



**NO
TIME
TO
WASTE**

**CONTINUING NHS HEALTHCARE
FOR PEOPLE WITH MND IN WALES**

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EXECUTIVE SUMMARY

No time to waste – *Continuing NHS Healthcare for people with MND in Wales* describes the experiences that people with MND and their family carers can have in relation to Continuing NHS Healthcare (CHC).

It shows that, when all goes well, CHC funding can make a significant positive difference to people with MND. It can allow them to maintain their independence and spend precious time at home with their families. It can ensure appropriate care is provided by skilled professional carers which meets their complex needs. It can also help to relieve the emotional, physical and financial pressures that people living with MND can experience.

However, the report goes on to demonstrate a range of hugely concerning issues with the current delivery of CHC for people with MND in Wales. In fact, examples are provided which indicate major problems with the delivery of every one of the seven core principles of CHC implementation in Wales:

- 1. People first**
- 2. Integrity of decision making**
- 3. No decision about me, without me**
- 4. No delays in meeting individual's needs based on funding discussions**
- 5. Understand diagnosis, focus on need**
- 6. Co-ordinated care and continuity**
- 7. Communication**

1.1 Summary of recommendations

Based on these insights, the report makes the following recommendations for change:

Recommendations for Welsh Government

- Make CHC a Healthier Wales priority area.
- Take urgent action to ensure CHC assessment is not a *'harrowing'* experience for individuals and families.
- Revise the National Framework for Implementation of CHC in Wales.
- Address the limitations of the Decision Support Tool.
- Increase the availability of trained care workers and nursing staff.

Recommendations for Local Health Boards

- Take urgent action to improve local delivery of CHC.
- Redesign provider contracts to ensure terms do not disadvantage those who are recipients of CHC.

2

INTRODUCTION

“When I did apply for Continuing Healthcare it was all so difficult. We only had three months after his diagnosis. I would have liked to have spent that just sitting with him.” Family carer

Motor neurone disease (MND) is a fatal, rapidly progressive disease that affects the brain and nerves. It kills one third of people within a year of diagnosis, and more than two thirds within two years. People with MND do not have time to waste.

Continuing NHS Healthcare (CHC) is a package of care provided by the NHS for individuals with complex and primarily health-based needs¹. The implementation of CHC has proved to be very challenging across the UK. This has resulted in delays and disruptions to the provision of vital care for people when they need it the most.

Due to the rapidly progressive nature of the disease, it is highly likely that individuals with MND will have primary health-based needs at some point. As a result, the way in which decisions are made for people with MND can be seen as a test of the success of the implementation of CHC.

The MND Association is highly concerned by the problems that people with MND experience in relation to CHC. This report seeks to provide a clear picture of these challenges based on input from individuals with MND, their family carers, volunteers and MND specialist professionals from across Wales. It goes on to identify the areas of CHC practice which are working well, and to make recommendations for change.

2.1 About CHC

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. 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 needs².

In order to determine whether an individual has a primary health need and is eligible for CHC, they are assessed using a decision support tool (DST) and their case is discussed by a CHC multi-disciplinary team (MDT). If it is agreed that they are eligible, care and equipment will be provided free of charge by the NHS – either in the individual's home or within residential care.

If it is decided that an individual is not eligible for CHC, care and equipment need to be found through other means. This will largely be through local authority social care services, which are means tested. Consequently, individuals themselves are likely to be responsible for funding at least a part, if not all, of their care.

2.2 CHC implementation in Wales

Health and social care policy is devolved to the Welsh Government. Specific measures have been taken within Wales to address challenges with CHC and improve delivery. These approaches reflect the particular way in which health and social care support in Wales is organised and delivered.

The Welsh NHS delivers services via seven Local Health Boards (LHBs), each of which have individual challenges in terms of geography and demographic profile. The Welsh Government provides guidance and advice for LHBs in the delivery of CHC through the *Continuing Healthcare - the National Framework for Implementation in Wales* (the implementation framework), which sets out a mandatory process for the seven LHBs, working together with relevant local authority partners, to assess health needs, decide on eligibility for CHC and provide appropriate care for adults.

¹ Continuing NHS Healthcare – The National Framework for Implementation in Wales, Welsh Government, June 2014

² Ibid

Oversight of the delivery of CHC is provided by the Welsh Government and local health boards (LHBs) are required to regularly report on progress.

A commitment is included within the 2014 implementation framework document that Welsh Government will review the Framework after three years of implementation and issue additional or interim guidance where this is required.

2.3 Concerns regarding the delivery of CHC in Wales

Reports by the Auditor General and Public Accounts Committee³ into the delivery of CHC Wales in 2013 concluded that equitable and timely access to CHC has not always been available. Problems were reported with the delivery of assessments, delays to decision making, the complaints and appeals process, communication and involvement of service users and the provision of information and advocacy.

A revised version of the implementation framework was introduced in June 2014. In order to support the delivery of the new framework, a Decision Support Tool (DST) was published to aid practitioners on decisions regarding an individual's eligibility for CHC. The DST is a document which provides assessors with a needs-led approach by portraying need based on 12 'care domains'.

In 2015, the Welsh Audit Office produced a report which suggested that while progress has been made, a stronger role was needed for Welsh Government in leading, monitoring and national oversight of CHC.

In 2016, the Welsh Institute for Health and Social Care (WIHSC) and the University of South Wales were commissioned by Welsh Government to undertake a study looking at CHC delivery. Their report highlighted the 'disconnect' between the new, person centred approach introduced by the Social Services and Well-Being Act (Wales) 2014, and the approach to CHC delivery in Wales. They also noted that while CHC is not *"a perfect system, but there are very many people who are fully committed to ensuring that it is improved. . . People work hard to ensure the current regime operates efficiently and there is a willingness to learn about shortcomings and to address them."*⁴

2.4 Recent developments in implementation of CHC in England

Despite structural differences between the health and social care systems in England and Wales, the nature and implementation of CHC is broadly similar in both nations. Consequently, it is useful to consider recent developments related to the system of CHC implementation in England.

In 2017, the Continuing Healthcare Alliance, a group of 17 charities and organisations who work together to improve CHC in England, published a report entitled *Continuing to Care* which raised concerns about CHC. The key findings of this report were:

- 66% of survey respondents felt the professionals in the assessment did not possess any in-depth knowledge – or knew very little – about the condition the person being assessed was living with.
- 80% of professionals surveyed said the DST was not fit for purpose, or there was room for improvement in some areas.
- 73% of survey respondents who applied for NHS CHC felt the DST did not ask relevant questions to elicit an accurate impression of a person's situation.

In October 2018, a revised version the National Framework for Implementation of CHC in England was published. The revised framework states that MDTs should include people with knowledge of the individual being assessed, saying *'the MDT should usually include both health and social care*

³ Implementation of the National Framework for Continuing NHS Healthcare Wales. National Assembly for Wales Public Accounts Committee (2013)

⁴ Scoping Study on CHC, WIHSC and University of South Wales, 2016

professionals who are knowledgeable about the individual's health and social care needs and, where possible, have recently been involved in the assessment, treatment or care of the individual.⁵

However, members of the Continuing Healthcare Alliance raised concerns that revisions to key assessment tools such as the DST did not go far enough.

2.5 Funding pressures

In their report *The path to sustainability: Funding projections for the NHS in Wales to 2019 and 2030/31*, the Health Foundation identified the following causes of funding pressures on the Welsh NHS:

- A growing and aging population.
- Increases in chronic conditions.
- Associated spending pressures on social care.

As CHC is a defined budget area which provides care to people with chronic conditions and older people in the community, it is subject to a great degree of scrutiny by the Welsh Government. According to a report by the Wales Audit Office⁶, NHS expenditure on CHC in Wales, increased from £66 million in 2004-05 to £295 million in 2010-11, accounting for 5% of the health boards' total net operating costs.

Data is not available on the amount of money which is saved by the state as a result of CHC funding, for example in terms of a reduction of emergency hospital admissions and an increased number of family carers who are able to remain in paid employment. In addition, data is not available on the costs of any delays, inefficiencies and appeals within the current process.

In England, a recent report by the National Audit Office⁷ provided data on key aspects of the process, such as numbers of people who were referred for CHC who were not found eligible and variation between CCGs in both the number and proportion of people assessed as eligible for CHC. This data is not currently available for CHC in Wales.

At a local level, local health boards (LHBs) are responsible for CHC implementation. At a time when the NHS budget is stretched, LHBs will feel under a certain amount of pressure to control spending. However, both the implementation framework and case law are very clear that decisions about CHC funding must be driven by clinical need, rather than on financial concerns.

Nevertheless, the evidence base suggests that the pressure of budgetary concerns at a delivery level can result in an adversarial approach to determining CHC eligibility. The WIHSC and University of South Wales scoping study found that *'Many respondents perceived that the framework and DST help obviate differences, but felt that attitudes and beliefs are not consistent amongst participants which can lead to "positions" being adopted that are disproportionately linked to a desire to protect budgets.⁸* An MND Association submission to a 2013 Westminster Parliamentary Inquiry into the provision of CHC also stated that the NHS is sometimes seen as attempting to pass back the financial responsibility to local authorities *'for instance by disputing what is a health need and what is a social care need. This is especially common around issues related to eating and drinking and administering gastrostomy feeds.⁹*

Regrettably, evidence submitted by contributors to this report shows that this can play out within assessment meetings both between health and social care services and towards individuals.

5 National Framework for the Implementation of NHS Continuing Healthcare and NHS-funded Nursing Care, (England), Department of Health and Social Care, October

6 Implementation of the National Framework for Continuing Healthcare, Wales Audit Office, 2013

7 Investigation into NHS continuing healthcare funding, National Audit Office, 2017

8 Scoping Study on CHC, WIHSC and University of South Wales, 2016

9 Submission by the MND Association to the inquiry into NHS CHC by the APPG on Parkinsons

3

POLICY CONTEXT

In order to consider the most effective recommendations that can be made with regards to CHC policy and practice improvements, it is useful to reflect on the policy context.

3.1 The social care context

If an individual is not found to be eligible for CHC, they may have needs which will be met within the social care system. This may include a requirement to financially contribute to their package of care.

The National Assembly for Wales Briefing Document on CHC states *'Most people needing residential care (who are not eligible for NHS CHC) will be expected to contribute towards the costs of their accommodation and personal care from their personal income.'*¹⁰ As a result, decisions about CHC have an impact on local authority budgets, and on the financial security of individuals.

The notion of determining needs as primarily those of health care rather than social care is also culturally and functionally different to the new model of assessment based on holistic understanding of wellbeing which was introduced by the Social Services and Wellbeing Act (Wales) 2014.

3.2 Health policy context

In 2015, Welsh Government endorsed the principles of Prudent Healthcare, as proposed by the Bevan Commission. Since then, Prudent Healthcare has been a driving force in thinking about health service improvement in Wales.

The four principles of Prudent Healthcare are:

- Achieve health and wellbeing with the public, patients and professionals as equal partners through co-production.
- Care for those with the greatest health need first, making the most effective use of all skills and resources.
- Do only what is needed, no more, no less, and do no harm.
- Reduce inappropriate variation using evidence based practices consistently and transparently.

In early 2018, the findings of a National Assembly Parliamentary Review of Health and Social Care in Wales were published entitled *A revolution from within: Transforming Health and Care in Wales*. This report set out an approach to building on the principles of Prudent Healthcare to create a seamless system of health and social care services. In order to do this, it designated a 'quadruple aim' as a structure for transformation work:

- Improve population health and wellbeing through a focus on prevention.
- Improve the experience and quality of care for individuals and families.
- Enrich the wellbeing, capability and engagement of the health and social care workforce.
- Increase the value achieved from funding of health and care through improvement, innovation, use of best practice and eliminating waste.¹¹

Later in 2018, Welsh Government responded to this report by publishing *A Healthier Wales: Our Plan for Health and Social Care*. This document describes the way that Welsh Government intends to bring health and social care services together, so that they are designed and delivered around the needs and preferences of individuals. Its goal is to create a *'wellness system, which aims to support and anticipate health needs, to prevent illness, and to reduce the impact of poor health,'*¹² and to ensure that

¹⁰ Continuing NHS Healthcare in Wales – what is it, and what do I need to know? National Assembly for Wales Research Briefing

¹¹ A revolution from within: Transforming Health and Care in Wales, National Assembly for Wales Parliamentary Review of Health and Social Care, 2018

¹² A Healthier Wales: Our Plan for Health and Social Care, Welsh Government, 2018

provision is equitable so that *“Services and support will deliver the same high quality of care, and achieve more equal health outcomes, for everyone in Wales.”*¹³

One of the key challenges for those seeking to influence the progress of integrated health and social care for service users in Wales will be to strike the balance between creating a more joined up system working in a holistic way towards the same goals, and ensuring that there is no dilution of the duty on the NHS to provide healthcare free at the point of use. In this respect, CHC could be seen as ideal frame through which to consider the challenge of greater integration.

4

METHODOLOGY

This report is not intended to demonstrate the experiences that every individual with MND in Wales will have in relation to CHC. Instead, it describes the experiences that we know people with MND can and do have. This evidence builds on the larger studies by WAO, WIHSC and University of South Wales into the problems with CHC, and provides an insight into the significant impact that these problems have on individuals, many of whom are at their most vulnerable.

In Wales, there are approximately 250 people living with MND. People with MND are more likely to gain access to CHC funded care as their needs progress and their situations are not necessarily conducive to responding to written surveys or taking part in interviews.

For this reason, detailed input was sought from individuals who were known to have relevant experience and to be keen to contribute. This input was provided through structured interviews and focus groups.

Contributors to this report included:

- 11 individuals with MND and family carers
- 1 paid carer
- 14 professionals who work with people with MND, including MND care coordinators, palliative care consultants, and those who work in hospice care, nursing, occupational therapy and physical therapy
- 4 MND Association staff and volunteers

Geographically, they were based within a range of LHBs from across Wales.

Contributors were asked the following questions:

1. Do you think CHC is important for people with MND, and if so, why is it important?
2. What would you say are the key barriers and challenges that people with MND and carers experience in relation to CHC?
3. Could you tell me about the impact that these barriers and challenges have on people with MND and carers?
4. What, if anything, do you feel would help to address these barriers and challenges?
5. Could you tell me about any aspects of the current CHC system are most helpful to people with MND in Wales?
6. What, if anything, do you feel would help to address these barriers and challenges, or to enhance the positive elements of the system?

¹³ Ibid

5

FINDINGS

5.1 Why CHC is important for people with MND?

"MND patients are the most complex ones I work with: they almost hit every domain of CHC eligibility."

Palliative care professional

MND is a complex, rapidly progressive and evolving, fatal condition. Individuals with MND have a wide range of needs which require frequent interventions, such as those which help with mobility, feeding, breathing and secretion management.

Contributors to this report explained that CHC is often important for people with MND, because at a certain stage their specific requirements are *'beyond what other kind of provision is going to be able to meet.'*

They were clear that the right CHC package can provide more appropriate support than social care when needs progress. Although individuals and family carers can be reluctant to lose the local authority funded carers that have initially supported them, professionals were clear that CHC packages can be a big step up from what social care has provided which can make a big difference to individuals and families.

Critically, CHC helps people with MND in Wales to remain in their own homes and retain as much independence as they can. One family carer said *"It works. When the care package got under way, my wife came home. That was the most important thing."*

It also helps people with MND in Wales and their families to be able to afford the care and equipment that they need to remain independent. Individuals and family carers were hugely appreciated of this. One family carer said, *"It's not just the care, it is all the equipment in the house, the list goes on and on. I'd have to live about 20 lives I think to pay for half of it."*

Although the purpose of CHC is not to relieve pressure on personal finances, the fact that it is provided free of charge can have a significant effect on the financial and emotional wellbeing of people with MND. One individual with MND described the difference this has made to her saying, *"Having continuing care has made an enormous difference to us. We were paying for care before that and were worrying about how we would afford extra care as I became worse and needed more help. All that worry has gone and I don't feel I am draining our savings."*

When CHC is not in place, professional contributors described the efforts they go to secure care and equipment for individuals with MND. One professional explained, *"Patients with this kind of disease are changing week by week. So, if they are not CHC funded then we are trying to pull resources from a wide number of professional groups: nursing, physio, OT, speech and language, dietetics. These patients often require a lot of equipment, and different funding streams. We struggle."*

However, as it currently works, CHC is not always seen as a positive experience for people with MND. Reasons given for this included:

- Disruption caused by delays to the provision of care under CHC.
- Restrictions on the packages of care that CHC provides in particular areas, such as on number of hours of care provided, on whether day time or night time care is provided, on place of care and on care provider.
- Lack of trained staff available to provide care even when it is funded by CHC, eg CHC funded care agencies who don't provide staff who can support patients who use a percutaneous endoscopic gastrostomy (PEG) feeding tube.

5.2 Is CHC being effectively delivered for people with MND in Wales?

The 2014 version of the implementation framework contains a wide range of very positive, person centred commitments. In order to test whether CHC is being delivered effectively for people with MND in Wales, we have chosen to focus on the extent to which the experiences of people with MND and family carers reflect the seven core delivery principles that are set out in the framework.

These underpinning principles are:

1. **People first**
2. **Integrity of decision making**
3. **No decision about me, without me**
4. **No delays in meeting individual's needs based on funding discussions**
5. **Understand diagnosis, focus on need**
6. **Co-ordinated care and continuity**
7. **Communication**

Evidence related to the challenges in the delivery of CHC for people with MND in Wales have been mapped against these core principles in the following section:

THE SEVEN CORE DELIVERY PRINCIPLES

Principle 1: People first

"It almost makes you feel guilty for asking for care." Individual with MND

The first principle which underpins the implementation framework is 'People first'. It says that individuals must feel that health and social care providers have their best interests at heart. They must be treated with dignity and respect, and they must feel supported throughout the process of determination of eligibility.

Sadly, experiences described by contributors to this report did not reflect this approach. Instead, assessment for CHC was described by many as a cold, tick box exercise and a *'harrowing process for people with MND'*.

Contributors talked about the positive experiences they had had with health and social care services prior to their assessment for CHC. One family carer said that when his wife was first diagnosed with MND, *"We didn't really put our hands up and ask for help - but all of these services came our way, which was tremendous."* However, they described a very definite shift of tone when they entered the process of assessment for CHC.

Adversarial tone

Those who had attended assessment meetings said that, far from being an environment in which they felt supported, the tone in assessment meetings can be highly adversarial towards individuals and their family carers. One contributor described the approach taken by assessors towards his family as, *"Let's push these people to the limit. Let's really put them through the mincer."*

Requirements to prove care needs

One family carer described the emotional impact of the requirements placed on them to prove the needs of her husband saying, *"He felt as if he was begging."*

Another described the lengths that they had been asked to go to in order to prove the level of care that was required. He explained, *"We had to document every intervention we did for about three weeks. We*

had a form at the end of the bed, and we would write: moved her mask, moved her leg, sip of tea, moved her to the left, moved her to the right, bed pan. And they could see then, it is round the clock."

As a result, he and his family felt that those involved in the assessment didn't understand the extent and impact of the needs of that someone with MND can have. It also gave them the impression that assessors believed their description of the care needs was exaggerated or untrue.

Funding disputes between services

Funding considerations seem to be writ large within the assessment process for many contributors. This led contributors to feel that those involved in decision making were driven more by funding considerations and process than by the best interests of the individuals involved.

Professional contributors who took part in a focus group commented that they were sometimes *"shocked"* by the level of hostility between health and social care staff in CHC meetings. Others said that they had observed them arguing in front of individuals and their families, and also cited examples of professionals talking over people in the CHC assessment meeting.

One professional who took part in an interview said, *"I do understand money is limited, but... some of the discussions that take place in the group meetings are not very appropriate for the clinical circumstances. I think it can leave a very uncaring impression for the people that are directly affected by the condition."*

Another explained the impact that they observed this having on individuals and family carers, saying that stress and anxiety is caused when people see that the care they need, *"is happening or not happening on a whim of what feels like a pretty arbitrary question of where the money should come from."*

Pressure on family to take on the care themselves

Individuals and family carers stressed that they had been very keen to be reasonable throughout the process. They talked about their awareness that there is not *"a bottomless pit of money"* and that there are a lot of people who need care.

However, they also talked about the pressure they felt was placed upon them during discussions about CHC care packages to provide care which was beyond their skills as non-medical professionals. The wife of one individual with MND explained, *"If they thought that he needed nursing care because his MND was progressing and he was bed bound, how did they think I could cope? I am not a trained nurse."*

The husband of a young mother with MND felt that the view of CHC assessors was that he should give up his job to be a full time carer. However, the care his wife required had already progressed to be beyond his skills, and as he explained, *"to give up your job clearly doesn't work when you've got a three-year-old child and a you need a house to live in."*

Principle 2: Integrity of decision making

The second principle of the framework states that CHC MDTs are responsible for the integrity of decision making and the professional advice they give about CHC eligibility. It says that they can only be challenged on the grounds of the quality of assessment, not on the basis of funding. It also says that CHC MDTs must deliver decisions which are underpinned with a clear rationale.

This report is concerned with the experiences of those who apply for and are supported by CHC. Transcripts of the decisions made by CHC MDTs have not been submitted. However, a great many comments on the way in which the process is managed and conducted have been provided by contributors. Consequently, this section focuses on evidence regarding the way in which the decision-making process is managed, and the quality of the assessment process from the point of view of individuals with MND, their family members/carers and the professionals and volunteers who support them.

It is important to note that many professional contributors were keen to stress that while there are flaws in the system, those who work within it are committed professionals who are doing their best. One contributor was clear that, *“What I see most of the time is people running this system who want to get the right thing done. The system can feel a bit clunky sometimes, but in my experience that is in spite of the good will of those involved not because of a lack of it.”*

It is also undoubtedly true that the process of agreeing eligibility for CHC works well in some cases. One individual with MND who contributed her experiences to this report said, *“It was approved without trouble. I have had no trouble since receiving it.”*

However, concerns were raised by several contributors about:

- The way assessment process is managed.
- The degree to which people with knowledge of the individual were involved in decision making.
- Whether there is a clear, consistent and equitable rationale for decisions that are made.

Poor administration and management of the assessment process

Some contributors commented on the management and administration of assessment meetings.

They had observed a lack of support and consideration of the individual and family carer in the way in which meetings were arranged. One contributor had supported people with MND who were going through CHC applications, they said, *“Meetings have been set up where there is allegedly going to be seven or eight professionals attending. Then only two of them turn up and the meeting doesn’t take place. I had another instance when nobody turned up to the meeting, and the carer was left sitting there.”*

One individual described the delays to decision making they had witnessed based on poor quality assessment practice saying, *“The hospital wanted to discharge him, but said he needed residential care. A nursing home was found but the funding took weeks due to cancelled meetings.”*

Bias in decision making towards those who know the system

Several professional contributors mentioned that it is easier to get CHC funding approved when you know the system and have experienced the idiosyncrasies of decision making within it. One summed this up saying, *“You need to ‘play the game’ and use the right words. When you have feedback saying this isn’t enough you learn what they need – we have learned what the buzz words are that help evidence needs for different patients.”*

This raises questions about the integrity of decision making for anyone involved who does not have this experience. As one contributor said, *“Most people making an application are not experts in applying for CHC.”*

Lack of clear rationale for decision making

In terms of clear rationale for decision making, contributors who work within palliative care tended to feel that decision making in terms of eligibility was fairly straightforward, but tended to happen at a point of crisis or when the needs of individuals were immediate and pressing.

However, input from other contributors indicates that the implementation framework and DST are not effectively facilitating consistency and equity in decision making in their current form.

Professionals and family carers shared their bemusement at some of the CHC decisions they had been involved with. One professional who described this saying, *“There are so many health needs with MND – the respiratory end of things, equipment, the dietician, feeding – that’s not about social stuff, that’s health. We are just constantly gobsmacked by the number of people who are turned down.”*

One contributor talked about geographical differences between decision made in different areas. He said, *“Decisions go either way in different parts of our geographical area for no clear reason. It is very difficult*

to compare one person's scenario in one geographical location with another one, and it seems to come down to how much money that geographical area has got."

Principle 3: No decisions about me without me

"She fought to the end, but to be honest the fight to get CHC was the one that nearly broke us." Family member of individual with MND.

The third principle is very clear that individuals and their carers (be they paid or unpaid) must be included as empowered co-producers in the assessment and care planning process. It goes on to stress that professionals must not avoid honest and mature conversations with the individual and/or their representative when available care options carry financial or emotional consequences. Finally, it states that professionals must be mindful that some individuals may need support or advocacy to express their wishes, feelings and aspirations.

It is true that individuals and carers are involved in the process, in as far as they answer questions related to the DST, they take part in assessment meetings, and in some cases these meetings take place in their own homes. However, the fact that they are involved in the process does not mean that individuals and family carers feel that they are empowered co-producers. Evidence provided by contributors to this report shows that action is urgently needed to improve the way that the participation of individuals in CHC decision making is supported.

Stressful process

One of the main challenges seems to be how to support the involvement of individuals and family carers in decision making, without placing undue stress upon them. One contributor who supports people with MND described this saying, *"It's a real stressor, and a lot of patients families, in hindsight, report how stressful that element is for them, on top of dealing with the disease."*

A paid carer who works with people with MND talked about how common this is, saying, *"We can see on a daily basis the effect that MND has on patients and their families. All this funding stuff makes matters worse and creates stress all round."*

Disempowered by lack of information

Several individuals and their families told us that they had not been provided with sufficient information about CHC and the assessment process prior to their assessment meeting.

Many described situations in which individuals and family carers did not know what the meeting was about, and that the purpose was to determine CHC eligibility. One contributor described a specific case saying, *"I attended as an advocate. The daughter and her father who had MND were like rabbits in a headlight. They hadn't been told that this is what the meeting was about. They were told the meeting was a planning meeting. They didn't know it was about who pays for it."*

Intimidating assessment meetings

Family members, individuals with MND and advocates described the experience of taking part in assessment meetings as *"scary"*. Reasons given for this were the number of people involved, the language used, the seeming lack of consideration that individuals, carers and advocates will not be familiar with the process and the absence of people with knowledge of the individual or the condition within MDTs.

One contributor said, *"The professionals decided to have the meeting about the final decision in the individual's home... they were inundated by eight or nine professionals who they had never seen in their life before, it absolutely terrified the pants off them."*

Contributors talked about the confusion they felt due to the language used in meetings. This included professional jargon and acronyms. One said, *"It made me frightened. People talked in language I didn't*

understand.” Another explained, “Sometimes there were so many people at the meetings I felt very nervous. I didn’t recognise many of them but they were saying things about our situation and talking about ‘reaching the score to get CHC’, I didn’t know what to say.”

In some of the examples that were described, assessors did not directly address the individuals that they were discussing, despite them being present in the room or in adjacent rooms. One said, *“they talked about my husband, not to him.”* Another provided an example based on an assessment she had attended as an advocate saying, *“They sat there with their big folders and talked about the gentleman who was in the room next door, who could hear them. He couldn’t have been in the room as he was bedridden, but they didn’t go into his bedroom to see him.”*

Principle 4: No delays in meeting individuals needs due to funding discussions

The fourth principle provides a clear commitment that individuals must not experience delays in having their needs met because agencies are not working effectively together. It specifically mandates that joint funding and pooled budget options must be considered wherever these can promote more efficient responses to individual needs and preferences, and that commissioners have a responsibility to resolve concerns/disputes at the earliest opportunity.

The implementation framework for CHC in Wales includes a commitment that ‘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’. However, as established through previous reports on CHC implementation in Wales, long delays to the provision of care through CHC are common.

Contributors to this report confirmed that this is often the case for people with MND. In fact, individuals with MND in Wales can wait far longer than eight weeks for a decision about CHC. One family carer told us, *“They said eight weeks but it was more like eight months in the end.”*

Professionals who have observed large numbers of people with MND go through CHC applications also confirmed this. One said, *“I don’t think I have ever seen it take eight weeks.”*

As MND is a rapidly progressive, fatal condition, these delays can have a significant impact on the time that individuals have after diagnosis. As one contributor put it, *“The process can be a great stressor. This has a negative impact, particularly in the last months of people’s lives when it should be just support.”*

In addition, these delays can result in significant physical and emotional hardship. The case studies below were provided by contributors to this report in order to indicate the impact that these delays have had on people with MND. They are real case studies, but their real names have not been used.

Physical hardship caused by delays in funding decisions

MRS A’S STORY

Mrs A is an individual with MND.

In early May 2018, an occupational therapist assessed Mrs A’s posture and seating needs as she was experiencing pain and discomfort whilst sitting in her chair. The assessment showed the need for a specialist chair. The assessed chair was trialled with Mrs A who found this comfortable and met her needs.

In May 2018, a CHC MDT meeting was held to discuss whether Mrs A had primary health needs which meant that this chair should be provided under CHC.

Five months later, the CHC application had still not been processed. The reason given for this was eligibility for funding had been disputed, and further information was required.

When a representative of the MND Association met Mrs A in October 2018, he was horrified to see the pain and discomfort she lives with every day because the chair she is using no longer meets her needs. In Mrs A's own words, "It is cruel."

Stress and anxiety caused by delays in funding decisions

MRS B'S STORY

Mrs B is 60 year old woman with MND who lives alone.

Mrs B is not able to move. She goes to bed at 7pm in the evening and remains in one position in her bed until the morning. She has reduced the amount of fluid she is taking in during the day so she doesn't need to go to the toilet at night.

Her application for CHC funding took several months, and then was declined on two separate occasions. During this time, the place in specialist residential care she had been offered was reassigned.

Emotional hardship caused by delays in funding decisions

MR C'S STORY

Mr C is an individual with MND who reported to his palliative care consultant that he was feeling actively suicidal. One reason he gave for this was that he knew his care needs were not adequately met.

Mr C's MND was rapidly progressive. He was admitted to a palliative care unit, and died before his CHC package was agreed.

Mr C's palliative care consultant said, "I asked him open questions, such as 'can you tell me why you are feeling that way?'. From the answers he gave I was able to conclude that he was describing needs that could have been met through CHC, if the whole thing had worked in an ideal fashion.

"When he was well cared for within the palliative care unit, his psychological state was altogether different. So, I take at face value the reasons why he said he felt as suicidal as he did. It is complex and its partly a question of physical comfort, but a lot of it is the sense of value and meaning. If you know you need caring for, and you know that no one is moving quickly to care for you, I think on a human level that feels quite degrading."

Evidence of delays due to funding disputes

While there could be a number of reasons for delays, many contributors to this report provided direct experience of delays that were based on funding disputes. One family carer talked about her husband, who she said had understood the system as he spent his whole career working in local government. She said, *"He knew that it was nothing other than a budgetary battle between social services and the health authority, with both of them having to watch every penny. He had always hoped that compassion and understanding would win when up against the £££ signs, but it wasn't the case. It was so hard to see his face when we heard that we hadn't been granted CHC. It came eventually but really it was too late."*

Delays due to disputes over funding sufficient packages of care

Delays in eligibility decision making regarding CHC were less prevalent in the experience of those working within palliative care. One explained that, *"Most of my experience comes from the hospice, and*

so they would tend to be complex to need a hospice admission anyway. But I think, my gut feeling from dealing with CHC, is that if a health professional provides evidence of the complex nature, they tend to accept that." In their experience, the delays come when the packages of care are being agreed. This can often be due to an inflexible approach to provision of care which causes difficulties and funding disputes over what can be provided. In addition, contributors pointed to examples where care packages were agreed based on arbitrary limits that the LHB had set on the amount of care that can be provided.

The case study below provides an example of this.

MRS D'S STORY

Mrs D was admitted to a hospice due to illness, which stabilised within a few days once antibiotics were provided. However, the illness had resulted in a progression of her MND, and Mrs D remained in the hospice while different packages of CHC care were discussed. This took place through a series of meetings.

At the first of these meetings, a nurse from the hospice told the assessment team that Mrs D needed 24 hours per day care from more than one person. As the meeting concluded, Mrs D was told that 24 hour care could not be provided as packages of that nature are never funded under CHC.

Mrs D's husband said, "So we asked what they could provide and they hadn't even had any discussions about that. So, we were almost in despair - and there were at least two weeks until the next meeting."

In subsequent meetings, a variety of packages were suggested which would not have provided sufficient care for Mrs D and her family to cope at home. Finally, after three months in the hospice, a package of care was put forward that the family felt would be physically possible.

Mrs D's husband said, "My wife and I looked at each other and we were like 'we can work with that, let's go for it'. So, we get three over nights per week - but that still leaves four nights a week where we haven't got someone.

"During the day as well, two carers come at 8am, one goes at 3pm and the other stays until 8pm. So, there is always a period of the day where there is only one carer here. We have to work with that, but it doesn't just leave my wife vulnerable, it also leaves the carer vulnerable as well."

Delays due to lack of joint working arrangements

Examples were also provided of the problems that can occur when shared equipment stores are not available. One professional contributor elaborated on this saying, *"One of the issues with that is, for example, that in one area social services had a piece of equipment in stores which was ready to go, but because it was decided that an individual with MND was eligible for CHC they weren't able to access this equipment. The LHB don't have equipment stores so they had to go out to tender, so this took more time."*

In addition, systemic and cultural barriers, which are either real or perceived/inferred due to precedent, can get in the way of joint working. This occurs despite the national policy intentions. One contributor explained, *"In Wales the government's position for some time has been if you know what is needed you do it, and you haggle afterwards about who is paying for it. I think that is a principled position, of course it doesn't exactly tally with the various bits of statute on who funds care, and it doesn't completely tally with the way people behave in reality at work."*

Principle 5: Understand diagnosis, focus on need

This principle states that health and social care providers must work together to gain a holistic understanding of need and the impact on the individual's daily life. It makes it clear that 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.

Lack of understanding of MND diagnosis

Contributors reported situations in which those involved in assessments did not fully understand what a diagnosis of MND means, in terms of the needs of individuals or the way in which needs are met.

One contributor who supports people with MND said, *"I have heard comments like 'well perhaps he will be walking next month.'"*

Family members described having to explain MND in assessment meetings. Others said that they had to work hard to explain the level of care needed, and felt that this was not listened to. One said, *"I can remember in the meetings it was quite difficult to explain to the people there that caring for someone with MND is a more than one person task."*

Several professional contributors made the point that decision making can be improved when the nurse assessor has established early contact with the individual who is being assessed, and when the MDT includes professionals with an ongoing relationship with them. This is explored more fully in the 'What works' section below.

DST not fit for purpose for people with MND

They also questioned whether the system as it currently stands helps those involved in assessment to build an accurate picture of the needs of individuals with MND.

One professional stated clearly that the DST is currently not fit for purpose for people with MND saying, *"Needs are given the weighted marking of high, low, moderate, no needs. That doesn't work for our patients. It is not as straightforward as that."*

Professionals also talked about the fact that some of the types of needs that people with MND have are not included in the domains of the DST. Those who took part in a focus group gave the example of secretion management, saying that in terms of the DST, *'secretion management doesn't fit into any of the domains so it tends to be left out.'*

Contributors felt that this was because assessors didn't have an appropriate level of knowledge of MND and therefore didn't see the significance of certain needs. In addition, they aren't necessarily able to add critical pieces of 'additional information' such as the nature of MND as a rapidly progressive, life limiting condition.

Needs scored as low because they are well managed

The approach mandated by the DST itself is that *'Needs should not be marginalised because they are successfully managed. Well managed needs are still needs.'*¹⁴ However, examples were given of individuals with MND who were given low scores because their needs were well managed. These included:

- Individuals who use a PEG feeding tube directly into their stomach whose needs were scored as 'low' because they were deemed not to be at risk of choking, even though they would have been at very high risk of choking had they tried to swallow.
- Individuals who had no mobility and used a hoist were scored as having no risk of falling because they were not moving independently, but they would have been at very high risk of falling if they had tried to move.

¹⁴ Decision support tool for Continuing Healthcare, Welsh Government, 2014

- Individuals are classed as either continent or incontinent, even though this doesn't allow for the fact that someone is continent if they are helped to the toilet, but would be incontinent without this assistance.

Another reason why the DST was seen as problematic was that it can be used in a dogmatic way. One contributor who has acted as an advocate for individuals with MND in the assessment process described situations in which assessors go through the form verbatim, without explanation of why certain topics are included or providing context for those involved in the process. Far from making people feel supported through the process, this can be a confusing and upsetting experience. He explained, *"I've seen them ask questions about mental health to a person with MND who has absolutely no cognitive issues at all. So, the carer thinks 'they think my mum has got a mental health problem!'. Why not just talk around the issue in some other way? But the assessors are told, this is your role, to complete this form."*

Focus on the perceived rules of the system, not on the needs of the individual

One professional who works with people with MND felt that those involved in decision making can tend to stick too rigidly to the process, *"Particularly from the people that are assessing, it is just too rule focused and there is no flexibility."*

However, the majority of the restrictions and rules – such as which were stated as fact by contributors - are not actually mandated within the implementation framework. In addition, some would appear to reflect practice which is in contradiction to the implementation framework and case law related to CHC, such as the placing of arbitrary limits on packages of care. For example, one contributor said, *"The most we have ever managed to get is 20 hours of care per week - that makes it impossible for some people to stay at home."*

Barriers to anticipatory planning

The challenge that was raised most frequently was that of barriers to anticipatory planning. It was the understanding of the majority of contributors that the evidence presented as part of a CHC claim needs to be based on current, demonstrable needs as they are in the current moment. Information about the highly likely progression of needs is not accepted. This is particularly problematic for people with MND, because their needs are so complex and can progress so rapidly. Consequently, the needs of individuals are likely to have changed significantly by the time a CHC assessment is complete. One contributor said *"Assessments look at the now but not next week, but people with MND are different every week."*

This means that individuals that professionals feel have clear primary health needs have been initially turned down for CHC because an application was made at a point when their needs were not as far progressed. In addition to funding disputes, this was seen to be a major cause of rejections of CHC claims. One professional said, *"Most of our experience in the day unit is the time it all takes, and then applications being refused because they are about anticipatory planning."* Another contributor explained this further, saying *"You start the DST and something changes. And by the time it gets to panel the information is not correct, it's moved on a stage."*

It is very important to note that this appears to be an approach which has developed through practice, rather than a reflection of what the implementation framework and DST state should occur. In fact, the DST document clearly says *'the domain levels selected should be based on current needs but the likely change in needs should be recorded in the evidence box for that domain and taken into account in the recommendation made'¹⁵.*

¹⁵ Continuing NHS Healthcare – The National Framework for Implementation in Wales, Welsh Government, June 2014

Applications made at the point of crisis

Over time, the established practice that anticipatory evidence is not accepted has led professionals who contributed to this report to feel that applications should only be made at the point when an intervention is urgently needed. One said, *“CHC assessments have to be based on the current situation, not anticipatory. That is a huge problem for professionals that comes up all the time. They can see the way it is going, we need to get a piece of equipment in in time, and yet we can't apply for it because it is not actually affecting the person at the moment, but it will do, shortly. So, we have to wait until it is actually affecting them, and then we can apply for it.”*

This means that when delays to agreeing a care package under CHC occur, the impact is particularly acute. Alternatively, it means that professionals consider CHC to be a less positive option for people with conditions such as MND than making do with social care. These occur for many reasons, such as lack of access to qualified carers, as one contributor explained saying, *“I have seen two cases recently where the individuals did get a CHC 20 hour package, but then it was another four or five weeks to recruit the staff and get them trained, which delayed them from going home. For people with a life limiting illness that is a significant amount of time.”*

Lack of tailored support

Some contributors shared the view that the aim of meetings related to CHC seemed to be more related to ensuring that individuals fit into services which they felt they could provide, rather than providing quality support which is tailored to the individual. Again, many contributors referenced caps that were placed on the amount of care available in their local areas. One professional explained this in detail saying, *“For most of our patients the maximum that CHC will cover is four visits a day, with no night time care. That is the limit for what CHC provides for people at home. But when you literally can't move a finger, and the need to move their thumb two centimetres to the right to make them more comfortable they can't do it, four times a day doesn't scratch the surface of that.”*

Loss of independence

Contributors talked about the way in which challenges related to CHC had resulted in loss of independence for individuals. In one example, residential care was suggested during the CHC assessment of one individual with MND, who is a young woman with a three year old daughter. Her husband described their feelings on this, *“There was talk of care homes, but even the health care professionals were saying that is not appropriate. You know, if she was a 70 year old lady or something you could think maybe that is appropriate. But not a young mother, with a child, who is going to have to go to some nursing home somewhere to see her. It's like no way, that's not right.”* The individual in question explained that the one of the reasons that this was discounted and her package for CHC at home was agreed was that *“I was told there isn't anywhere for me to go.”*

Professionals described situations in which individuals have been institutionalised because it has not been possible to agree a package of care that meets their needs. One professional explained, *“There have been a few cases where people have been institutionalised not against their own will but kind of resigned to the fact that that is all that is going to work.”* They went on to explain that this can have an impact on clinical decision making, *“It affects the decision making before you do an intervention. We have to make patients aware that if they have a gastrostomy put in, which medically they might need, it is potentially going to have an effect on their place of residence.”*

Principle 6: Co-ordinated care and continuity

The sixth principle describes the importance of avoiding fragmented care, saying that every effort must be made to avoid disruption to care arrangements. It also says that every effort must be made to provide smooth and safe transitions where change is required.

Three contributors shared experiences relating to disruptions to care because of issues with continuing care providers. These situations related to individuals being admitted to hospice care because providers had become unavailable. One of these related to the further experiences of Mrs D, whose experience of assessment meetings was covered earlier.

Case study five – Mrs D (continued)

MRS D'S STORY CONTINUED

Mrs D left the hospice after three months, and was able to return home due to the package of care provided through CHC.

10 months after Mrs D had left the hospice, her husband received a phone call to say that the agency that was providing her care was pulling out of Wales. Due to the nature of the contract, this was done very swiftly and the LHB and recipients of care were only notified at the last minute. The LHB had no replacements lined up, and so Mrs D returned to the hospice and remained there for eight weeks.

Mrs D described this as “Abrupt. I felt that I had no control over my life.” She also explained the impact that this had on her and her family saying, “My daughter was just starting school. I missed out and she had to deal with two big changes in her life.”

While a replacement agency was found, Mrs D had to retrain a new set of care workers to meet her needs.

Mrs D's husband highlighted the concerns that their experience raised in terms of the contracts which care agencies have with LHBs saying, “What I couldn't believe, is the contract arrangement between the health board and these companies. As I understand it, the provider companies are on a framework and they set the terms of the contract.”

He went on to suggest ways in which this situation could be improved, “The directors of the care agency, who would have known about their financial situation, should have been talking to the health board saying ‘we are going to be calling in our month's notice soon’, so the health board could be looking around for another company.”

Principle 7: Communicate

The final principle makes it clear that good communication is vital to maintain trust. It says that it is unacceptable for professionals to claim not to have time to communicate, and highlights the fact that extra care must be taken to communicate carefully and using the preferred means of communication with the individual.

Contributors felt that communication between the CHC teams and individuals and their family carers could be improved.

In some cases, the concerns raised related to communication about the progress of a claim. In the case of Mrs A, the family received no communication from the LHB for five months after her claim had been submitted. One contributor who supports people with MND explained, *“One lady actually said to me ‘they slap their folders together and go off, and that's the last I see of them’. I'm not criticising the people who do this, but it is lack of understanding and lack of thought.”*

Other contributors felt that improving communication would mean looking at the way CHC teams approach the meetings. Addressing the adversarial tone and the use of jargon in meetings was seen as a very high priority. They also felt that the involvement of people with an ongoing knowledge of the individual was key.

In addition, contributors felt it was important that professionals should see the meetings as places to find solutions, not opportunities to inform individuals and family carers about the restrictions of the system. One contributor described the way they felt this should be handled saying, *“You do all you can with the options you have. You get all the facts together so when you are there with people, you may have to take something away but you have got something in your pocket to give them. But in the CHC assessment meeting there wasn't any preparation for that.”*

Concerns relating to communication did not always relate to information provided or the way in which things were communicated. They also related to the way in which timing and *“tactics”* are used by professionals in order to manage the outcome. Contributors felt that this can have a significant impact on individuals at a vulnerable, stressful and anxious time. One contributor said, *“I've been to meetings about CHC and rather than actually saying to a carer in that meeting ‘no I am sorry we don't have the budget to be able to do that’ they will make promises or hint at promises and then leave meeting and the expectations of that person that this is all going through, this is wonderful.”*

5.3 What works

In addition to discussing the challenges related to CHC, contributors were asked to comment on what currently works well.

Information and advocacy

One contributor felt that it was useful to give individuals with MND and family carers information leaflets about CHC created by the MND Association prior to their involvement in assessments.

Another talked about the way in which an informed advocate can help to improve the quality of assessments saying, *“It helped that I was there because I was challenging things. I think advocacy is important.”*

Building early relationships with nurse assessor

Professionals explained how helpful it can be when a relationship is established at an early stage between the nurse assessor, which is likely to be a district nurse, and individuals with MND. One contributor said, *“For complex patients you know that the nurse assessors will be involved long term, so I will get them to build a relationship with the patient and get involved in updating the patient. This is useful because the nurse assessor tends to present evidence to the CHC MDT.”*

Establishing these relationships between nurse assessors and individuals with MND, their family carers and professionals who work with them was seen as hugely useful in ensuring that CHC assessments provide a genuine picture of need.

Clinical expertise on CHC MDTs

One professional contributor felt that the quality of the assessment process is improved when those taking part have clinical experience. They explained, *“It is not so much the disease specific expertise that you need, it's just common or garden clinical common sense really.”*

Including people with ongoing knowledge of the individual within MDTs

Contributors suggested it would be useful for CHC assessors to include people who know the individual in MDT decision making to ensure they approach the assessment in the right way. One contributor talked about a situation in which they had flagged concerns saying, *“There is something about trusting people's knowledge of the patient as well. I remember ringing the community team to say a lady was getting worse in our opinion. The district nurses said, ‘oh we called in to see her and she answered*

the door, she was fine' – but actually, she was in respiratory failure and she died within a couple of days of that phone call."

Accepting evidence of highly likely imminent need in appropriate cases

One contributor explained that they have been able to find a way to persuade CHC MDTs to accept speculative evidence on the highly likely progression of needs in order to determine eligibility for CHC. They cited instances where assessment panels had accepted evidence relating to highly likely imminent need based on the way it has been presented, and who has presented it. They explained that a good starting point for this is to be very clear that the needs of people with MND will not reduce over time saying, *"In some cases we have been able to have mature conversations about it. I think where the prediction is more useful is in saying 'this isn't going to get better.'" Once this had been established, evidence can be presented that the needs of someone with MND are more likely to progress, potentially quite rapidly. They explained, "Where a panel might be able to look at it with one eye arched and say 'maybe that is a transient thing; what we can say is 'no – in fact it's going to get worse and we are going to be back to you in a month with a request for additional care."*

They also made it clear that it helps to be honest with panels about the fact that this is still speculative saying, *"In terms of the predictions, I think one of the important things to say is that we don't know exactly what is going to happen to this person, but if you take 100 people in this situation then for 70 of them it is going to get worse over the next month. If the panel needs to review the situation in two months, then do that, but that doesn't change the expectation."*

Flagging patients early

Contributors also felt that the opportunity to flag patients earlier to those involved in CHC decision making, or establishing a relationship between CHC teams and those involved in local condition specific MDTs, could result in a more cost effective process and reduce the need for long delays. One focus group participant said, *"Flagging patients early before they get to the crisis point. We know that it takes time to recruit and get the right care in, and that is all going to happen as a delayed hospital or hospice admission if you can't get CHC started before that crisis point. I think early planning and discussion around this is key."*

Professionals and MND Association staff felt that this might be possible with this type of patient group because they have regular contact with services and are relatively well co-ordinated. One explained, *"Our MND patients are seen in the MDT clinic in theory every three months and that's often the best point to discuss when to initiate that. Individual team members, often physios, would have access to them, would be going in and seeing them in between those three months, and then reviewing at the clinic and the OTs often have input."*

Fast track

One of the elements of practice that is seen as helpful is the fast track system. This is a much-abridged version of the assessment process for people who are nearing the end of life. One contributor said, *"We now have better, more flexible systems for when prognosis is expected to be very short through fast track."* He went on to explain that use of fast track for people with MND *"is the minority, and usually means that we missed a trick earlier on."*

However, other contributors noted instances when they had not been able to proceed quickly enough with fast track as they were not clear of requirements or staff had not been available to complete the assessment.

Others felt that fast track is useful, but that it can be counter-productive in cases where prognosis was unclear as *"You feel with DST that you have a bit more robustness in the decision making, and you are less likely to cause distress because they have to have a reassessment if they are still alive in three months."*

Joint funding of teams and equipment stores

Positive examples were provided of the way that joint health and social care teams, and shared equipment stores, can be helpful in reducing the funding disputes which lead to delays in the provision of care. One professional explained, *"In a neighbouring locality to where I work there is a very good joint health and social care 'let's get people sorted' team, for people with complex needs. Some of them are care workers and some of them are health support workers, and they access some training around MND and found that really useful to give them confidence."*

Flexibility in social care provision through ability to 'top up'

Under the social care system individuals are likely to need to provide at least some of the funding to cover their care. If individuals and their families can afford to, they can pay extra to 'top up' the care they receive in order to improve their quality of life. In addition, innovations such as direct payments can make provision more amenable to the wishes of the individual.

One contributor felt that although CHC is required to meet all of the assessed needs, the fact that individuals are not able to 'top up' the funding they receive in the same way can limit their sense of self determination. They explained, *"The set up under social care is very different, you can employ your own people with direct payments. I am told you can't top up CHC, and you can't choose a more expensive nursing home and make up the difference with CHC funding."*

In England, those who access NHS services are able to use Individual Health Budgets, and the CHC framework has recently been revised to make it possible to 'top up' CHC services to enhance care beyond basic provision to meet assessed needs.

6

CONCLUSION

MND is a rapidly progressive, fatal condition. One third of people diagnosed with MND die within one year of diagnosis, and two thirds die within two years. People with MND do not have time to waste.

The nature of MND means that individuals are highly likely to have needs related to respiration, mobility, secretion management and feeding at some point in the progression of the condition. This means that they will require support from professional carers with specific training and specialist equipment.

Within Wales, coordination of care for people with MND has improved greatly in recent years. As a result of the work of the South Wales MND Care Network, the Powys Neuroscience Network and the Disease Specific Advisory Group in North Wales, as well as MND MDTs, care coordinators, specialist NHS staff and third sector organisations, care for people with MND is more likely to be monitored and their needs are increasingly met through anticipatory care.

However, the experiences and views of contributors to this report demonstrate that CHC is an area where anticipatory care does not happen and the fault lines between health and social care services are particularly prominent. In their view, the drivers for this appear to be financial and administrative. The result they describe is a system which too often treats vulnerable people as adversaries.

Contributors to this report were clear that when CHC works well and is appropriate for the individual, it has the potential to make a significant positive impact. Considering what can be inferred from the challenges raised by contributors, and taking note of the examples of practice which they feel helps CHC to work well, recommendations for change can be made.

7

RECOMMENDATIONS

7.1 Recommendations for Welsh Government

Make CHC a *Healthier Wales* priority area

The 2018 Welsh government policy document *Healthier Wales: Our Plan for Health and Social Care*¹⁶ sets the ambition to bring health and social care services together, so that they are designed and delivered around the needs and preferences of individuals.

A Transformation Programme and Transformation Fund will help to drive the delivery of these goals. As part of this programme, successful regional models will be transformed into national models to be applied across Wales. The Transformation Fund will initially focus on areas such as the seamless alignment of health and social care services and local primary and community-based health and social care delivery.

The evidence presented in this report, as well as previous reports from the Wales Audit Office and WHSC and University of South Wales, paints a stark picture of CHC as a battle ground between health and social care services. It is clear that CHC is a perfect example of an imperfect system, which places pressure on professionals and individuals alike.

Urgent action must be taken to address this. We urge the Welsh Government to consider CHC as a priority area for the *Healthier Wales* agenda and to:

- Commission a review of the legal, structural, procedural and financial barriers which stand in the way of swifter and more effective delivery of CHC.
- Publish data on CHC claims broken down by LHB related to key factors such as numbers of people who apply, numbers of people found eligible, numbers of successful appeals and time taken for decisions to be made.
- Create an action plan to address the budgetary concerns which can act as barriers to delivery at a national and local level.
- Provide Regional Partnership Boards and/or Local Health Boards with funding to develop and promote models of good practice in the delivery of CHC through the Transformation Fund.
- Monitor progress in addressing the challenges of CHC and report on this at a national level as part of the *Healthier Wales* agenda.
- Jointly fund care teams and equipment stores in order to prevent delays in delivery for individuals.

Take urgent action to ensure CHC assessment is not a “harrowing” experience for individuals and families

CHC can make a real difference to the lives of people with MND in Wales, but for too many people the system is not working. In fact, for some it is actively causing harm.

Evidence presented in this report demonstrates that the reality of the experiences of people with MND in relation to CHC falls very short of the intentions set out by Welsh Government in the implementation framework. The system is not working on its own terms.

It should go without saying that assessment for CHC should be conducted in a way which is compassionate and respects the dignity of those who are involved in the process. Individuals and families should be informed and supported. They should be allowed to be involved in the process in a way which ensures they are at the centre of decision making but does not cause them unnecessary distress and anxiety.

¹⁶ A Healthier Wales: Our Plan for Health and Social Care, Welsh Government, 2018

Although these expectations are already written into the implementation framework, the reality of experiences of contributors to this report has been starkly different.

No one working in health and social care services wants to create experiences for individuals and families that are “cold” or “harrowing.” Contributors to this report have made it clear that it is the way in which the current system works, and associated pressures on those involved in assessment, which has resulted in the poor experiences reported. Progress will only be made when these challenges are addressed.

However, it is also critical to refresh the approaches taken by professionals involved in the CHC process and to ensure that they are informed by the needs and experiences of individuals and their family carers.

Welsh Government should require LHBs to provide evidence on the quality of delivery of the core principles of the implementation framework and to include evidence of the experiences of local CHC claimants as part of their regular reporting process. They should also be asked to demonstrate the action they are taking to address concerns, and support the development of good practice.

Revise the National Framework for Implementation of CHC in Wales

Welsh Government has committed to review the CHC implementation framework in 2019. In order to implement this revised framework, good practice guidance and training will be required. This represents a perfect opportunity to address the lack of specificity within the framework which leaves the door open for poor practice and to support consistent and equitable delivery. In particular, clarity should be provided around who should take part in MDT decision making, how person centred planning should be conducted and how evolving needs should be taken into account when determining eligibility.

In addition, this report reveals the ways in which certain ‘red lines’ have been ingrained into the delivery of CHC which do not appear in the implementation framework or DST. These include the requirement to focus only on needs as they are in the current moment, and the arbitrary capping of care packages based on a perception of the way things ‘must be done’.

To assist LHBs and professionals on the ground, Welsh Government should add specific guidance to the framework to clarify what constitutes acceptable practice.

In addition, the implementation framework should be updated to include specific detail on key areas in order to avoid confusion and promote equitable practice, for example:

- Carry over the wording from the 2018 revised CHC framework in England which says the *‘MDT should usually include both health and social care professionals, who are knowledgeable about the individual’s health and social care needs and, where possible, have recently been involved in the assessment, treatment or care of the individual.’*¹⁷
- Provide greater clarity to stress that assessors should provide evidence of *‘the likely change in needs’*¹⁸ which *‘should be recorded in the evidence box for that domain and taken into account in the recommendation made’*¹⁹ and that MDTs should ask for and consider evidence of the highly likely imminent needs so that eligibility can be agreed before people reach crisis
- Include clear statements that arbitrary limits on care packages are not acceptable, as CHC provision must be tailored to the needs of the individual
- Bring the framework into line with updated legislation such as the Social Services and Wellbeing (Wales) Act 2014

¹⁷ National Framework for the Implementation of NHS Continuing Healthcare and NHS-funded Nursing Care, (England), Department of Health and Social Care, October 2018

¹⁸ Continuing Healthcare – the National Framework for Implementation in Wales, Welsh Government, 2014

¹⁹ Ibid

Update the process in order to address key challenges and reflect good practice:

Create an 'early flag' process for individuals who are highly likely to need CHC support, eg because they have a complex and rapidly progressing life limiting condition, in order to ensure that it is possible to proceed swiftly with assessment when CHC funded care is likely to be needed

Address the limitations of the Decision Support Tool

DST not fit for purpose for conditions such as MND

Many concerns were raised by contributors to this report about the limitations of the DST in creating an accurate picture of the needs of people with MND. It is safe to assume that these concerns would be likely to also apply to other conditions which result in support needs related to breathing, feeding and secretion management.

Welsh Government should work with professionals who support people with these needs, individuals with relevant conditions and family carers in order to improve the DST to better reflect these needs.

In doing this, they should:

- Add key areas which the DST does not cover such as secretion management
- Provide guidance and training which helps assessors to understand the level of detail which should be included in order to accurately describe the needs of individuals, particularly in relation to the nature of a specific condition and the cumulative effect which different needs can have on each other
- Make it clear that input should be sought from health and social care professionals, who are knowledgeable about the individual's needs and, where possible, have recently been involved in the assessment, treatment or care of the individual

Empower assessors to improve the way in which the DST is used

Welsh Government should create good practice guidance and training which empowers assessors to use the DST in a way which is not dogmatic, but is sensitive to individuals and promotes understanding of the process.

Guidance and training should also provide assessors with an understanding of the importance of gaining as much information as possible about the nature of an individual's condition, the impact of the needs that they have and any other potentially relevant information – such as the likelihood of swift progression of an individual's needs. In addition, that this information should also be gathered from professionals who are knowledgeable about the individual's health and social care needs and, where possible, have recently been involved in the assessment, treatment or care of the individual.

Increase the availability of trained care workers and nursing staff

Health Education and Improvement Wales (HEIW) is a special health authority within NHS Wales. Sitting alongside health boards and trusts, HEIW has a leading role in the education, training, development and shaping of the healthcare workforce in Wales. Its key functions include: education and training, workforce development and modernisation, leadership development, strategic workforce planning, workforce intelligence, careers, and widening access.

HEIW should be tasked with considering the way in which workforce development could contribute to the improvement of CHC. Key factors to consider would be the potential to provide additional non-conditions specific training in meeting the needs of individuals with complex conditions. There is also a need to consider staffing levels for the provision of CHC to ensure sufficient numbers of staff are available within the system. This could help to avoid costly delays and early admission to residential care.

7.2 Recommendations for Local Health Boards

Take urgent action to improve local delivery of CHC

The implementation framework for CHC in Wales states that 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
- The provision of strategic leadership, organisational and workforce development, and ensuring local systems operate effectively and deliver improved performance.²⁰

Action is being taken to improve CHC practice within individual LHBs. It is these areas of good practice that will be critical to the success of any new models developed through *Healthier Wales*, and their development should be supported through Transformation Fund investment.

However, it is clear from the experiences of contributors to this report that CHC is not currently being consistently delivered according to the requirements set out in the implementation framework.

Swift action should be taken by LHBs to address the disconnect between the policy intention set out in the framework and the reality of delivery on the ground.

This should include the introduction of:

- Zero tolerance of adversarial approaches within CHC meetings which include individuals and family carers, alongside a user friendly feedback process which allows people to flag concerns or make complaints when necessary.
- Monitoring mechanisms to ensure that LHBs can be confident that their staff are delivering the commitments set out within the implementation framework effectively.
- Resources and support for CHC assessors to help them to create strategic relationships, for example with local planning groups for conditions that are likely to result in CHC claims such as the South Wales MND Care Network or North Wales MND Disease Specific Advisory Group.
- Good practice sharing mechanisms for CHC assessors which consider areas such as the use of expert opinions in assessments, building local networks with care coordinators for individuals with relevant conditions.
- Specific support, guidance and training to help assessors develop skills in co-production with individuals and family carers.

Again, this work should be informed by the participation of individuals, family carers, relevant professionals and third sector organisations.

Redesign provider contracts to ensure terms do not disadvantage those who are recipients of CHC

LHBs should review and redesign their contract arrangements with care providers for CHC, to ensure that they are not able to withdraw their services so swiftly that vital care for individuals is disrupted.

²⁰ Continuing Healthcare – the National Framework for Implementation in Wales, Welsh Government, 2014



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