence care is problematic and requires timely and skilled intervention, beyond routine care (for example frequent bladder wash outs, manual evacuations, frequent re-catheterisation).	High

Decision Support Tool for Continuing NHS Healthcare

Section 2 – Care Domains

Please refer to the user notes

4. Skin (including tissue viability): Evidence of wounds should derive from a wound assessment chart or tissue viability assessment completed by an appropriate professional. Here, a skin condition is taken to mean any condition which affects or has the potential to affect the integrity of the skin.

1. Describe the actual needs of the person, providing the evidence that informs the decision overleaf on which level is appropriate, including the frequency and intensity of need, unpredictability, deterioration and any instability.
2. Circle the assessed level overleaf.

Decision Support Tool for Continuing NHS Healthcare

Section 2 – Care Domains

Please refer to the user notes

4. Skin (including tissue viability)

Description	Level of need
No risk of pressure damage or skin condition.	No needs
Risk of skin breakdown which requires preventative intervention once a day or less than daily without which skin integrity would break down. **OR** Evidence of pressure damage and/or pressure ulcer(s) either with 'discolouration of intact skin' or a minor wound(s). **OR** A skin condition that requires monitoring or reassessment less than daily and that is responding to treatment or does not currently require treatment.	Low
Risk of skin breakdown which requires preventative intervention several times each day, without which skin integrity would break down. **OR** Pressure damage or open wound(s), pressure ulcer(s) with 'partial thickness skin loss involving epidermis and/or dermis', which is responding to treatment. **OR** An identified skin condition that requires a minimum of daily treatment, or daily monitoring/reassessment to ensure that it is responding to treatment.	Moderate
Pressure damage or open wound(s), pressure ulcer(s) with 'partial thickness skin loss involving epidermis and/or dermis', which is not responding to treatment **OR** Pressure damage or open wound(s), pressure ulcer(s) with 'full thickness skin loss involving damage or necrosis to subcutaneous tissue, but not extending to underlying bone, tendon or joint capsule', which is/are responding to treatment. **OR** Specialist dressing regime in place; responding to treatment	High
Open wound(s), pressure ulcer(s) with 'full thickness skin loss involving damage or necrosis to subcutaneous tissue, but not extending to underlying bone, tendon or joint capsule' which are not responding to treatment and require regular monitoring/reassessment. **OR** Open wound(s), pressure ulcer(s) with 'full thickness skin loss with extensive destruction and tissue necrosis extending to underlying bone, tendon or joint capsule' . **OR** Multiple wounds which are not responding to treatment.	Severe

Decision Support Tool for Continuing NHS Healthcare

Section 2 – Care Domains

Please refer to the user notes

5. Mobility: This section considers persons with impaired mobility. Please take other mobility issues such as wandering into account in the Behaviour domain where relevant. Where mobility problems are indicated, an up-to-date Moving and Handling and Falls Risk Assessment should exist or have been undertaken as part of the assessment process, and the impact and likelihood of any risk factors considered. The assessment should ordinarily have been completed within the last 3 months. However professional judgement should be applied to determine whether there is anything of relevance outside this timeframe that ought to be considered. It is important to note that the use of the word 'high' in any particular falls risk assessment tool does not necessarily equate to a high level need in this domain.

1. Describe the actual needs of the person, providing the evidence that informs the decision overleaf on which level is appropriate, with reference to movement and handling and falls risk assessments where relevant. Describe the frequency and intensity of need, unpredictability, deterioration and any instability.
2. Circle the assessed level overleaf.

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

Please refer to the user notes

5. Mobility

Description	Level of need
Independently mobile	No needs
Able to weight bear but needs some assistance and/or requires mobility equipment for daily living.	Low
Not able to consistently weight bear. **OR** Completely unable to weight bear but is able to assist or cooperate with transfers and/or repositioning. **OR** In one position (bed or chair) for the majority of time but is able to cooperate and assist carers or care workers. **OR** At moderate risk of falls (as evidenced in a falls history or risk assessment)	Moderate
Completely unable to bear weight and is unable to assist or cooperate with transfers and/or repositioning. **OR** Due to risk of physical harm or loss of muscle tone or pain on movement needs careful positioning and is unable to cooperate. **OR** At a high risk of falls (as evidenced in a recent falls history and risk assessment). **OR** Involuntary spasms or contractures placing the person or others at risk.	High
Has a clinical condition such that, on movement or transfer there is a high risk of serious physical harm and where the positioning is critical.	Severe

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

Please refer to the user notes

6. Communication: This section relates to difficulties with expression and understanding, in particular with regard to communicating needs. A person's ability or otherwise to communicate their needs may well have an impact both on the overall assessment and on the provision of care. Consideration should always be given as to whether the person requires assistance with communication, for example through an interpreter, use of pictures, sign language, use of Braille, hearing aids, or other communication technology.

1. Describe the actual needs of the person, providing the evidence that informs the decision overleaf on which level is appropriate, including the frequency and intensity of need, unpredictability, deterioration and any instability.
2. Circle the assessed level overleaf.

Decision Support Tool for Continuing NHS Healthcare

Section 2 – Care Domains

Please refer to the user notes

6. Communication

Description	Level of need
Able to communicate clearly, verbally or non-verbally. Has a good understanding of their primary language. May require translation if English is not their first language.	No needs
Needs assistance to communicate their needs. Special effort may be needed to ensure accurate interpretation of needs or additional support may be needed either visually, through touch or with hearing.	Low
Communication about needs is difficult to understand or interpret or the person is sometimes unable to reliably communicate, even when assisted. Carers or care workers may be able to anticipate needs through non-verbal signs due to familiarity with the person.	Moderate
Unable to reliably communicate their needs at any time and in any way, even when all practicable steps to assist them have been taken.	High

Decision Support Tool for Continuing NHS Healthcare

Section 2 – Care Domains

Please refer to the user notes

7. **Psychological and Emotional Needs:** In considering the individual's level of need in this domain, careful consideration should be given to the individual's ability to engage in care planning or withdrawal from activities due to their psychological and emotional needs and the degree of support required. If an individual has a level of need in the domain of cognition the individual may not be able to engage in care planning or has withdrawn from any attempts to engage them in daily activities, however the inability or withdrawal should be carefully considered to establish if there is any evidence of psychological or emotional needs that are having an impact on their health and well-being.

1. Describe the actual needs of the person, providing the evidence that informs the decision overleaf on which level is appropriate, including the frequency and intensity of need, unpredictability, deterioration and any instability.
2. Circle the assessed level overleaf.

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

Please refer to the user notes

7. Psychological and Emotional Needs

Description	Level of need
Psychological and emotional needs are not having an impact on their health and well-being.	No needs
Mood disturbance, hallucinations or anxiety symptoms, or periods of distress, which are having an impact on their health and/or well-being but respond to prompts, distraction and/or reassurance. **OR** Requires prompts to motivate self towards activity and to engage them in care planning, support, and/or daily activities.	Low
Mood disturbance, hallucinations or anxiety symptoms, or periods of distress, which do not readily respond to prompts and reassurance and have an increasing impact on the person's health and/or well-being. **OR** Due to their psychological or emotional state the person has withdrawn from most attempts to engage them in care planning, support and/or daily activities.	Moderate
Mood disturbance, hallucinations or anxiety symptoms, or periods of distress, that have a severe impact on the person's health and/or well-being. **OR** Due to their psychological or emotional state the person has withdrawn from any attempts to engage them in care planning, support and/or daily activities.	High

Decision Support Tool for Continuing NHS Healthcare

Section 2 – Care Domains

Please refer to the user notes

8. Cognition: This may apply to, but is not limited to, persons with learning disability and/or acquired and degenerative disorders. Where cognitive impairment is identified in the assessment of need, active consideration should be given to referral to an appropriate specialist if one is not already involved. A key consideration in determining the level of need under this domain is making a professional judgement about the degree of risk to the person.

Please refer to the National Framework guidance about the need to apply the principles of the Mental Capacity Act in every case where there is a question about an individual's capacity. The principles of the Act should also be applied to all considerations of the person's ability to make decisions and choices.

1. Describe the actual needs of the person (including episodic and fluctuating needs), providing the evidence that informs the decision overleaf on which level is appropriate, including the frequency and intensity of need, unpredictability, deterioration and any instability.
2. Where cognitive impairment has an impact on behaviour, take this into account in the Behaviour domain, so that the interaction between the two domains is clear.
3. Circle the assessed level overleaf.

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

Please refer to the user notes

8. Cognition

Description	Level of need
No evidence of impairment, confusion or disorientation.	No needs
Cognitive impairment which requires some supervision, prompting or assistance with more complex activities of daily living, such as finance and medication, but awareness of basic risks that affect their safety is evident. **OR** Occasional difficulty with memory and decisions/choices requiring support, prompting or assistance. However, the person has insight into their impairment.	Low
Cognitive impairment (which may include some memory issues) that requires some supervision, prompting and/or assistance with basic care needs and daily living activities. Some awareness of needs and basic risks is evident. The person is usually able to make choices appropriate to needs with assistance. However, the person has limited ability, even with supervision, prompting or assistance, to make decisions about some aspects of their lives, which consequently puts them at some risk of harm, neglect or health deterioration.	Moderate
Marked or short-term memory issues, or both, associated with disorientation to time and/or place, with possible inability to recognise various family members, friends or care staff. The individual has insight into only a very limited range of basic needs and lacks awareness of the risks of their environment. Despite having supervision, guidance or assistance they are constantly unable to make choices or decisions relating to basic issues, thereby putting themselves at a significant risk of harm and deterioration to their health. The individual is completely dependent on others to anticipate their needs and maintain their safety.	High

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

Please refer to the user notes

9. Behaviour: Human behaviour is complex, hard to categorise, and may be difficult to manage. Challenging behaviour may be caused by a wide range of factors. These may include extreme frustration associated with communicating difficulties, an inappropriate environment or fluctuations in mental state.

Challenging behaviour in this domain includes but is not limited to:

- aggression, violence or passive non-aggressive behaviour
- severe disinhibition
- intractable noisiness or restlessness
- resistance to necessary care and treatment (this may therefore include non-concordance and non-compliance)
- severe fluctuations
- inappropriate interference with others
- identified high risk of self harm or suicide

The assessment of needs of a person with serious behavioural issues should include specific consideration of the risk(s) **to themselves, others or property** with particular attention to aggression, self-harm and self-neglect and any other behaviour(s), irrespective of their living environment.

1. Describe the actual needs of the person, including any episodic needs. Provide the evidence that informs the decision overleaf on which level is appropriate, such as the times and situations when the behaviour to likely to be displayed across a range of typical daily routines and the frequency, duration and impact of the behaviour.
2. Note any overlap with other domains.
3. Circle the assessed level overleaf.

Decision Support Tool for Continuing NHS Healthcare

Section 2 – Care Domains

Please refer to the user notes

9. Behaviour

Description	Level of need
No evidence of ‘challenging’ behaviour.	No needs
Some incidents of ‘challenging’ behaviour. A risk assessment indicates that the behaviour does not pose a risk to self, others or property or a barrier to intervention. The person is compliant with all aspects of their care.	Low
‘Challenging’ behaviour that follows a predictable pattern. The risk assessment indicates a pattern of behaviour that can be managed by skilled carers or care workers who are able to maintain a level of behaviour that does not pose a risk to self, others or property. The person is nearly always compliant with care.	Moderate
’Challenging’ behaviour of a type and/or frequency that poses a predictable risk to self, others or property. The risk assessment indicates that planned interventions are effective in minimising but not always eliminating risks. Compliance is variable but usually responsive to planned interventions.	High
‘Challenging’ behaviour of severity and/or frequency that poses a significant risk to self, others or property. The risk assessment identifies that the behaviour(s) require(s) a prompt and skilled response that might be outside the range of planned interventions.	Severe
‘Challenging’ behaviour of a severity and/or frequency and/or unpredictability that presents an immediate and serious risk to self, others or property. The risks are so serious that they require access to an immediate and skilled response at all times for safe care.	Priority

Decision Support Tool for Continuing NHS Healthcare

Section 2 – Care Domains

Please refer to the user notes

10. Drug Therapies and Medication: Symptom Control: The person's experience of how their symptoms are managed and the intensity of those symptoms is an important factor in determining the level of need in this area. Where this affects other aspects of their life, please refer to the other domains, especially the psychological and emotional domain. The location of care will influence who gives the medication.

In determining the level of need, it is the knowledge and skill required to manage the clinical need and the interaction of the medication in relation to the need that is the determining factor. In some situations, a person or their carer will be managing their own medication and this can require a high level of skill. References below to medication being required to be administered by a registered nurse do not include where such administration is purely a registration or practice requirement of the care setting (such as a care home requiring all medication to be administered by a registered nurse).

1. Describe below the actual needs of the person and provide the evidence that informs the decision overleaf on which level is appropriate, including the frequency and intensity of need, unpredictability, deterioration and any instability.
2. Circle the assessed level overleaf.

Decision Support Tool for Continuing NHS Healthcare
Section 2 – Care Domains
Please refer to the user notes

10. Drug Therapies and Medication: Symptom Control

Description	Level of need
Symptoms are managed effectively and without any problems, and medication is not resulting in any unmanageable side-effects.	No needs
Requires supervision/administration of and/or prompting with medication but shows compliance with medication regime. **OR** Mild pain that is predictable and/or is associated with certain activities of daily living. Pain and other symptoms do not have an impact on the provision of care.	Low
Requires the administration of medication (by a registered nurse, carer or care worker) due to: refusal or misuse of medication, or type of medication (for example insulin), or route of medication (for example PEG). **OR** Moderate pain which follows a predictable pattern; or other symptoms which are having a moderate effect on other domains or on the provision of care.	Moderate
Requires administration and monitoring of medication regime by a registered nurse, carer or care worker specifically trained for the task because there are risks associated with the potential fluctuation of the medical condition or mental state, or risks regarding the effectiveness of the medication or the potential nature or severity of side-effects. However, with such monitoring the condition is usually non-problematic to manage. **OR** Moderate pain or other symptoms which is/are having a significant effect on other domains or on the provision of care.	High
Requires administration and monitoring of medication regime by a registered nurse, carer or care worker specifically trained for this task because there are risks associated with the potential fluctuation of the medical condition or mental state, or risks regarding the effectiveness of the medication or the potential nature or severity of side-effects. Even with such monitoring the condition is usually problematic to manage. **OR** Severe recurrent or constant pain which is not responding to treatment. **OR** Risk of refusal or misuse of medication, which is likely to have a significant impact on the individual’s health and well-being.	Severe
Has a drug regime that requires daily monitoring by a registered nurse to ensure effective symptom and pain management associated with a rapidly changing and/or deteriorating condition. **OR** Unremitting and overwhelming pain despite all efforts to control pain effectively.	Priority

Decision Support Tool for Continuing NHS Healthcare

Section 2 – Care Domains

Please refer to the user notes

11. Altered States of Consciousness (ASC): ASCs can be caused by a range of conditions, including transient ischemic attacks (TIAs), epilepsy and vasovagal syncope.

General drowsiness, for example, would not constitute an ASC for the purposes of this domain, unless associated with a diagnosed clinical condition.

1.Describe below the actual needs of the person providing the evidence that informs the decision overleaf on which level is appropriate (referring to appropriate risk assessments), including the frequency and intensity of need, unpredictability, deterioration and any instability.
2. Circle the assessed level overleaf.

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

Please refer to the user notes

11. Altered States of Consciousness (ASC)

Description	Level of need
No evidence of altered states of consciousness (ASC).	No needs
History of ASC but it is effectively managed and there is a low risk of harm.	Low
Occasional (monthly or less frequently) episodes of ASC that require the supervision of a carer or care worker to minimise the risk of harm.	Moderate
Frequent episodes of ASC that require the supervision of a carer or care worker to minimise the risk of harm. **OR** Occasional ASCs that require skilled intervention to reduce the risk of harm.	High
Coma. **OR** ASC that occur on most days, do not respond to preventative treatment, and result in a severe risk of harm.	Priority

Decision Support Tool for Continuing NHS Healthcare

Section 2 – Care Domains

Please refer to the user notes

12. Other Significant Health Care Needs to be taken into consideration: There may be circumstances, on a case-by-case basis, where a person may have particular needs which do not fall into the care domains described above or cannot be adequately reflected in these domains. If the boxes within each domain that give space for explanatory notes are not sufficient to document all needs, it is the responsibility of the assessors to determine and record the extent and type of these needs here. The lack of availability of information to complete this domain should not be used to inappropriately affect the overall decision on eligibility.

1. Enter below a brief description of the actual needs of the person, including providing the evidence why the level in the table overleaf has been chosen (referring to appropriate risk assessments), and referring to the frequency and intensity of need, unpredictability, deterioration and any instability.

Decision Support Tool for Continuing NHS Healthcare

Section 2 – Care Domains

Please refer to the user notes

Assessed Levels of Need

Care Domain	**P**	**S**	**H**	**M**	**L**	**N**
Breathing						
Nutrition – Food and Drink	■					
Continence	■	■				
Skin (including tissue viability)	■					
Mobility	■					
Communication	■	■				
Psychological Needs	■	■				
Cognition	■					
Behaviour						
Drug Therapies and Medication						
Altered States of Consciousness		■				
Totals						

Decision Support Tool for Continuing NHS Healthcare

Section 2 – Care Domains

Please refer to the user notes

Please note below any views of the person on the completion of the DST that have not been recorded above, including whether they agree with the domain levels selected. Where they disagree, this should be recorded below, including the reasons for their disagreement. Where the person is represented or supported by a carer or advocate, their understanding of the person's views should be recorded.

Decision Support Tool for Continuing NHS Healthcare
Section 3 – Recommendation
Please refer to the user notes

Recommendation of the Multi-disciplinary Team filling in the DST

Please give a recommendation on the next page as to whether or not the person is eligible for Continuing NHS Healthcare. This should take into account the range and levels of need recorded in the Decision Support Tool and what this tells you about whether the person has a primary health need. Any disagreement on levels used or areas where needs have been counted against more than one domain should be highlighted here. Reaching a recommendation on whether the person's primary needs are health needs should include consideration of:

- **Nature**: This describes the particular characteristics of a person's needs (which can include physical, mental health, or psychological needs), and the type of those needs. This also describes the overall effect of those needs on the person, including the type ('quality') of interventions required to manage them.

- **Intensity:** This relates to both the extent ('quantity') and severity (degree) of the needs and the support required to meet them, including the need for sustained/ongoing care ('continuity').

- **Complexity:** This is concerned with how the needs present and interact to increase the skill needed to monitor the symptoms, treat the condition(s) and/or manage the care. This can arise with a single condition or can also include the presence of multiple conditions or the interactions between two or more conditions. It may also include situations where an individual's response to their own condition has an impact on their overall needs, such as when a physical health need results in the individual developing a mental health need.

- **Unpredictability:** This describes the degree to which needs fluctuate, creating challenges in managing them. It also relates to the level of risk to the person's health if adequate and timely care is not provided. Someone with an unpredictable healthcare need is likely to have either a fluctuating, or unstable or rapidly deteriorating condition.

Each of these characteristics may, in combination or alone, demonstrate a primary health need, because of the quality and/or quantity of care required to meet the person's needs. The totality of the overall needs and the effects of the interaction of needs should be carefully considered when completing the DST.

Also please indicate whether needs are expected to change (in terms of deterioration or improvement) before the case is next reviewed. If so, please state why and what needs you think will be different and therefore whether you are recommending that eligibility should be agreed now or that an early review date should be set.

Where there is no eligibility for Continuing NHS Healthcare and the assessment and care plan, as agreed with the person, indicates the need for support in a care home setting, the team should indicate whether there is the need for registered nursing care in the care home, giving a clear rationale based on the evidence above.

Decision Support Tool for Continuing NHS Healthcare
Section 3 – Recommendation

Please refer to the user notes

Recommendation on eligibility for Continuing NHS Healthcare, below, detailing the conclusions on the issues outlined on the previous page. This should include the following headings:

- Overview;
- Nature;
- Intensity;
- Complexity;
- Unpredictability; and
- Recommendation.

Signatures of MDT making above recommendation:

Health professionals

Printed Name	Designation	Professional Qualification	Signature	Date

Social care/other professionals

Printed Name	Designation	Signature	Date

Decision Support Tool for Continuing NHS Healthcare
Glossary

Glossary

Assessment
A process whereby the needs of a person are identified and their impact on daily living and quality of life is evaluated.

Care
Support provided to persons to enable them to live as independently as possible, including anything done to help a person live with ill health, disability, physical frailty or a learning difficulty and to participate as fully as possible in social activities. This encompasses health and social care.

Care Coordinator
A person who coordinates the assessment and care planning process where a person needs complex and/or multiple services to support them. Care coordinators are usually the central point of contact with the person. Regionally, different terms may be used to describe this role.

Care package
A combination of support and services designed to meet a person's assessed needs.

Care plan
A document recording the reason why and what support and services are being provided and the outcome that they seek.

Care planning
A process based on an assessment of a person's need that involves working with the person to identify and agree the level and type of support to meet those needs, and the objectives and potential outcomes that can be achieved.

Care worker
Care workers provide paid support to help people manage the day-to-day activities of living. Support may be of a practical, social care nature or to meet a person's healthcare needs.

Carer
Carers look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is usually unpaid.

Cognition
The higher mental processes of the brain and the mind, including memory, thinking, judgement, calculation, visual spatial skills and so on.

Cognitive impairment
Cognitive impairment applies to disturbances of any of the higher mental processes, many of which can be measured by suitable psychological tests. Cognitive impairment, especially

memory impairment, is the hallmark and often the earliest feature of dementia.

Compliance

The extent to which a patient takes, or does not take, medicines as prescribed.

Concordance

An agreement between a patient and a health professional regarding the provision of care. Concordance and compliance are frequently used interchangeably.

Continuing NHS Healthcare

A complete package of ongoing care arranged and funded solely by the NHS, where it has been assessed that the person's primary need is a health need. It can be provided in any setting. Where a person lives in their own home, it means that the NHS funds all the care that is required to meet their assessed health and social care needs. Such care may be provided both within and outside the person's home, as appropriate to their assessment and care plan. In care homes, it means that the NHS also makes a contract with the care home and pays the full fees for the person's accommodation, board and care.

Contracture

Abnormal, usually permanent, condition of joint flexion and fixation caused by atrophy and shortening of muscle fibres or loss of normal elasticity of skin causing muscle contraction.

Long-term conditions

Those conditions that cannot, at present, be cured, but can be controlled by medication and other therapies.

Mental capacity

The ability to make a decision about a particular matter at the time the decision needs to be made. The legal definition of a person who lacks capacity is set out in section 2 of the Mental Capacity Act as: ‘a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain’.

Multi-disciplinary

Multi-disciplinary refers to when professionals from different disciplines, such as social work, nursing, occupational therapy, work together to address the holistic needs of their patients/clients in order to improve delivery of care and reduce fragmentation.

Multi-disciplinary assessment

Multi-disciplinary assessment is an assessment of a person's needs that has actively involved professionals from different disciplines in collecting and evaluating assessment information.

Multi-disciplinary Team

A team of at least two professionals, usually from both the health and the social care disciplines. It does not refer only to an existing multi-disciplinary team such as an ongoing team based in a hospital ward. It should include those who have an up-to-date knowledge of the person's needs, potential and aspirations.

Near future

Refers to needs that are reasonably considered by the Multi-disciplinary Team to be likely to arise before the next planned review of the person.

Pressure-related injury

Area of damage to the skin or underlying tissue which has occurred as a result of prolonged pressure to that area.

Pressure ulcer

Also known as decubitus ulcer or bed sore. Area of local damage to the skin and underlying tissue due to a combination of pressure, sheer and friction.

Registered nurse

A nurse registered with the Nursing and Midwifery Council. Within the UK all nurses, midwives and specialist community public health nurses must be registered with the Nursing and Midwifery Council and renew their registration every three years to be able to practise.

Rehabilitation

A programme of therapy and re-enablement designed to maximise independence and minimise the effects of disability.

Social care

Social care refers to the wide range of services designed to support people to maintain their independence, enable them to play a fuller part in society, protect them in vulnerable situations and manage complex relationships (*Our health, our care, our say: a new direction for community services*, paragraph 1.29). It is provided by statutory and independent organisations and can be commissioned by Local Authorities on a means-tested basis, in a variety of settings.

Social services

Social services are provided by 22 local authorities in Wales. Personally and in partnership with other agencies, they provide a wide range of care and support for people who are deemed to be in need.

Spasm

A sudden, involuntary contraction of a muscle, a group of muscles, or a hollow organ, or a similarly sudden contraction of an orifice. A spasm is usually accompanied by a sudden burst of pain.

Specialist assessment

An assessment undertaken by a clinician or other professional who specialises in a branch of medicine or care, for example stroke, cardiac care, bereavement counselling.

Decision Support Tool for Continuing NHS Healthcare
Section 4 – Equality Monitoring Form

This need only be completed if a CHC Checklist hasn’t been completed (as this includes an equality monitoring form).

Please provide us with some information about yourself. This will help us to understand whether everyone is receiving fair and equal access to CHC. All the information you provide will be kept completely confidential by the NHS. No identifiable information about you will be passed on to any other bodies, members of the public or press.

Please tick only one box in each category.

1. SEX	
Male	
Female	
Transgender	

2. SEXUAL ORIENTATION

Only answer this question if you are aged **16 years** or over. Which applies to you? (*If ‘Other’, please highlight and write in box provided)

Heterosexual / Straight	Lesbian / Gay Woman	Gay Man	Bisexual	Prefer not to say	*Other

* Any other, write here

3. AGE GROUP –

Which applies to you?

0-15	16-24	25-34	35-44	45-54	55-64	65-74	75-84	85+

4. DISABILITY

<table>
<tr><td colspan="2">Do you have a disability, as defined by the Equality Act 2010?</td><td>The Equality Act defines a person with a disability as someone who 'A physical or mental impairment which has a substantial and long term adverse effect on your ability to carry out normal day to day activities.
https://www.gov.uk/definition-of-disability-under-equality-act-2010</td></tr>
<tr><td>Yes</td><td></td></tr>
<tr><td>No</td><td></td></tr>
</table>

5. ETHNIC GROUP –

Which applies to you? (*If ‘Other’, please highlight and write in box provided)

White		Mixed		Asian *or* Asian British		Black *or* Black British		Chinese or other group	
British		White and Black Caribbean		Indian		Caribbean		Chinese	
Irish		White and Black African		Pakistani		African		Other*	
Other *		White and Asian		Bangladeshi		Other*			
		Other*		Other*					

* Any other, write here

6. RELIGION
Which applies to you? (*If ‘Other’, please highlight and write in box provided) *Christian includes Church of Wales, Catholic, Protestant and all other Christian denominations*

Christian	Buddhist	Hindu	Jewish	Muslim	Sikh

* Any other, write here