

National Federation of Women's Institutes

2015 Annual Meeting Resolution Briefing Notes

Overview

The NFWI Public Affairs Department has compiled these notes to facilitate members' discussions on the resolution that will be voted on at the 2015 AM.

The notes outline the key issues addressed in the resolution, the current status and policy environment on the issues raised, and the main groups already working on the subject.

Please use the notes to inform your further research.

2015 Resolution

Failing to care – assessment of need in long term care

This meeting calls on HM government to remove the distinction between nursing care and personal care in the assessment of the needs of individuals, in order to advance health and wellbeing.

North Duffield WI, North Yorkshire East federation

These briefing notes are available online at www.theWI.org.uk/resolutions and on the Moodle. For further information contact:

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Proposer's Position

The proposer is concerned that 'inequality in how needs are assessed' is leading to 'vulnerable patients being denied their right to NHS Continuing Care' resulting in an unfair system, in which many families are having to rely on local authority social care, to which they may have to contribute financially.

Overview

Some people need practical or emotional care or support to lead an active life and do everyday things. In England and Wales this is called social care. Having meals delivered, help with washing, dressing, feeding or using the toilet, can make a big difference to people's lives. Social care is also about giving help in the home with things like cleaning and shopping; adaptations to make the home safer; day centres and care homes; and financial support.¹ An estimated 2 million older people in the UK have social care related needs.² Local authorities delivered £19 billion worth of social care services in 2012-13,³ and over 1.5 million people work in the social care sector (employed by local authorities, independent providers, the NHS or directly by those needing care).⁴ About 420,000 people are currently living in care and nursing homes across the UK, while about 1 million get help in their own home.⁵ There are another 1.5 million people who rely on friends and family for support. This unpaid care equates to £119 billion every year.⁶

In England and Wales there is a NHS funding package, called 'NHS Continuing Care'. This is arranged and funded by the NHS for people that are not in hospital but have complex ongoing healthcare needs requiring full time care. This may include services from a community nurse or specialist therapist, and help with bathing and dressing for example. To be eligible for NHS Continuing Care individuals must have a medical condition which often involves complex, ongoing and significant care needs. A person must have a 'primary health need', which means that your main or primary need for care must relate to your health. Patients receiving NHS Continuing Care do not pay any fees.⁷ 58,809 people were listed in receipt of NHS Continuing Care in England at the end of 2013.⁸

The resolution concerns the uneven access to NHS Continuing Care, despite a National Framework being in place to guide England and Welsh authorities. The Framework is designed to guide clinical commissioning groups in assessing people for eligibility to access the fund. In order to assess eligibility, a 'Decision Support Tool' which considers needs across a range of areas from breathing, to skin (including ulcers and wounds) continence, mobility and nutrition, is also in place to help ensure national uniformity in the award of NHS Continuing Care.

Despite these levers being in place to help with consistency in decision making about eligibility, concerns have been raised by health groups and campaigners about fair and consistent access to NHS Continuing Care and poor public awareness about the package. Individuals that are assessed as having 'personal' caring needs as opposed to 'health' care needs, may have to pay for their care as part of the local authority care and support system. This can have significant financial implications for individuals. The local authority care and support system is often referred to as 'in crisis'. There have been several successful court cases where people have fought for access to the free NHS Continuing Care they need to meet the physical and mental health care needs resulting from disability, illness or injury.

However, there are millions of people in Britain who have social care needs that NHS Continuing Care will not fulfil. Cuts to local authority social care budgets have had severe consequences. A recent study by the Strategic Society Centre estimated that 1.4 million older people 'who struggle to look after themselves do not receive community support'.⁹ Richard Humphries, an expert in social care policy at the King's Fund think tank, believes the current outlook is far bleaker than most people realise.¹⁰ The NFWI's own Social Care Conference in 2013 discussed the massive impact on society and the economy when a person is diagnosed with dementia every three minutes in Britain.

Focussing on making sure a limited number of individuals get access to the free NHS Continuing Care that they need does not necessarily address these wider, systemic challenges which are also having a tremendous impact on WI members and their families, as well as the wider public, today, and will continue to do so in the future.

Recently, more and more health organisations, think tanks and health experts have come to the conclusion that only a radical change to health and social care in Britain can ensure that we have a care system which is financially sustainable and delivers care with dignity and compassion into the 21st century.

About NHS Continuing Care

Individuals over the age of 18 must have complex and significant health needs over an extended period to be eligible to access NHS Continuing Care. A National Framework is in place which sets out the process which clinical commissioning groups must follow when assessing a person for eligibility. There have been several court cases in England and Wales that have influenced debates around NHS Continuing Care eligibility, such as that of Pamela Coughlan who decided to go to court following an attempt by the NHS to move her from an NHS-funded residential facility to a social services-funded facility. Cases such as this have provided a landmark, establishing how access should be granted and leading to the development of the National Framework, and the accompanying 'Decision Support Tool', used to help with consistency in decision-making. Yet campaigners and advocates claim many authorities do not acknowledge these cases and carry out the assessment improperly, denying people access to the free health care they are entitled to.¹¹ There has also been speculation that because 'Decision Support Tool' thresholds are higher than those set out in case law, should Pamela Coughlan be reassessed under today's thresholds, she might not receive Continuing Care, despite the importance of her case in establishing the legal precedent.¹²

Recently in Wales, a court case over access to Continuing Care has ruled a family was unfairly denied, and those who had paid for nursing care between 1 April 2003 and 31 July 2013 were encouraged to register their intent for reimbursement by the end of July 2014. But only 93 families had made enquiries by the end of that period despite a Welsh government advertising campaign, suggesting that public understanding of the case or the system is poor.¹³

In March 2013, the All Party Parliamentary Group on Parkinson's, a cross-party group of MPs and Peers, with an interest in the condition, launched a unique inquiry into NHS Continuing Care. The Group's report, *Failing to Care: NHS Continuing Care in England* was based on evidence from 12 organisations and 41 individuals. It found the system was not fit for purpose, and abandoned people at their most vulnerable. Particular problems with the assessment process and the complexity of the system were highlighted. Based on the report's recommendations, in November 2013, the charity Parkinson's UK launched its 'Failing to Care' campaign.¹⁴ It has since worked closely with NHS England, the Department of Health, the Parliamentary and Health Service Ombudsman and Healthwatch England to examine ways to improve the system. As part of its campaigning it has established the 'Failing to Care Coalition' which brings a range of organisations together to campaign for improvements to NHS Continuing Care. The Alzheimer's Society, MS Society, MND Association and several others are part of the Coalition.

Alzheimer's Society believes that there are many more people who should be getting NHS Continuing Care but are not because they do not know how to apply or have been wrongly denied funding.¹⁵ They are calling for health authorities to promote public awareness of NHS Continuing Care and increased knowledge of the scheme among health and social care professionals. They have set up a NHS Continuing Care Volunteer Support Group which offers advice to people who have been turned down for NHS Continuing Care funding and want to challenge the decision.¹⁶

The NHS Continuing Care system is not designed to replace the social care system; the court cases which patients have won have not concluded that social care should be free for everyone on the NHS. It is purposefully designed to help a small section of people with severe and enduring health problems. The Money Advice Service advises that 'most people with long-term-care needs don't qualify for NHS Continuing Care: 'There's no clear-cut list of health conditions or illnesses that qualify for funding and not everyone with ongoing health needs will be eligible. The assessment is quite strict, and being frail isn't enough.'¹⁷

While a small section of people battle for access to NHS Continuing Care, millions of other people are living with social care needs in a system that is being stretched to breaking point, and where there is almost universal agreement that major change is necessary.

The NFWI may wish to look at the resolution more widely to encompass how we assess and meet the health and care needs of people throughout their lives, whatever frailty or illness they face.

What's wrong with social care in Britain?

As the demands for social care increase as the population ages, over a third of local government spending goes on social care. Local authorities have long complained that social care is chronically underfunded - over the last five years, local authorities have been given 37% less money to deliver social care services.¹⁸ In the past 10 years, the number of people aged 65 and over in England has increased by 1.4 million, a 17% rise.¹⁹ The result is a "ridiculous situation," according to head of the Local Government Association, David Sparks. "It's basic arithmetic. If you freeze local council spending and the population is increasing all the time and the demand for services is increasing, it means other people will suffer. There's an inadequate amount of funding going in for a civilised level of care in the 21st century".²⁰

Age UK research shows the impact of the cuts between 2010-11 and 2013-14. The overall number of people getting social care help from councils has dropped by one fifth. 185,000 fewer people are getting help at home for tasks such as washing and dressing, and the number of people getting meals on wheels fell to 29,500 - a decline of 64%.²¹ Research by the BBC shows the average amount of care spending per person over the last 10 years has dropped by 20%.²² Age UK director, Caroline Abrahams said: "Our state-funded social care system is in calamitous, quite rapid decline.... Hundreds of thousands of older people who need social care are being left high and dry. The lucky ones have sufficient funds to buy in some support, or can rely on the goodwill of family, neighbours and friends. But there are many who are being left to struggle on entirely alone".²³

The passing of the Care Act 2014 and the Well-being of Future Generations (Wales) Bill has helped to standardise who gets Local Authority social care and who doesn't. The Westminster Act creates a national minimum eligibility threshold across England. Where an adult's or carer's needs reach this threshold, the local authority has a legal obligation to consider how these needs can be met and, depending on their financial means, the local authority may be under a duty to provide services to meet these eligible needs. By creating a new national minimum threshold the Act aims to ensure that there is clarity and consistency around local authority determinations on eligibility.²⁴ Similarly in Wales, the new Act provides a single statutory framework covering local authorities' responsibilities in relation to all those who need care and support, and including their carers.²⁵ The government in Wales says the new system will focus on people's wellbeing and the prevention of problems.²⁶

However, Richard Hawkes, chair of charity coalition the Care and Support Alliance, said that the threshold had been set too high, leaving too many people without access to Local Authority help. He argued that the "only long-term solution to the crisis in care" was an increase in funding.²⁷ Similarly, the Public Accounts Select Committee was concerned the government "do not fully understand the scale of the challenges facing local authorities, or the costs associated with implementing the Care Act".²⁸

The government has also introduced a 'cost cap' following on from the Dilnot Commission on social care finance. From April 2016 the government is capping care costs after the age of 65 at £72,000 over the rest of a person's life. However, concerns about shortcomings with this system have been raised. Only when an individual is deemed to be eligible for care does their spending count towards the cap. But 'eligibility' is only rationed to people with high care needs. More than 4 million people aged 65 and over - about one in two - have what could be classed as a care need, according to the charity Independent Age. For half, it will be a pretty low level need. But of the remaining 2 million, only between 500,000 and 1 million older people - the estimates suggest - would qualify for help in the new system. "It means there will be an awful lot of people paying for care or relying on friends and family who are not even classed as being 'in the system'. Any expenses they incur will not even count towards the cap."²⁹

The care sector also suffers from a crisis in employment. Flagged by the Low Pay Commission as a sector of concern, the pay of a typical direct care worker hovers not far above the national minimum wage. Alongside low and sometimes illegal pay levels, one-third of social care workers are employed on zero-hours contracts. Training is infrequent and basic, lacking a focus on common job requirements such as caring for those with dementia.³⁰ Increasing demand for services may create close to 1 million additional jobs in the next decade, but commentators say pay must improve to ensure people have more incentive to work in the sector; low pay threatens the viability of a service that "we or our loved ones will probably require at some point."³¹

What can be done?

By December 2014, accident and emergency units in England missed their waiting time targets for the 80th week in a row.³² Similarly, only 81% of patients were treated within four hours at A&E units in December in Wales when the target is 95%.³³ Part of the reason for these failings was the situation with social care. Charities say that wards are full because a lack of social care in the community means far too many elderly people remain in hospital when they could have been sent home, with the right support.³⁴ The example of the pressure of A&E units this winter shows how social care and the NHS are inexorably linked in people's lives and the way the systems work together impacts their overall wellbeing. NHS England is hoping local clinical commissioning groups will begin to use their 'NHS' spending for innovative, preventative social care that stops costly NHS treatment down the line³⁵ – funding home improvements to keep people safe and warm in their homes, for example.

On a grander scale, Carers UK, the King's Fund, Age UK and many other expert groups and charities believe a radical new way of jointly approaching health and social care is the only way Britain will be able to care for its elderly population sustainably, with compassion and dignity.³⁶ They believe the distinction between the entire NHS and social care budget isn't working for service users and isn't the best use of scarce public resources. Carers UK says:

In the current system the distinctions between what are health needs and what are social care needs are often arbitrary, contested by professionals on both sides and incomprehensible to families and service users. Carers UK firmly believes in the principle of equal support for equal need and that the needs of older and disabled people and carers should be the priority – not how those needs are viewed through the different prisms of the NHS and social care.... we are not yet convinced that case for the structural reorganisation which this would entail has been made... but in line with our members' views, believe that risk should be shared - with general taxation providing the right mechanism for funding both health and social care.³⁷

Age UK says,

NHS and social care, often perceived as a single service, cannot be fully fit for purpose until they work effectively together.... Age UK believes there must be a singular focus on delivering a seamless service that maintains wellbeing and independence. Better coordination of health and care is a long-standing priority for Government, regardless of which party is in power .³⁸

The independent Commission on the Future of Health and Social Care in England (the Barker Commission) concluded in its September 2014 report that moving to a single, ring-fenced budget for the NHS and social care, with a single commissioner for local services was appropriate for a health and care system fit for the 21st century.³⁹ The Commission, 'recommends a focus on more equal support for equal need, which in the long term means making much more social care free at the point of use.' Because of this, the Commission estimates that an extra £5 billion will be needed and so a 'comprehensive review of various forms of wealth taxation needs to be undertaken.'⁴⁰

Carers UK has also identified the need for better information and support for people and their carers in the current system. 1 in 5 carers receive no practical support, an estimated £1 billion in carers' benefits go unclaimed each year and 42% of carers have missed out on financial support as a result of not getting the right information and advice. Many people do not know about the benefits they could get to help them, or feel demonised if they claim because of a culture of 'benefits scroungers'.⁴¹ 17% of carers report being treated negatively because they received benefits and a shocking 14% had been victims of crime like damage to property or verbal abuse.⁴² Similarly, Age UK point to recent changes with pensions and the legal system making access to information and advice even more important. 'For many older people, face-to-face advice is also important, but the local voluntary organisations that provide such services struggle to maintain stable funding.'⁴³

The NFWI's work in the 1990s with the *Caring for Rural Carers* project focussed on information for those with caring needs and their carers, using the network of WIs as a support system across England and Wales. With the passing of care legislation in England and Wales and the new 'care cap', the situation for health and social care has changed and the NFWI could be well placed to help WI members navigate new territory with confidence.

Points to consider

- Recent court cases have found that people have been incorrectly denied access to NHS Continuing Care. In calling for more uniform assessments, and publicising NHS Continuing Care, the NFWI could help make sure more people get the care they need when suffering from illness.
- As the population ages and people's needs bisect the arbitrary health and social care divide, the arguments for merging health and social care are more compelling than ever. An integrated health and social care system could benefit millions of people and safeguard the care system for generations to come. The resolution is concerned with ending the blurred boundaries between nursing and personal care for a relatively small, yet vulnerable, section of society, but does the solution lay in ending the distinction between 'NHS health care' and 'local authority social care' for all of us, for the future?
- The resolution does not address the wider problem of finding a sustainable solution to shore up social care funding for the future; is there a risk that some people could consider the NFWI looks out of touch by having such a narrow focus on a major issue and calling for an impractical 'solution' to the funding crisis?
- If more people are granted access to the NHS Continuing Care fund, that simply places the burden of cost onto the NHS instead of social care, and the NHS is facing its own £20 billion

funding problem. More money must be put into both systems if demand for complex, multi-faceted health and care demands are to be met.⁴⁴

Existing NFWI mandates on the issue

- That it be the recognised policy of the National Federation of Women's Institutes to take full advantage of all existing health services and to do all in its power to secure such further development, both practical and educational, as may help to improve the standard of health of the rural population. *NFWI Executive Committee, 1928.*
- This meeting urges all WI members to press for the provision of more Day Hospitals, Day Centres and ancillary services, thus enabling older members of the family to share the home without undue hardship and stress for the younger generation. *Sonning Common WI, Oxfordshire Federation, 1967.*
- That this meeting urges the government to provide a sufficient allowance for a housewife disabled by chronic illness, injury or congenital handicap, to remain in her own home and so enable the family to live as a unit. *Newham WI, Gloucestershire Federation, 1968.*
- This meeting of Women's Institutes urges its members to promote and support the provision of hospice care for those patients who desire it. *Stockland WI, Devon Federation, 1983.*
- This meeting urges HM government to ensure that full support is available to assist school-aged children who are carers in order that their welfare and education are protected. *Broughton Pastures WI, Buckinghamshire Federation, 1998.*
- This meeting calls upon HM government to take urgent action in order to ensure that the necessary facilities and services are provided to enable older people, irrespective of their means, to spend their remaining years in comfort and dignity, whether this be in their own home, or in a nursing or residential home of their choice. *Sheringham Evening WI, Norfolk, 2003.*

Other campaigns and further information

Parkinson's UK

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Tel: 020 7931 8080

Web: www.parkinsons.org.uk

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Endnotes

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