



Llywodraeth Cymru
Welsh Government

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Continuing NHS Healthcare The National Framework for Implementation in Wales

June 2014

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Introduction

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.

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. There are around 5,500 people in Wales who receive CHC at an annual cost to the LHBs of approximately £278 million.

CHC is different from 'Funded Nursing Care' provided for people in nursing homes. The provision of NHS Funded Nursing Care derives from Section 49 of the Health and Social Care Act, 2001, which excludes nursing care by a registered nurse from the services which can be provided by local authorities. 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.

The existing arrangements for CHC are set out by the Welsh Government in the 2010 National Framework for Implementation. This stipulates LHBs 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.

In response to a report by the Wales Audit Office Report ¹ and feedback received from a range of stakeholders, Welsh Government undertook a collaborative review of the 2010 Framework, followed by a formal consultation exercise. The revised 2014 Framework has been informed by this feedback.

In addition, over the last twelve months Welsh Ministers have issued interim guidance to clarify and strengthen arrangements relating to eligibility for CHC and financial restitution for backdated (retrospective) claims. These new measures are built into the revised 2014 National Framework for Continuing NHS Healthcare, which strengthens guidance and strategic oversight given to LHBs.

This Framework replaces the previous arrangements set out in the 2010 National Framework for Continuing NHS Healthcare. It also incorporates and replaces the interim guidance.

¹ Implementation of the National Framework for Continuing NHS Healthcare (June 2013)

It is supported through:

- Public information leaflets;
- A national joint training programme;
- an online Complex Care Information & Support site www.cciss.org.uk ;
- structured opportunities for shared learning, including an annual conference and a relaunch of the Complex Care Forum; and,
- a National Performance Framework, to be implemented from the 1st October 2014.

This Framework refers to various legislation, regulations 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.

June 2014

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 result in significant financial costs for them and can lead 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 There must be a clear and transparent rationale to support the decision making process. Professional integrity is vital.

K5 The NHS is responsible for assessing, funding and providing services to meet the needs of its population. Local authorities are responsible for the provision of social services and there may be a charge to the individual for some of these. Individuals may require services from both the NHS and local authority.

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 has produced this 2014 Framework (referred to throughout this document as “the Framework”) for Continuing NHS Healthcare (CHC). It sets out the Welsh Government’s policy for eligibility for CHC, and the responsibilities of NHS organisations and local authorities under the Framework and related matters.
- 1.2 The effective date for implementation of this Framework is 1st October 2014 and it will replace the 2010 ‘Continuing NHS Healthcare: The National Framework for Implementation in Wales’.
- 1.3 This Framework sets out a process for the NHS, working together with local authority 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 comprehensive joint training programme.
- 1.4 The purpose of the Framework is to provide 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 of and provision for care for children and young people is addressed in the Welsh Government’s Children and Young People’s Continuing Care Guidance 2012.

Action

1.6 NHS bodies must:

- confirm to the Welsh Government that the principles and processes in this Framework are used throughout their organisations;
- ensure all relevant staff are fully aware of the procedures for assessing, determining eligibility and the providing CHC services, through participation in the national joint training programme;
- ensure the national information leaflets provided on the Complex Care Information & Support site www.cciss.org.uk are available in a range of formats to individuals in need of care, their families and carers.
- review their current assessment, quality assurance, discharge processes and commissioning arrangements to ensure they comply with this Framework.

1.7 Local authorities should:

- consider how their current practice fits with the responsibilities set out in this Framework and make any necessary changes.

1.8 NHS bodies and local authorities should:

- work together in a partnership approach 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 need to 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.

1.9 The Welsh Government gives a commitment to review the Framework after three years of implementation and to issue additional or interim guidance where this is required.

Note: The NHS Funded Nursing Care in Care Homes Guidance 2004² remains in effect, though will be subject to review.

² WHC 2004 (024)

Governance Arrangements

Strategic Oversight

- 1.10 The effective delivery of Continuing NHS Healthcare 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.
- 1.11 The named Director must have access to the data and management information required to enable them to undertake this role effectively.
- 1.12 Each local authority should have a named link with equivalent organisational status, who will liaise closely with their LHB's CHC director and be responsible for reporting to their scrutiny committee or equivalent.
- 1.13 The named Directors of the Local Health Board and Local Authority should actively engage with the local independent sector provider organisation, to ensure that the views and experiences of providers are included as part of the scrutiny process. These arrangements should comply with any concordant negotiated to replace the Memorandum of Understanding: Securing Strong Partnerships in Care.

Reporting arrangements

- 1.14 The named Director should present, as a minimum, an agreed quarterly performance report to their Board, copied to Welsh Government. The Director should escalate required actions for which the Board will be held to account.
- 1.15 These reports should also be shared with any local partnership board with local authorities. Partnership boards should be monitoring the pressures, activity, expenditure, and outcomes achieved across the health and social care sector.
- 1.16 LHBs are required to utilise the agreed national Performance Framework which can be accessed via the Complex Care Information & Support site www.cciss.org.uk and includes the Self-Assessment Tool developed by the Wales Audit Office (2013).

Organisational Responsibilities

Welsh Government

- 1.17 Welsh Government will work with LHBs to collate a national report and will provide the support mechanisms required to share learning and promote improvement.

Local Health Boards

- 1.18 LHBs have a role in establishing and maintaining governance arrangements for CHC eligibility considerations 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;
 - 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.

- 1.23 Arrangements must be in place to ensure regular reviews are undertaken.

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 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 Complex Care Information & Support Site www.cciss.org.uk.
- 2.4 CHC should not necessarily be viewed as a permanent arrangement. Care provision should be needs-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 balanced against 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 and/or physical and mental health needs. These services are normally provided free of charge.
- 2.6 Local authorities 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. Local authorities must charge for residential care in accordance with the Charging for Residential Care Guidance (CRAG) and they may charge for other care services, including care packages provided in the community, subject to any guidance or regulation by the Welsh Government.

- 2.7 It is the responsibility of the local authority 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 local authority 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 NHS bodies and local authorities 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. Local Health Boards 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

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.

The Duties of the NHS and Local Authorities

2.14 Furthermore, 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”³. 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.

2.15 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.

2.16 Each local authority is under a duty to assess fully any person who appears to it to be in need of community care services⁴. Community care services can include residential accommodation for persons who by reason of age, illness or disability are in need of care and attention which is not otherwise available to them⁵ as well as domiciliary and community-based services enabling people to continue to live in the community.

³ section 3, particularly section 3(1)(e) of the National Health Service (Wales) Act 2006

⁴ National Health Service and Community Care Act 1990, Section 47

⁵ National Assistance Act 1948, Section 21

- 2.17 The local authority, having regard to the result of that assessment, must then decide whether the individual's needs call for the provision of community care services. The local authority must also notify the relevant LHB if, in carrying out the assessment, it becomes apparent that the person has needs which may fall under the National Health Service (Wales) Act 2006, and invite them to assist in the making of the assessment (see National Health Service and Community Care Act 1990 section 47(3)).
- 2.18 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 community care services that may fall within a local authority's responsibilities, it should notify the authority of this and consider inviting it to participate in the assessment process.

Extent of Local Authorities' Powers

- 2.19 Section 21(8) of the National Assistance Act 1948 states that nothing in section 21 authorises or requires a local authority to make any provision that is authorised or required to be provided under the National Health Service (Wales) Act 2006 (formerly the NHS Act 1977). This was considered by the Court of Appeal in *Coughlan* where it was held that a local authority is excluded from providing services if the NHS has, in fact, decided to provide those services.

"[Section 21] should not be regarded as preventing a local authority from providing any health services. The subsection's prohibitive effect is limited to those health services which, in fact, have been authorised or required to be provided under the 1977 Act. Such health services would not therefore include services which the Secretary of State legitimately decided under section 3(1) of the 1977 Act it was not necessary for the NHS to provide."

- 2.20 Local authorities also have the function of providing services under section 29 of the National Assistance Act 1948 (which includes functions under the Chronically Sick and Disabled Persons Act 1970)⁶. Section 29(6)(b) of the National Assistance Act 1948 prohibits local authorities from providing services under section 29 which are "required" to be provided under the National Health Service (Wales) Act 2006 so excludes only those services which must, as a matter of law, be provided under the National Health Service (Wales) Act 2006.
- 2.21 Section 49 of the Health and Social Care Act 2001 prohibits local authorities from providing or arranging for the provision of nursing care by a registered nurse in connection with the provision by them of community care services. "Nursing care by a registered nurse" is defined as "services provided by a registered nurse and involving either the provision of care or the planning, supervision or delegation of the

⁶ Chronically Sick and Disabled Persons Act 1970, Section 2

provision of care other than any services which, having regard to their nature and the circumstances in which they are provided, do not need to be provided by a registered nurse”.

Case Law

- 2.22 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.
- 2.23 The decision of the Court of Appeal in *R v North and East Devon Health Authority ex parte Coughlan* [1999]¹¹ considered the responsibilities of Health Authorities and local authority social service provision.
- 2.24 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.
- 2.25 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.
- 2.26 This case was decided before the enactment of section 49 of the Health and Social Care Act 2001. The key points from this judgment are set out at **Annex 1**.
- 2.27 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.

- 2.28 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. The key points from this judgment are set out at **Annex 1**.

Equality and Human Rights Legislation

- 2.29 The Equality Act 2010 (the 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 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 Act as 'protected characteristics'.
- 2.30 The Act received Royal Assent on 08.04.2010 and came into force from 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 Act, and which became law on 6th April 2011.
- 2.31 Part 3 is based on the principle that people with the protected characteristics defined in the Act should not be discriminated against when using any service provided publicly or privately, whether that service is for payment or not.
- 2.32 Public authorities also have a duty under the Human Rights Act 1998 (HRA) to act compatibly with rights under the European Convention for the Protection of Fundamental Rights and Freedoms (the Convention). It is unlawful for public authorities to breach Convention rights in any area of their activity, including service provision or employment and work-related activities.
- 2.33 Human rights issues can arise in relation to the exercise of any public function or the provision of any public service where a person's dignity, personal freedom or other Convention right is at stake. If a public authority or any other body discriminates when carrying out a function of a public nature, 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.

2.34 LHBs and Local Authorities have statutory duties to have due regard to the need to promote equality and human rights which should be integral to the way in which health and social care is prioritised and delivered, allowing 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 local authorities 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 the NHS and local authorities should work together with individuals to identify and overcome any barriers to economic and social participation within society.

Consent and Capacity

2.35 As with any examination or treatment, the individual's informed consent should be obtained and documented before the process of determining eligibility for CHC begins and before any decisions are made. It is acceptable to gain the individual's consent for the whole assessment and care planning process at the outset, rather than require repeated consent for the individual components of the assessment. However, it must be made clear to the individual or their representative that they that they are consenting to the whole process and that they may withdraw consent at any point, if they so wish. The consistent application of the 'no decision about me without me' principle will ensure that subsequent implied consent is re-affirmed throughout the process.

2.36 Many individuals likely to be offered a CHC assessment have significant health care needs. Their ability to participate in the consenting process can often be impaired by their mental capacity or physical ill-health that affects their ability to communicate their decision.

2.37 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.
- **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.

- 2.38 Because an individual may have significant difficulty in expressing their views it does not in itself mean that they lack capacity. Appropriate support and adjustments should be made available in compliance with the Mental Capacity Act 2005 and with disability discrimination legislation.
- 2.39 If an individual lacks the mental capacity either to consent or refuse an assessment, a 'best interests' decision should be taken as to whether or not to proceed with the assessment for eligibility for CHC. This decision must be recorded. Those making this decision 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 on behalf of a person who lacks capacity, unless they have a valid and applicable Lasting Power of Attorney (LPA- Welfare) or they have been appointed a Welfare Deputy by the Court of Protection.
- 2.40 Where a 'best interests' decision needs to be made, the LHB must consult with any relevant third party who has a genuine interest in the individual's welfare. This will normally include family and advocates.

Valid Voluntary Consent

- 2.41 To be valid, consent must be given voluntarily and freely, without pressure or undue influence being exerted on the individual either to accept or refuse the assessment. Such pressure can come from partners or family members as well as health or social care professionals. Professionals should be alert to this possibility and, where appropriate, should arrange to see the individual on their own to establish that the decision is truly theirs.

Where there are concerns about undue influence these should be documented on the consent form.

2.42 For consent to be valid, the individual must:

- have capacity to agree to the assessment;
- have received sufficient information to take an informed decision to proceed with the assessment ;
- give consent voluntarily and not under any form of duress or undue influence from professionals or family members; and,
- in practice be able to communicate their decision.

2.43 When an individual has capacity, then only they can give consent – no-one else can give it on their behalf.

2.44 When an individual gives valid consent to the assessment that consent remains valid during the current assessment process unless it is withdrawn by them. If a further assessment is to be carried out in the future, consent will need to be obtained on that occasion.

Refusal to Consent to the CHC Assessment (see Figure 1)

2.45 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. LHBs should take into account the Guidance 'Patient Consent to Examination and Treatment'⁷. Although focussed on examination and treatment issues, the principles of the guidance should be taken into account when consenting to an assessment.

2.46 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.

2.47 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 NHS or local authority to provide appropriate services.

2.48 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 local authority sharing responsibility and, as a result, the individual may be charged for a contribution to the local authority arranged

⁷ WHC (2008) 10 'Patient Consent to Examination and Treatment' (revised Guidance)

services. The individual must be provided with a detailed care plan setting out who will provide which services and what they may be charged.

- 2.49 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.
- 2.50 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.
- 2.51 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.
- 2.52 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 local authority, taking into account each organisation's statutory legal powers and duties. Where necessary, each organisation should seek legal advice.
- 2.53 Although refusal of consent only occurs in a minority of cases, LHBs and local authorities 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 organisations responsibilities and the appropriate way forward.

Advocacy

- 2.54 The Independent Mental Capacity Advocate (IMCA) is a statutory service, whose purpose is to help vulnerable individuals who lack capacity and who are facing important decisions made by the NHS and local authorities. This may include serious medical treatment or change of residence, for example, moving into a care home. LHBs and local authorities have a duty under the 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) for consultation on their behalf.
- 2.55 The Mental Health (Wales) Measure 2010 expanded the provision of Independent Mental Health Advocate(IMHA) services to include more patients detained under the Mental Health Act 1983 and those receiving

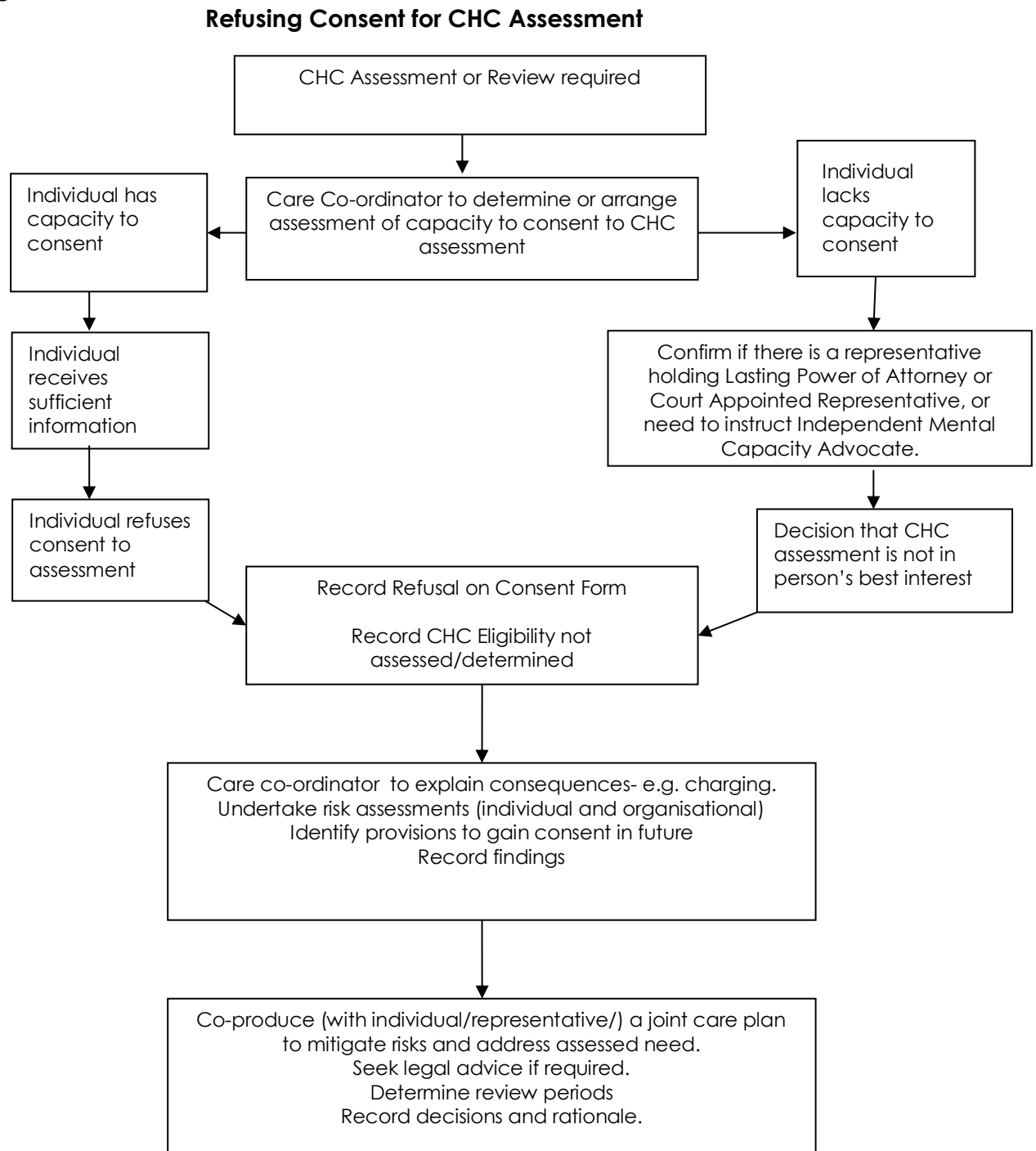
treatment for their mental disorder in a hospital setting anywhere in Wales. IMHAs provide statutory advocacy and patients will be offered this support in all decisions regarding their care and treatment.

- 2.56 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 local authorities should ensure that individuals are made aware of local advocacy 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 local authorities) to act as an advocate on their behalf.

Carers

- 2.57 Where informal carers are being asked, or are offering, to provide support, LHBs and local authorities should bear in mind that a carer who provides a substantial care on a regular basis has a right to have their needs as a carer assessed. LHBs and local authorities must inform carers of this right in accordance with what may be provided under community care legislation, the Children Act 1989 or the Carers and Disabled Children's Act 2000, as amended by the Carers (Equal Opportunities) Act 2004. It should never be assumed that the carer is able or willing to continue to assume the role. Which legislative basis is used will depend on individual circumstances and what is in the best interests of the service user and carer.
- 2.58 Arrangements for support for carers will be subject to further development and change when the Social Services and Well-being (Wales) Act is implemented from 2016. In particular, 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 will be triggered where it appears that the carer may or will have needs as part of their caring role);
 - have a new 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.

Figure 1



***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**

Annex 1: Legal Judgements

The Coughlan judgment

(R v. North and East Devon Health Authority ex parte Pamela Coughlan)

A1.1 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.

A1.2 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 judgement 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.

4. 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
5. The services that can appropriately be treated as responsibilities of a local authority under section 21 may evolve with the changing standards of society
6. 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
7. 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
8. 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)
9. 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)

- A1.3 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.
- A1.4 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.

- A1.5 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.

Section 3: Assessment & Eligibility

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 those underpinning the Integrated Assessment, Planning and Review Arrangements for Older People – Guidance for Professionals in supporting the Health, Care and Wellbeing of Older People; aged 65+), the Unified Assessment Process for other users groups and the Framework for the Delivery of Services for Older People with Complex Needs.

Principle 1: People first.

- 3.3 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 Continuing NHS Healthcare funding; they should 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 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.

- 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 individuals 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 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 longer-term care planning/commissioning 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 and costly. It can result in unnecessary changes 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.
- 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, 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 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.
- 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 'All Wales Electronic and Assistive Technology Service'.

Key Roles and Responsibilities

In implementing the principles detailed above, all of those involved have key roles and responsibilities to play. These include:

The person whose needs are being assessed.

- 3.17 It is essential that the individual whose needs are being assessed is central to the assessment and care planning process. They are the experts 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

- 3.18 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 multidisciplinary 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.

Care Co-ordinator/Lead Professional

- 3.19 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.
- 3.20 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.
- 3.21 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.

- 3.22 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.
- 3.23 The 'Care Co-ordinator' role is also referred to in some documents e.g. the Integrated Assessment Framework ⁸ as the Lead Professional. We use the term 'Care Co-ordinator' in this document but it reads across to the Lead Professional function.
- 3.24 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.**

Multidisciplinary team members

- 3.25 Multidisciplinary team 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 NHS Continuing Health Care, and for making recommendations as to the setting and skill set required to deliver the co-produced care plan.
- 3.26 Members of the multi-disciplinary team are responsible for the integrity of their assessments, professional advice and decisions which should be underpinned with a clear rationale. Members of the multi-disciplinary team 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.

⁸ '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

Commissioning team

- 3.27 Each Local Health Board 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 Complex Care Information & Support site www.cciss.org.uk). It will have the responsibility for identifying and addressing gaps in local service provision.
- 3.28 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 local authorities, 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.

The Assessment Process for Longer-Term Care and Support

Right Process

- 3.29 Continuing NHS Healthcare (CHC) is just one part of a continuum of services that local authorities and NHS bodies 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.
- 3.30 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.
- 3.31 Rather the health and social care practitioners involved are expected to comply with existing Welsh Government and practice guidance on assessment and care planning including:
- 'Integrated Assessment, Planning and Review Arrangements for Older People – Guidance for Professionals in supporting the Health, Care and Wellbeing of Older People; aged 65+)'.
 - The Unified Assessment Process for other Adult User groups.
 - 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).

- 3.32 Individuals should refer to this guidance directly and it can be accessed via the Complex Care Information & Support site www.cciss.org.uk. There is no attempt to replicate in this framework.
- 3.33 A summary overview of the assessment and CHC eligibility decision-making process is provided as **Annex 3**.

Using a 'Trigger Tool' prior to assessment for CHC eligibility

- 3.34 The use of a screening tool or checklist is not mandated in this Framework. It is acknowledged however, that there may be specific circumstances where such a tool may be useful. For example, care home residents whose condition has changed and earlier than planned review may be required, or to provide a structured rationale where the Multidisciplinary Team (MDT) believes a complex care package is clearly not required.
- 3.35 In those circumstances where a checklist is employed, the NHS CHC Checklist developed by the Department of Health in England should be used in order to ensure that a consistent approach adopted <https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care> .
- 3.36 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.
- 3.37 When used in Wales it should be completed by at least two practitioners, including a representative of the Local Authority. When completing the Checklist, practitioners must be mindful not to make premature assumptions regarding reablement and comprehensive assessment outcomes.

Right Place

- 3.38 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. 'Home first' should be the default position and rehabilitation/reablement to support the retention of as much independence as possible, must always be considered.

- 3.39 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. Options to be considered include step-down/intermediate assessment facilities in the community, or the person's own home with intensive short-term support.
- 3.40 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 Guidance⁹.
- 3.41 Using an 'adopt or justify' approach, in circumstances where it is deemed clinically inappropriate to provide such a period of 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.

Right People.

- 3.42 The assessment process should draw on those who have direct knowledge of the individual and their needs.
- 3.43 When it becomes apparent through discussion with the individual, their carers and the 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.
- 3.44 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.
- 3.45 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.
- 3.46 A detailed description of the role is attached as **Annex 3**.
- 3.47 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

⁹ NAFWC 17/2005 Hospital Discharge Planning Guidance

needs such as sensory loss. Language need and preference must be recorded.

- 3.48 It is recognised that in Wales 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.
- 3.49 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.
- 3.50 Public Information Leaflets to support this dialogue are available on the Complex Care Information & Support site www.cciss.org.uk . Individuals being assessed for CHC, and their carers, should routinely be offered access independent advocacy services.
- 3.51 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.
- 3.52 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.
- 3.53 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.
- 3.54 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.
- 3.55 Whilst the benefit of multi-disciplinary team 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. The consideration of eligibility, using the Decision Support Tool, must however be undertaken in a formal MDT meeting to which the individual and if they wish, their family/carer/advocate, are invited.
- 3.56 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.

Determining Primary Health Need

Sole Criterion for Eligibility

- 3.57 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.

Determination of a Primary Health Need

- 3.58 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.

- 3.59 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.
- 3.60 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.
- 3.61 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.
- 3.62 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.
- 3.63 The MDT should also advise commissioners 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)

- 3.64 The Decision Support Tool 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.
- 3.65 The multidisciplinary 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.
- 3.66 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.
- 3.67 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 (in Wales) to only complete:

- the DST Summary Sheet (matrix),
- the summary record of the MDT decision on eligibility and the rationale,
- the Equality Monitoring Form.

The focus must be on a rounded and holistic assessment of the individual rather than DST scores.

- 3.68 The final discussion and determination of CHC eligibility must be undertaken in a formal MDT meeting, to which the individual and/or their carers must be invited.
- 3.69 The individuals and/or carer(s) should be encouraged and supported to attend. 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.cciss.org.uk). The Chair of the MDT is responsible for ensuring that they know what to expect, are actively included in the discussion and understand the rationale for the decision made. The Care Co-ordinator should make contact within 48 hours 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.

Quality Assurance

- 3.70 It is the responsibility of the MDT to undertake robust needs assessment, to provide the LHB with consistent expert advice on CHC eligibility, to develop the care plan to meet the individual's needs and to make recommendations regarding the setting and skill set required to most effectively deliver the care plan.
- 3.71 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 to take the responsive action required to support service improvement.
- 3.72 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.
- 3.73 Only in exceptional circumstances and for clearly articulated reasons should the LHB not accept the multidisciplinary team's expert advice on CHC eligibility.
- 3.74 LHBs must have robust quality assurance mechanisms in place to ensure consistency of decision making. This should 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.
- 3.75 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.

TIMESCALES AND COMMENCEMENT OF CHC FUNDING

- 3.76 An individual may require services from the NHS and/or local authority. Both the NHS and local authority therefore have responsibilities to ensure that assessment of eligibility for and provision of, CHC takes place in a timely and consistent fashion. The consideration for CHC must always be made first.
- 3.77 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.

- 3.78 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 the point of which it is clear that the individual has a primary health need (see 'Fast Track Assessments').
- 3.79 In exceptional circumstances time scales 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, reabled, during this period. The Care Co-ordinator should ensure that time scales, decisions and rationales relating to eligibility are transparent from the outset for individuals, carers, family and staff.
- 3.80 Any exceptions should be monitored locally as part of the performance framework and actioned as appropriate.
- 3.81 It is the responsibility of the MDT to undertake robust assessment and to provide the LHB with expert advice as to whether the individual has a primary health need. It is the responsibility of the LHB to ensure consistency and fairness of the decision-making process; it should only be in exceptional circumstances that the LHB does not accept the MDT's advice. 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.
- 3.82 Such reimbursement would normally commence from the date on which the MDT met and made its determination of eligibility. However the MDT should advise the Health Board 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.
- 3.83 The timescale for the provision of care following assessment can vary between the remainder of an individual's life and episodes of care; 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.

FAST TRACK ASSESSMENTS

- 3.84 Occasionally, individuals with a rapidly deteriorating condition who may be entering a terminal phase will require 'fast tracking' for immediate provision of CHC so that they 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.
- 3.85 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.
- 3.86 Fast track assessment 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.
- 3.87 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 NHS Co-ordinator.
- 3.88 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.

- 3.89 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
- 3.90 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.
- 3.91 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 policy¹⁰.

Links to Other Policies and Specialist Areas of Practice

Links to Mental Health Act 1983 After Care Services

- 3.92 Under section 117 of the Mental Health Act 1983 (the 1983 Act) health and social services authorities have a duty to provide 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.
- 3.93 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 yearly. Detailed guidance regarding Care and Treatment planning is given in the Code of Practice to Parts 2 and 3 of the Measure.
- 3.94 Section 117 is a free-standing joint duty. Local Health Boards 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

¹⁰ Together for Health: End of Life Delivery Plan 2013

additional guidance on this issue, but focusses on the interface between section 117 and eligibility for Continuing NHS Healthcare.

- 3.95 Responsibility for the provision of section 117 lies jointly with LAs and the NHS. Where a patient is eligible for services under section 117 these should be provided jointly under section 117 and not under CHC.
- 3.96 There are no powers to charge for services provided under section 117 of the 1983 Act, regardless of whether those services are provided by the NHS or local authorities. 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
- 3.97 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 e.g. following a stroke, which may then trigger the need to consider NHS continuing healthcare.
- 3.98 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 result, have the services required to meet their total care needs funded by the NHS, but this does not necessarily remove the joint duty under section 117. The section 117 joint duty remains unless a joint assessment and agreement by both the LA and the LHB determines that those arrangements are no longer needed.
- 3.99 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.
- 3.100 Where an individual is to be discharged from section 117, eligibility for CHC or funded nursing care will need to be considered where the transition assessment and plan indicate that these may be required. Information should be provided to the individual or their representative in regards to the effect that discharge from section 117 arrangements may have on their finances and/or welfare benefits.

Example local section 117 local policies, section 117 pack and case scenarios can be accessed via the Complex Care Information & Support site www.cciss.org.uk .

Deprivation of Liberty Safeguards

- 3.101 The Mental Capacity Act 2005 contains provisions that apply to a person who lacks capacity and who, in their own best interests, needs to be deprived of their liberty in a care home or hospital, in order for them to receive the necessary care or treatment. The fact that a person who lacks capacity needs to be deprived of his or her liberty in these circumstances does not affect the consideration of whether that person is eligible for CHC.

The Transition from Child and Young Person's to Adult Services

- 3.102 The 2014 Framework should be used to determine eligibility for NHS Continuing Health Care 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). Both of these documents can be accessed via the Complex Care Information & Support site www.cciss.org.uk.
- 3.103 The legislation and the respective responsibilities of the NHS, social services and other services are different in child and adult services. The term 'continuing care' also has different meanings in child 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 Local Authority will retain the responsibility for meeting any ongoing educational needs.
- 3.104 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 Complex Care Information & Support site www.cciss.org.uk.
- 3.105 While service provision and the meaning of the term Continuing Care 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.

- 3.106 Transition is an area that can cause anxiety for children, their parents and carers. When some young people 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. Each Local Health Board must draw up a robust local transition policy with its partner agencies. A template document is provided in the Complex Care Information & Support site www.cciss.org.uk .
- 3.107 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 children's services into adult services.
- 3.102 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's presenting needs.
- 3.103 Planning for transition to adult CHC services must commence when the young person is aged 14. 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 .
- 3.104 Support during transition should be provided from 14 years 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.
- 3.105 At the age of 17, eligibility for adult CHC should be determined in principle by the relevant LHB, bearing in mind that, in complex cases, needs can change in the course of a year. Local multidisciplinary 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.
- 3.106 Even if a young person is not entitled to adult CHC, they may have certain health needs that are 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 appropriate arrangements are in place for services that meet these needs to be commissioned or provided. The focus should always be mutually agreed and take in to account the individual preferences.

- 3.107 A key aim is to ensure that a consistent package of support is provided. 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 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.
- 3.108 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.
- 3.109 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 Carers Measure.
- 3.110 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 budget arrangements to ensure that the right care is provided at the right time.
- 3.111 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 over-whelmed by the numbers of people involved. Care co-ordination, designated lead professional, and effective communication will do much to mitigate that risk.
- 3.112 In order to continue to provide effective support to the increasing numbers of children 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.

3.113 Compliance with the guidance on transition will be assessed via the Performance Management Framework.

Applying the CHC Framework to Adults with a Learning Disability

3.114 The Statement on Policy and Practice for adults with a learning disability announced in March 2007, sets out the Welsh Government's values and vision underpinning support for individuals with learning disabilities. The 1983 All Wales Mental Handicap Strategy and 1994 Revised Guidance required local authorities to develop strategic planning in partnership with local stakeholders.

3.115 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 principles¹¹:

- Community Presence
- Relationships & Partnerships
- Choice
- Competence
- Respect & Status
- Individuality & Continuity

3.116 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 but disruption to the individual should be minimised as far as possible.

3.117 The meaning of 'Primary Health Need', the limits of local authority responsibility and the primary health need test are not repeated here.

3.118 The principles and process set out in this Framework should be implemented for all adults who require assessment for CHC, irrespective of their client group/diagnosis. The assessment focuses on the individual's needs, not on their diagnosis. If someone has a primary health need they must be deemed eligible for CHC.

3.119 In all cases eligibility for CHC should be informed by good quality multi-disciplinary assessment. It will be important to involve all

¹¹ O'Brien, J. (1984) A guide to personal futures planning. Lithonia, GA: Responsive Systems Associates.

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'.

- 3.120 The assessment process must be person-centred and family members/carers supported to be fully and appropriately involved.
- 3.121 It is emphasised that the Decision Support Tool (DST) must be used in context. It cannot and should not replace professional judgement on whether the totality of an individual's needs demonstrate the four key characteristics of a primary health need. It simply supports multidisciplinary teams (MDTs) to demonstrate that they have implemented a rational and consistent approach to their advice.
- 3.122 The reasons given for a decision on eligibility should not be based on the use or not of NHS employed staff to provide care; the need for/presence of "specialist staff" in care delivery or any other input related (rather than needs-related) rationale.
- 3.123 NHS and social care service providers have a responsibility to ensure that their staff have the inclusive skills required to assess and support this client group. Access to care should not be restricted to specialist learning disability services.
- 3.124 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.
- 3.125 Where an individual is eligible for CHC, Local Health Boards have responsibility to ensure that effective case management is commissioned. Consideration should be given as to who is best placed to provide this function, and clear responsibilities agreed. Amongst other options it may be appropriate to secure this from the local authority who may have previous knowledge of the individual concerned or have staff with particular skills and experience to undertake this function on behalf of the LHB.

Entitlement to other NHS Funded Care

- 3.126 Those in receipt of CHC continue to be entitled to access to the full range of primary, community, secondary and other health care services regardless on care setting.
- 3.127 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 4).

Community Equipment

- 3.128 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.
- 3.129 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. A draft protocol on the responsibilities of nursing homes, residential care homes and joint equipment partnerships will be published for consultation later this year.
- 3.130 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.
- 3.131 LHBs should ensure that there is clarity about which of the above arrangements is applicable in each individual case.

Annex 2: The Role Of The Care Co-Ordinator In Assessment For Longer-Term Care And CHC Eligibility.

The 'Care Co-ordinator' role is also referred to in some documents e.g. the Integrated Assessment Framework¹², as the Lead Professional. We use the term 'Care Co-ordinator' in this document but it reads across to the Lead Professional function.

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?

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).

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?

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.

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.

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.

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.

¹² '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

Ideally, the Care Co-ordinator should follow the patient wherever their location may be during the assessment process 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?

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.

They must ensure that the individual and/or their representative is kept informed of the process and fully involved in discussions about their care.

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 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.

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					
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.)				1 week max.	2 weeks
PROCESS	Comprehensive assessment for longer-term care needs triggered.	Deliver rehabilitation/reablement programme (unless clinically contra-indicated)		Complete The quality assurance process	
	Identify the Care Co-ordinator/Lead Professional			Collate co-produced comprehensive assessment.	
	Obtain valid consent to comprehensive assessment.			Arrange the MDT meeting at which CHC eligibility will be considered.	
	Transfer individual (if required) to the most appropriate environment for assessment.			At the meeting, review the comprehensive assessment and determine whether the individual has a primary health need.	
				Ensure the individual and/or their representatives have the information and support they need to fully participate.	
				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.	

Annex 4: Example Standard Assessment & Eligibility Process Checklist

	Care Co-ordinator/Lead Professional identified. Name: Contact details: Individual/family informed		
	Most appropriate place for assessment agreed. Rationale/justification required if assessment takes place in acute hospital environment.		
	Transfer completed.		
	Rehabilitation/reablement programme commenced. Date:		
	Assessment process explained to individual and their family/carer(s)		
	Preferred language for assessment identified. Mechanisms in place to accommodate language preference e.g. Welsh speakers in MDT.		
	Advocacy offered		
	CHC Public Information Leaflet provided and discussed		
	Appropriate and proportionate MDT input determined: (tick as appropriate) • The individual • Nominated family member as key contact or other unpaid carer • Advocate • Specialist and/or community-based practitioner who has regular contact • Existing service provider(s) e.g. care home, domiciliary care agency, voluntary sector service • Social worker • Occupational therapist • Physiotherapist • Dietician		

	• Speech and language therapist • Housing support • Benefits advice • Other		
	Assessments completed and collated		
	Formal CHC eligibility meeting arranged. Date: Venue:		
	Individual and /or carer or advocate prepared for meeting Leaflet provided.		
	CHC eligibility determined by MDT		
	Outcome and rationale clearly recorded and communicated to individual and/or carer or advocate		
	Individual/representative contact within 2 working days to discuss and answer questions		
	MDT eligibility decision confirmed by LHB and LA. Date:		
	Referred for Peer Review?		
	Dispute/Appeal/Complaints procedure required?		
	Care package agreed Confirmed with individual/representative: Verbally: In writing: 'What Receiving CHC Funded Services Means for You' leaflet provided		
	Transfer arranged if appropriate Date of commencement of CHC care package:		
	Date of first review:		

Section 4: Service Provision and Review

Care Provision and Monitoring

- 4.1 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. Partners may use formal partnerships with pooled funding arrangements to underpin their integrated approach to commissioning. The pooled budget may include funds to cover local authority Funded Nursing Care and CHC commitments.
- 4.2 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 NHS Continuing Health Care 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.
- 4.3 Support for carers is a health and social care responsibility and must be considered and provided. This includes:
- The provision of appropriate information and advice;
 - Active engagement with and involvement of carers when making decisions about provision of services to or for carers or the person cared for;
 - The duty to consult with carers with regard to the planning, commissioning and delivery of local services that affect carers or the individuals they look after. This extends to individual care plans;
 - The right to a Carers Assessment.
- 4.4 The UAP and Integrated Assessment Framework provide guidance on the arrangements for ongoing monitoring and management of care for adults. In particular it:

- Emphasises the importance of monitoring and review of both needs and effectiveness of 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

- 4.5 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.
- 4.6 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 local authority's 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.
- 4.7 Decisions on 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.
- 4.8 In order to support prompt arrangements for service delivery, LHBs should consider having a single CHC budget which sits across specialities and a single commissioning panel/team which brings together the appropriate expertise within its membership. The single

budget can still have budget lines which relate to specific user groups. This should prove helpful if partners decide to pool budgets at some stage.

- 4.9 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. LHBs can delegate their functions in terms of commissioning to local authorities and vice versa, under agreed formal partnership arrangements¹³. The LHB and its partners may wish to consider this option to develop a coherent integrated approach to securing services with one approach to negotiating contracts, service specifications, fee negotiations and quality assurance. Both agencies retain their statutory functions and they continue to exercise control through a partnership board.
- 4.10 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.
- 4.11 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).
- 4.12 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.
- 4.13 Clear contract arrangements must be established with the service provider. The contract must be outcomes-focussed and include arrangements for regular review.
- 4.14 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.
- 4.15 LHBs will have in place service specifications and contracts for registered settings which cover health and social care and take into account relevant regulations, National Minimum Standards, Standards

¹³ S33 of The NHS Act (Wales) 2006

for Health Services and other relevant guidance and best practice. LHBs will be expected to utilise the national CHC service specification, terms and conditions and contract monitoring proforma, which will be made available via the Complex Care Information & Support site www.cciss.org.uk . This should link to the work of local government on the development of model terms and conditions for contracts/ specifications for residential and nursing homes.

- 4.16 Where individuals eligible for CHC are cared for in a care home, escalating concerns will be managed in accordance with the Welsh Governments '*Escalating Concerns With, and Closures of, Care Homes Providing Services for Adults*' Guidance (May 2009). This statutory guidance addresses the management of escalating concerns with, and closures of, care homes that are registered with the Care and Social Services Inspectorate Wales (CSSIW) to provide services to adults, including those providing nursing care. It is issued under section 7 of the Local Authority Social Services Act 1970 and sections 12 and 19 of the National Health Service (Wales) Act 2006.
- 4.17 In accordance with the Welsh Governments '*Escalating Concerns With, and Closures of, Care Homes Providing Services for Adults*' Guidance, LHB's and social care agencies will 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.
- 4.18 LHBs should develop operational procedures to ensure its responsibility for commissioned services are effectively secured and monitored where care is provided by external agencies.
- 4.19 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.
- 4.20 The individual should be advised that Social Security and other welfare benefits available to support the person's living costs may be affected by eligibility for CHC, and should be signposted to appropriate advice.
- 4.21 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).
- 4.22 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.

- 4.23 LHBs and local authorities 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

- 4.24 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.
- 4.25 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.
- 4.26 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.
- 4.27 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.

- 4.28 Where a provider receives a request for privately funded additional services from an individual who is funded by NHS continuing healthcare they should refer the matter to the LHB for consideration.
- 4.29 '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 Local Health Board is responsible
- 4.30 Any decision to purchase additional private services must be borne purely through personal choice and not through a lack of appropriate NHS or Local Authority 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 vulnerable individuals are safeguarded against 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.
- 4.31 An example where an individual may choose to purchase private services would be someone 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. Another example would be where 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 chose 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.
- 4.32 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

- 4.33 As stated above, the funding provided by LHBs in NHS continuing healthcare 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.
- 4.34 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 in that locality.
- 4.35 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.
- 4.36 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 All Wales Policy for Sustainable Care Planning.
- 4.37 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.

- 4.38 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 Local Health Board 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.
- 4.39 "Topping up" is legally permissible under legislation governing Local Authority Social Care but it is not permissible under NHS legislation. In

such situations, Local Health Boards 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.

- 4.40 There may also be circumstances where an individual in an existing out of area placement becomes entitled to NHS continuing healthcare 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 Local Health Board where the placement is located.
- 4.41 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.
- 4.42 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 them funding an existing higher cost placement or services that they have inherited responsibility for, 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.
- 4.43 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.
- 4.44 Where an individual wishes to dispute a decision not to pay for higher-cost accommodation, they should do this via the NHS complaints process. 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.
- 4.45 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.

Direct Payments¹⁴ and Continuing NHS Health Care

- 4.46 As a matter 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.
- 4.47 It is currently unlawful for Direct Payments to be used to purchase health care which the NHS is responsible for providing. Direct Payments can only be used for social care provision.
- 4.48 Where an individual whose care was arranged via Direct Payments becomes eligible for Continuing Health Care 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.
- 4.49 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.
- 4.50 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 2. 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.

¹⁴ Direct Payments Guidance: Community Care, Services for Carers & Children's services (Direct Payments) (Wales) Guidance 2011.

Where a person is not eligible for CHC

- 4.51 Where it has been determined that a person is not eligible for CHC and an alternative package of care is required (e.g. NHS Funded Nursing Care 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.
- 4.52 This care plan must not require a local authority 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.
- 4.53 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.
- 4.54 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.
- 4.55 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

- 4.56 Increasing numbers of people with complex care needs are being supported in the community. If services are to be truly needs (not diagnosis) -led, citizen focussed and supporting independence, then it is logical that individuals will be supported for longer at home with joint packages of care, where this is sustainable.
- 4.57 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. 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 local authority to agree their respective responsibilities in joint care packages.

Joint funding in care home placements.

- 4.58 Where an individual is not eligible for CHC but has health needs which are different from, or additional to, those supported by NHS Funded Nursing Care, 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.
- 4.59 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 Funded Nursing Care rate and what can be reasonably expected for a local authority to commission. 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.
- 4.60 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.
- 4.61 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.

- 4.62 More, and increasingly complex, packages of care are being delivered in an individual's own home. Where an individual is not eligible for NHS CHC, a comprehensive joint health and social care package must be developed to meet their assessed need. This must be detailed in a clear interagency care plan, with a named care co-ordinator/lead professional, which is jointly owned by commissioners, providers and the individual and/or their representative.
- 4.63 According to each local authority's 'Fair Access to Care' eligibility criteria, they will be responsible for providing such social care, including personal care, as can lawfully be provided. See CHC Toolkit for public information leaflet.
- 4.64 The joint funding arrangements will be determined locally and in accordance with the needs 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.
- 4.65 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 what the individual will be responsible for.

Reviews

- 4.66 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.
- 4.67 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.
- 4.68 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. Where there is an obvious deterioration in circumstances, reviews should also be held within 2 weeks and acted upon appropriately.

- 4.69 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.
- 4.70 Review timescales should be identified and communicated to the individual and their relatives verbally and in writing. For those receiving secondary mental health 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.
- 4.71 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.
- 4.72 If the local authority is also responsible for any part of the care, both the LHB and the local authority will have a requirement to review needs and the service provided. 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.
- 4.73 Individuals who are in receipt of Funded Nursing Care in a care home must also be reviewed on an at least annual basis. 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 providers may find it helpful to use the Department of Health Checklist themselves and alert the LHB when an assessment for CHC eligibility is required.
- 4.74 When reviewing the need for NHS Funded Nursing Care, potential eligibility for CHC must always be considered and a full assessment should be carried out, where necessary.
- 4.75 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, describe who was involved, those individuals not involved and reasons why, location and method of review and issues that the individual (or carer/advocate) raised.
- 4.76 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.

- 4.77 The outcome of a review will determine whether the individual's needs have changed, which then determines whether the package of care needs to be revised or the funding responsibilities altered. 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.
- 4.78 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.
- 4.79 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.
- 4.80 The CHC Independent Review Panel (see Section 5) 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.
- 4.81 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.
- 4.82 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.
- 4.83 Neither the LHB nor the local authority 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. 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 5) should be invoked and current funding arrangements should remain in place until the dispute has been resolved.

Section 5: Disputes and Appeals

Formal Challenges to Eligibility Decisions between Organisations

- 5.1 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.
- 5.2 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 manager and access peer review from within, or outside of, their LHB.
- 5.3 In order to assess the consistency of CHC eligibility decision making and to support continuous service improvement across Wales, LHBs are expected to participate in an annual peer review or external audit exercise which will be co-ordinated by Welsh Government and supported with materials on the Complex Care Information & Support site www.cciss.org.uk.
- 5.4 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. LHBs and local authorities 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.
- 5.5 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 local authorities in different geographical areas, the relevant NHS body and local authority 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.
- 5.6 All stages of disputes procedures will normally be completed within two weeks. All stages will be appropriately documented.

An example disputes process can be accessed via the Complex Care Information & Support site www.cciss.org.uk.

Challenges to Eligibility Decisions from Individuals

- 5.7 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.
- 5.8 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.
- 5.9 LHBs should deal promptly with any request to review decisions about eligibility for either CHC or NHS Funded Nursing Care. A clear and written response should be given including the individual's rights to complain under the NHS Complaints Procedure.
- 5.10 Each LHB should agree local review processes, including timescales, which is available publicly. These local review processes should set out the stages involved in dealing with any requests for a review.
- 5.11 Once local procedures have been exhausted, the case should be referred to the Independent Review Panel. (See below).
- 5.12 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.
- 5.13 The individual's rights under the existing NHS Complaints procedures 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.

Appeals and Complaints

- 5.14 Local Health Boards are accountable for ensuring that the processes are place and that their staff have the skills and resources required to determine CHC eligibility correctly first time.
- 5.15 NHS organisations 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.

5.16 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
- The application of the primary health need consideration.

5.17 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.

Independent Review Panel

5.18 The Independent Review Panel (IPR) procedure (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 approach) has not been correctly applied in their case, or that appropriate procedures have not been followed.

5.19 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.

5.20 If the individual or their representative has significant additional information to present or exceptional circumstances apply again, there should be recourse to the IRP process.

5.21 Before taking a decision the LHB will seek the advice of the chairman 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.

5.22 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 continuing NHS healthcare.

5.23 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 on NHS Funded Nursing Care (NHS FNC). See www.cciss.org.uk for a template policy.

- 5.24 When reviewing the need for NHS FNC, potential eligibility for CHC should always be considered and a full assessment carried out where necessary.
- 5.25 LHBs must ensure that arrangements are in place for:
- the establishment and operation of independent panels (see Annex 5)
 - access to independent clinical advice, taking into account the range of medical, nursing and therapy needs in each case. Advisors 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.
- 5.26 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.

Promoting Consistency in the operation of Independent Review Panels

- 5.27 Local Health Boards 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.
- 5.28 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 Independent Review Panel member should be reflected in their employing organisations via their job description and personal objectives.
- 5.29 The Panel's deliberations must be properly recorded and communicated, with a clear rationale provided for their decision. A template format is available via www.cciss.org.uk.

Complaints

- 5.30 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'.
- 5.31 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 Local Health Board. Following the implementation of the Care Standards Act in April 2002 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 and Social Services Inspectorate for Wales (CSSIW) 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 the protection of vulnerable adults.
- 5.32 It is good practice for the NHS and local authorities 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. The regulations relating to Partnership Agreements also allow for a joint approach to complaints procedures. Further information is contained in the NHS Bodies and Local Authorities Partnership Arrangements (Wales) Regulations 2000.
- 5.33 Information on all relevant complaints procedures should be available in all service provision settings. The need for advocacy should be considered where appropriate.
- 5.34 Individuals who are dissatisfied with the way in which the NHS, a local authority or the CSSIW investigates their complaint may complain to the Public Services Ombudsman 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.
- 5.35 Further information on the NHS complaints procedure is contained in: Putting Things Right: raising a concern about the NHS (Welsh Assembly Government, 2011). The procedure can also be accessed via www.cciss.org.uk

ANNEX 5: Setting Up A 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, representative of a LHB and 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 are encouraged to operate a regional panel system such as that illustrated below:

South & West Region	
Local Health Boards	Local Authorities
Hywel Dda Abertawe Bro Morgannwg	Carmarthen Ceredigion Pembrokeshire Swansea Neath Port Talbot Bridgend

North & Mid Region	
Local Health Boards	Local Authorities
Betsi Cadwaladr Powys Hywel Dda (for North West)	Anglesey Conway & Denbighshire Wrexham Powys Ceredigion

South & East Region	
Local Health Boards	Local Authorities
Aneurin Bevan Cardiff & Vale Cwm Taf Powys	Newport Torfaen Blaenau Gwent Caerphilly Monmouthshire Rhondda Cynon Taff Merthyr Cardiff Vale of Glamorgan

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 local authority(ies) 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 are 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 chairman of the review panel. In all cases where a decision not to convene a panel is made, the LHB should give the patient, his or her 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, his or her 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), local authority 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.

Section 6: Retrospective Claims for Reimbursement.

- 6.1 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 criteria for CHC which were applicable at that time. A retrospective review claim is different from an appeal against a current CHC assessment and decision on eligibility; that Appeals process is outlined in Section 5.
- 6.2 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. Welsh Government is aware of a current backlog of claims being managed by LHBs and has made clear its expectation that these claims should take no longer than two years to process.
- 6.3 As with the process of determining CHC eligibility, the retrospective claim process is not a legal process. It is delivered by the LHB and therefore no charge will be made to the individual.
- 6.4 The process for making a claim is set out 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.
- 6.5 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 Complex Care Information & Support site www.cciss.org.uk.
- 6.6 The claim may be submitted by:
- Patient.
 - Person authorised by the patient to receive reimbursement on his/her behalf.
 - Person holding a registered Power of attorney or who is a Court-appointed receiver for a mentally incapacitated patient.
 - In the case of a deceased patient, 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.

Reimbursement, should eligibility be found, will only be paid to the above.

- 6.7 For the periods between 1st April 2003 and 31st July 2013 the cut-off date for registering intent to make an application for a retrospective review will be 31st July 2014. Thereafter, no applications for a retrospective review pertaining to this period will be considered, other than in exceptional circumstances. Exceptional circumstances can

include for example, the claimant suffering critical illness, serving with the armed forces or living abroad.

- 6.8 It is anticipated that the maximum 2 year timescale for resolution will also apply to these cases, but this may be subject to review in response to the numbers of applications received.
- 6.9 Within 5 months of registering the claim, claimants will be required to provide evidence of:
- Their right to make the claim on the individual's behalf (i.e. via Lasting Power of Attorney or Grant of Probate as detailed above);
 - Proof of fees paid to care home or domiciliary agency.
- 6.10 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.
- 6.11 From 1st October 2014 the process for considering the claim period for a retrospective review is as follows.
- The claim period to be considered will be no longer than 12 months from the date of application.
 - If the claim period is after a MDT/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.
- 6.12 Claims outside of the stated cut-off dates may be considered in exceptional circumstances. Exceptional circumstances can include for example, the claimant suffering critical illness, serving with the armed forces or living abroad.
- 6.13 In order to ensure fairness during the transition period between the 2010 and 2014 Frameworks, claims relating to the period from 1st August 2013 to 30th September 2014 will be accepted up to 1st October 2015. These claims should normally be resolved within 12 months of receipt.
- 6.14 The resolution of claims submitted after 1st October 2014 i.e. under the annual rolling cut-off date, should normally be achieved within 6 months.

6.15 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 questionnaire (including a request for the claimant's views) and Information/Frequently Asked Questions Booklets are sent to the claimant.
- iii. On receipt of the completed questionnaire, requests are made to the appropriate care providers for records.
- 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 All Wales Needs Assessment Document (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 and by applying the Primary Health Need approach for the whole of the claim period. If no eligibility is found using these criteria, the criteria that were applicable at the time of the claim period should be applied.
- vi. 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 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)
- vii. In cases of no eligibility found, the document will be peer reviewed by 2 different clinicians to ensure that the evidence supports the recommendation made.
- viii. 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
 - Partial- eligibility is found for part of the claim period
 - No eligibility found for any part of the claim period
 - Panel- the reviewer has been unable to make a decision as the information available is complex.
- ix. 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 go for negotiation
 - Panel cases- an Independent Review Panel will be convened.

The claimant/representative will be invited to a meeting for cases where partial or no eligibility has been found:

- Partial eligibility- to discuss the recommendation made and reach a mutually acceptable period of eligibility based on the evidence available and/or new evidence that has not previously been available to consider. If agreement is reached at this stage, the case will be forwarded for ratification. If no agreement is reached, the case will be forwarded for IRP consideration.
- No eligibility- Where no evidence of eligibility is found, a meeting will take place with the claimant/representative to provide opportunity for further explanation of CHC criteria and to check that the claimant/representative has understood the lack of evidence on eligibility.

If peer review indicates that there is an element of doubt then recourse to the IRP process should be granted.

If the individual or their representative has significant additional information to present or exceptional circumstances apply again, there should be recourse to the IRP process.

Before taking a decision the LHB will seek the advice of the chairman 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.

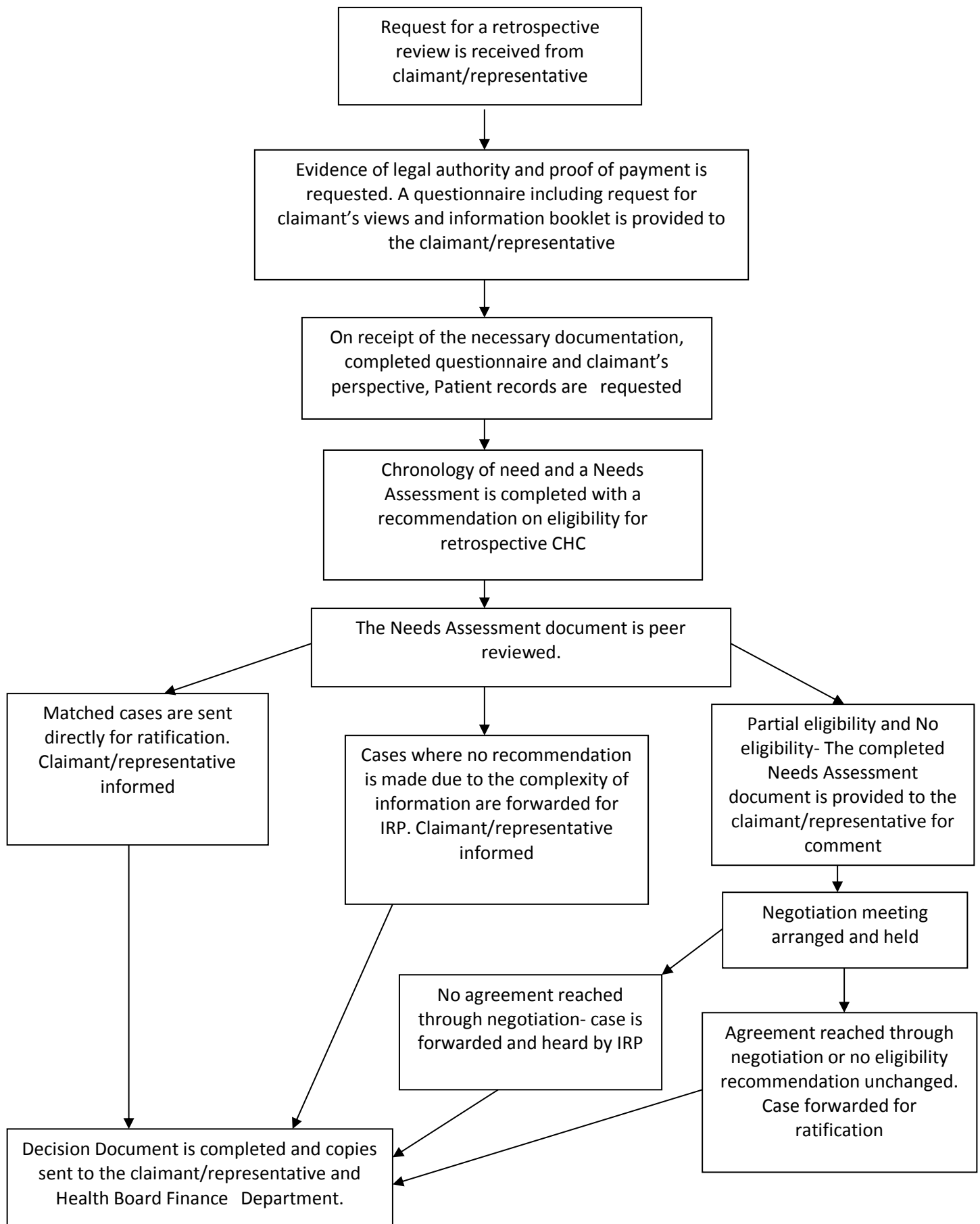
- In all cases, an All Wales Decision Document will be completed by the person ratifying the recommendation made/Chair of the IRP.
- A copy of the completed Decision Document is provided to the claimant/representative and the LHB Finance Department.

Responsibility for the management of claims

- 6.16 Welsh Government Circular 13/2011 set out the arrangements for the processing of claims by the 'Powys Project'. This referred to claims relating to the periods:
- Between 1996 and 2003;
 - After April 2003 and up to 15th August 2010 where the application was received prior to 16th August 2010; and
 - Claims straddling these two periods.
- 6.17 Applications received after 16th August 2010 are dealt with by the relevant Local Health Board. Both the Powys Project and the LHBs will follow the process detailed above.
- 6.18 In November 2013 the Welsh Government issued interim guidance in respect of proof of payment for specific cases dealt with by the Powys Project.
- 6.19 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.
- 6.20 Claimants who are dissatisfied with the review process are able to access the NHS Complaints process and recourse to the Public Services Ombudsman for Wales as outlined in paragraphs 5.31 to 5.36.

See Figure 2 for an overview of the process for undertaking a retrospective review.

Figure 2: Process for undertaking a Retrospective Review



Appendices

Glossary of Terms

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.

Care Home

An establishment registered under the Care Standards Act 2000 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 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 Carers Strategy for Wales (2013)¹⁵ defines a carer as anyone, of any age, who provides unpaid care and support to a relative, friend or neighbour who is disabled, physically or mentally ill, or affected by substance misuse. The definition excludes those who provide care under, or by virtue of, a contract or 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.

¹⁵ The Carers Strategy for Wales, Welsh Government (2013)

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.

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. It is the responsibility of each Local health board to implement the Framework and to gain assurance that it is doing so via the performance 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 of 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 option is open towards facilitating 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.

Domain

These refer to the content of the integrated assessment and the decision support tool.

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.

General Household Support

Such services as cleaning, laundry, meal preparation, shopping, cooking, collecting benefits, sitting with or accompanying on social outings.

Intermediate Care¹⁶

The term 'intermediate care' has been defined as a "range of integrated services to promote faster recovery from illness, prevent unnecessary acute hospital admission, support timely discharge and maximise independent living". (NSF for Older People, DOH, June 2002). 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.

¹⁶ Further work will be undertaken to achieve consistent definitions of intermediate care, reablement, rehabilitation, hospital home, virtual wards, rapid response, etc. to inform service developments.

For people with mental health needs the Mental Health Measure makes specific requirements regarding who the Care Co-ordinator should be.

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 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 should be distinct from intermediate care (which has specific time limited outcomes for rehabilitation, reablement or recuperation) and transitional/interim care (where the care setting is temporary and different from where people are expected to receive any long term care they need).

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

Multi-disciplinary refers 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

The provision of NHS Funded Nursing Care derives from Section 49 of the Health and Social Care Act, 2001, 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, "sensitive personal information" (e.g. health information). Those terms have the same meaning as "personal data" and "sensitive personal data" in the Data Protection Act.

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.

Reablement¹⁷

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.

Rehabilitation¹⁸

A programme of therapy and reablement designed to maximise independence and minimise the effects of disability

¹⁷ Further work will be undertaken to achieve consistent definitions of intermediate care, reablement, rehabilitation, hospital home, virtual wards, rapid response, etc. to inform service developments.

¹⁸ Further work will be undertaken to achieve consistent definitions of intermediate care, reablement, rehabilitation, hospital home, virtual wards, rapid response, etc. to inform service developments.

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 Welsh government to move to a more integrated approach. The Social Services and Well-being (Wales) Bill 2013 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.

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.