



Consortium for the Regional Support for Women in Disadvantaged and Rural Areas

Response to: The Reform of Adult Social Care

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Foyle Women's
Information
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Women's Regional Consortium: Working to Support Women in Rural Communities and Disadvantaged Urban Areas

1. Introduction

1.1 This response has been undertaken collaboratively by the members of the Consortium for the Regional Support for Women in Disadvantaged and Rural Areas (hereafter, either the Women's Regional Consortium or simply the Consortium), which is funded by the Department for Communities and the Department of Agriculture, Environment and Rural Affairs.

1.2 The Women's Regional Consortium consists of seven established women's sector organisations that are committed to working in partnership with each other, government, statutory organisations and women's organisations, centres and groups in disadvantaged and rural areas, to ensure that organisations working for women are given the best possible support in the work they do in tackling disadvantage and social exclusion.¹ The seven groups are as follows:

- ♀ Training for Women Network (TWN) – Project lead
- ♀ Women's Resource and Development Agency (WRDA)
- ♀ Women's Support Network (WSN)
- ♀ Northern Ireland's Rural Women's Network (NIRWN)
- ♀ Women's TEC
- ♀ Women's Centre Derry
- ♀ Foyle Women's Information Network (FWIN)

1.3 The Consortium is the established link and strategic partner between government and statutory agencies and women in disadvantaged and rural areas, including all groups, centres and organisations delivering essential frontline services, advice and

¹ Sections 1.2-1.3 represent the official description of the Consortium's work, as agreed and authored by its seven partner organisation

support. The Consortium ensures that there is a continuous two-way flow of information between government and the sector. It also ensures that organisations/centres and groups are made aware of consultations, government planning and policy implementation. In turn, the Consortium ascertains the views, needs and aspirations of women in disadvantaged and rural areas and takes these views forward to influence policy development and future government planning, which ultimately results in the empowerment of local women in disadvantaged and rurally isolated communities.

1.4 The Women's Regional Consortium appreciates the opportunity to respond to the Reform of Adult Social Care consultation. This is particularly the case given that care is a gendered issue which impacts disproportionately on women who are the main providers of both paid and unpaid care work. As the Family Resources Survey shows across the United Kingdom in all age groups, up to the age of 74, women were more likely to provide informal care than men (2.7million female versus 1.8million male).² In Northern Ireland statistics show that in 2019/20, 7% of the population were informal carers in Northern Ireland and 65% of the adult carers were female compared to 35% male.³

1.5 Throughout this response the Consortium has sought to ensure the voices of women are represented. We believe that it is essential for policy makers and Government to listen to the voices of the women who live here and for whom caring has such significance in their lives. We have attempted to include throughout this response some of what local women have said at focus group sessions in relation to care and which detail their lived experience of providing care. Their words are included as quotes throughout this document.

² Family Resources Survey 2019/20, Department for Work and Pensions, March 2021
<https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2019-to-2020/family-resources-survey-financial-year-2019-to-2020#care-1>

³ Family Resources Survey 2019/20, Department for Communities, November 2021
[The Family Resources Survey for Northern Ireland 2019-2020 \(communities-ni.gov.uk\)](https://communities-ni.gov.uk/the-family-resources-survey-for-northern-ireland-2019-2020)

1.6 We wish to endorse the response made by Carers NI. We fully endorse their response and support their recommendations in relation to the reform of adult social care in Northern Ireland.

2.0 General comments

In Northern Ireland there are 318,000 carers and it is estimated that by 2037 the number of carers is expected to grow to at least 400,000. Carers' support in Northern Ireland has been valued at £6.93 billion for a full year outstripping the value of the NHS.⁴

Caring remains a gendered issue and it is still very much seen to be seen to be “women’s work”. In more traditional, patriarchal societies like Northern Ireland it often falls to women to provide this care. Figures show that 64% of carers are women and 36% are men. Around 1 in 5 women aged 45 to 54 are providing unpaid care to someone with a disability or illness, or who is older.⁵

Northern Ireland has a large rural population. Over 80% of the Northern Ireland land mass is rural and more than one in three of the population (36%) live in rural areas.⁶ Research by the Northern Ireland Rural Women’s Network (NIRWN) shows that rural women are under increasing pressure from the economic climate: *“Historic underfunding of rural women’s activities and underinvestment in rural areas; centralisation of service support; lack of infrastructure, and the burden of caring responsibilities is leaving rural women experiencing more poverty and social isolation than ever before.”*⁷

In addition, Northern Ireland is a small business economy. Small businesses account for 99.9% of all businesses in Northern Ireland and employ more people

⁴ State of Caring 2021, A snapshot of unpaid care in Northern Ireland, Carers NI, March 2022
[State of Caring in Northern Ireland - Carers UK](#)

⁵ Ibid

⁶ Key Rural Issues, Northern Ireland 2019, Department of Agriculture, Environment and Rural Affairs,
<https://www.daera-ni.gov.uk/sites/default/files/publications/daera/Key%20Rural%20Issues.pdf>

⁷ Rural Women’s Manifesto, NIRWN, September 2015

<https://www.nirwn.org/wp-content/uploads/2016/12/NIRWN-Rural-Womens-Manifesto.pdf>

than all the larger businesses and the entire public sector combined.⁸ It can be more difficult for small businesses to provide flexible working opportunities and to provide enhanced leave for carers as they can experience more problems with disruption to their business.

“NI lags behind the UK in support for carers. The Bill of Rights would help to give carers more rights.”

2.1 Caring and Women

Statistics outlined above, both locally and nationally, show that women are more likely than men to provide care. By the time they are aged 46, half of women have been a carer. Men have the same 50:50 chance by age 57 – eleven years later.⁹

The Women and Equalities Committee said in 2016 about the causes of the gender pay gap: *“a large part of the gender pay gap is down to women’s concentration in part-time work. Many women are trapped in low paid, part-time work that doesn’t make use of their skills. This is partly due to women’s disproportionate responsibility for unpaid caring, but also because many of the sectors women work in, like retail and care, offer predominantly low-paid, part-time work.”*¹⁰

These findings show that caring is a feature of many women’s lives and typically happens at a younger age for women than men. This means that women are more likely to find themselves in a caring role at an age when they would be expected to be in paid work. Women are more likely than men to be forced out of the labour market by caring responsibilities. Caring affects their participation in the workforce and ultimately reduces their earnings over their lifetime. This has clear implications for gender equality.

⁸ <https://www.fsb.org.uk/standing-up-for-you/national-offices/northern-ireland>

⁹ Will I care? The likelihood of being a carer in adult life, CarersUK, November 2019
http://www.carersuk.org/images/News_campaigns/CarersRightsDay_Nov19_FINAL.pdf

¹⁰ Gender Pay Gap, Second Report of Session 2015-16, House of Commons Women and Equalities Committee (HC 584), March 2016
<https://publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/584/584.pdf>

The issue of unpaid care has been brought into sharper focus as a result of the Covid19 pandemic. New figures released by Carers UK for Carers Week 2020 show an estimated 4.5 million people in the UK have become unpaid carers as a result of the Coronavirus pandemic.¹¹ These figures show that of all unpaid carers, 58% are women and 42% are men.

“The value of care, care work and all the stuff normally done within the home. It is at the root of everything and why women can’t participate properly. Caring work is not valued in society and is the bedrock of everything. There is a circular relationship between not valuing care work and undervaluing women. It is undervalued because it is something that women do – there is underlying misogyny.”

“We should all go on strike! We saw what happened with Covid in the emergency responses women were always sidelined. There is a need to value what women do. Women are always the add on at the end and it’s totally frustrating.”

“Caring mostly falls to women, it’s a big issue for women.”

“It is just expected that a daughter will take on a caring role.”

“There is still the assumption that it is women who will provide care. If there is care needed it is assumed that women will provide it whether for parents, children or grandchildren. Women are expected to care yet there are not the services there to support them.”

“Women are often forced out of education/training/work to provide care – it often looks like a choice but it is not. They get stuck with a meaningless right but with no way to exercise it.”

“I got no support to care for my aunt at all other than carers calling in. It was all boys in the family so I was asked to do it. I was staying with her until the carers were organised.”

“It’s a fairly common view that women will be the ones to provide care.”

¹¹ Carers Week 2020 Research Report: The rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak, Carers UK, June 2020
https://www.carersuk.org/images/CarersWeek2020/CW_2020_Research_Report_WEB.pdf

2.2 The Personal Impact of Caring

Caring can be difficult and can put stress on a carer's health and wellbeing. Carers Week research¹² found that 6 out of 10 people (61%) said their physical health has worsened as a result of caring, while 7 out of 10 (72%) said they have experienced mental ill health. Carers providing 50 hours or more of care per week are more than twice as likely to be in bad health than non-carers.

Carers can experience loneliness and isolation particularly if they are providing substantial amounts of care. Carers are seven times more likely to say they are always or often lonely compared with the general population. Over half (54%) of the population of the UK say they are never or hardly ever lonely compared with just 1 in 5 (21%) of unpaid carers in Northern Ireland. Just over 7 in 10 (74%) of all carers reported having ever felt lonely or isolated as a result of their caring role.¹³

Research by Carers NI¹⁴ also revealed that carers in the UK are nearly twice as anxious as the general population. Carers in Northern Ireland reported significantly lower life satisfaction and lower happiness compared with the NI average and their anxiety levels were almost twice as high as those reported by the population of Northern Ireland as a whole (5.3 compared to 2.7).

The case of Barbara MacArthur, a 93-year old sole carer for her disabled son received a huge reaction on social media following her letter to The Guardian.¹⁵ Barbara described her life as a carer for her son as *"continuous years of strain"* and that she felt that *"more cutbacks mean that there is even less help available than ever."* She also described that in her 60s and 70s she was *"caring for elderly relatives for 16 or 17 years who otherwise could have cost the state quite a lot as they had no money, but they dreaded the thought of going into care so gave up their council flat to live with us. It was hard, unpaid work as I was ineligible for Carer's Allowance."*

¹² Supporting Carers to be Healthy and Connected, Research Summary for Carers Week 2018, Carers UK, June 2018

https://www.carersweek.org/images/Resources/CW18_Research_Report.pdf

¹³ State of Caring, A snapshot of unpaid care in Northern Ireland, Carers NI, October 2019
<https://www.carersuk.org/northernireland/news-ni/state-of-caring-in-northern-ireland-2019>

¹⁴ Ibid

¹⁵ <https://www.theguardian.com/society/2020/jul/29/at-93-i-am-still-my-sons-sole-carer>

The Covid19 pandemic has also had an impact on the health of carers. Almost two thirds of carers (64%) say that their mental health has worsened as a result of the pandemic. This was significantly higher for carers who were struggling financially (74%). 65% of women said their mental health had suffered compared to 58% of men. 58% of carers say their physical health has worsened as a result of the pandemic. This was slightly lower for men (54%) compared with (58%) of women, but carers who were struggling financially had seen a higher impact on their physical health with 70% having seen it worsen as a result of the pandemic.¹⁶

“Care doesn’t stop.”

“It is just expected that we will continue to provide this care for nothing.”

“I was writing down a list of all the jobs I have ever done in my life, volunteering, etc. But I didn’t think to write down I’m a full-time carer. I forgot. It’s a very lonely experience. We should all celebrate what we do as carers and be very proud.”

“The country relies on carers. They are not appreciated the way they should be.”

“Two years ago I had to leave work and become a full time carer for my son who has autism. I felt very lonely when I left the job.”

“When you are caring for someone who is not well, you never know what the next day will bring so it’s hard to plan in advance.”

“All those providing unpaid care – they don’t get to participate in society in the same way.”

“My sons have Asperger’s and they are 43 but there is no support available for them. I worry about them every day. It’s always the women who have to pick up the pieces.”

“I feel that there is almost a discrimination there between those who care for people who are mentally ill compared to those who are physically ill. I feel that those with mental illness are discriminated against and treated like it is less.”

¹⁶ Caring behind closed doors: six months on, Carers UK, October 2020
[Caring behind closed doors Oct20.pdf](#)

“I’m over 80 and live along with my son who has mental health issues and I care for him. I have friends who live alone and they get a discount on their rates. I care for my son (unpaid) and I don’t qualify for the discount because my son lives with me. That’s not fair.”

2.3 Covid and Caring

The Covid19 pandemic and subsequent lockdown has brought a sharp focus on the importance of caring. Care work is the invisible unpaid contribution to the economy that has largely been unrecognised and accounted for. The pandemic has shown that care work, mostly carried out by women, is vitally important to the economy yet is massively undervalued and needs to be at the forefront of social and economic recovery plans.

New figures released by Carers UK for Carers Week 2020 show an estimated 4.5 million people in the UK have become unpaid carers as a result of the Coronavirus pandemic.¹⁷ This adds to the 9.1 million unpaid carers already providing care before the outbreak, bringing the total to 13.6 million. There are 2.8 million extra workers juggling work and unpaid care since the start of outbreak. These figures show that of all unpaid carers, 58% are women and 42% are men and that of the unpaid carers who have started caring since the start of the pandemic 59% are women and 41% are men.¹⁸

Carers NI have reported that around 290,880 people in Northern Ireland are supporting a relative, close friend or neighbour because of chronic illness including mental ill-health, dementia, disability or old age. Carers NI found that the number of unpaid carers in Northern Ireland has increased by more than 70,000 since the start of the pandemic meaning that a fifth of adults are working as unpaid carers.¹⁹

¹⁷ Carers Week 2020 Research Report: The rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak, Carers UK, June 2020

https://www.carersuk.org/images/CarersWeek2020/CW_2020_Research_Report_WEB.pdf

¹⁸ Ibid

¹⁹ <https://www.irishnews.com/news/northernirelandnews/2022/06/08/news/fifth-of-adults-in-north-working-as-unpaid-carers-report-shows-2736414/>

A survey by Carers UK in April 2020²⁰ showed that 70% of unpaid carers in the UK are having to provide more care for their loved ones during the Coronavirus outbreak. On average carers are picking up an additional 10 hours of unpaid care per week, helping their loved ones with personal care, practical tasks and emotional support. A third (35%) of them are providing more care because their local care and support services have been reduced or closed. This has particular impacts for many women who may find themselves unable to return to work if special schools, day centres and other support services are not in place.

Specific to Northern Ireland Carers UK research²¹ found that:

- 15% of respondents said they were already providing care before the Covid19 outbreak (212,000 people) and a further 7% stated that they have started caring since the outbreak (98,000 people). Using population projections, it can be estimated that there are as many as 312,000 unpaid carers in Northern Ireland;
- 59% of respondents stated that unpaid caring responsibilities was having a detrimental impact on their ability to do paid work;
- 54% identified the financial impact of additional care costs as a key concern;
- 49% expressed high concern over not having anyone to talk to about the challenges of caring;
- 54% of respondents in Northern Ireland stated that they are now more aware of the role of unpaid carers than before and 74% thought that carers were not well valued or valued at all;
- 72% of respondents in Northern Ireland do not believe that unpaid carers have been supported by the Government during the Covid19 pandemic;
- 74% of the public in Northern Ireland believed that the government should increase support; for example, through increased financial support, investment in care and support services so unpaid carers can take a break and through further investment in social services.

²⁰ Caring behind closed doors, Forgotten families in the coronavirus outbreak, Carers UK, April 2020 https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_final.pdf

²¹ Carers Week 2020 Research Report: The rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak, Carers UK, June 2020 https://www.carersuk.org/images/CarersWeek2020/CW_2020_Research_Report_WEB.pdf

The pandemic has compounded the challenges for carers with many unable to take breaks from their caring roles and many having to spend more money on household bills and necessities during the outbreak. Research carried out by Carers UK in April 2020²² showed that 81% of carers had to spend more money on necessities such as food and household bills and almost two thirds (64%) of unpaid carers have not been able to take breaks from their caring role.

Statistics also show that carers are twice as likely to have relied on a foodbank due to the pandemic. They show that over 106,000 carers in the UK said that their household had used a foodbank in the last month. The figure for foodbank use by female carers was twice as high as that for male carers.²³

Pre-existing inequalities only make the economic challenges of Covid19 worse. The pandemic has underscored the income inequality that exists after a decade of austerity following the financial crisis. Women are paid less on average than men, women are more likely to work part-time and in low-paid, insecure work. Women are also more likely to be caring for children/family members and are more likely to claim social security benefits. We do not wish to see the situation repeated following the financial crash in 2008 which resulted in austerity and welfare reform measures that disproportionately impacted on women.²⁴ The Coronavirus pandemic has shone a light on the importance of caring work and it is vital that coming out of the pandemic that measures to support and enhance the lives of carers should be part of the Government's social and economic recovery plans.

²² Caring behind closed doors, Forgotten families in the coronavirus outbreak, Carers UK, April 2020 https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_final.pdf

²³ CARING and COVID-19, Hunger and mental wellbeing, University of Sheffield, University of Birmingham, Carers UK, Economic and Social Research Council, June 2020 https://www.carersuk.org/images/publications/Caring_and_COVID-19_Hunger_and_mental_wellbeing.pdf

²⁴ Research by the House of Commons Library shows that 86% of the savings to the Treasury through tax and benefit changes since 2010 will have come from women <https://researchbriefings.files.parliament.uk/documents/SN06758/SN06758.pdf>

2.4 The Cost of Living Crisis and Caring

Many carers are facing huge financial difficulties as a result of the Cost of Living Crisis. This crisis follows quickly on the heels of the Covid pandemic which as highlighted in Section 2.3 also hit carers hard.

It is already the case that many carers face additional costs and suffer financial hardship as a result of the care they provide. Many have had to leave work or are working reduced hours as a result of their caring responsibilities. The rising price of essentials especially for energy costs and food will undoubtedly see many carers face even greater financial hardship.

Carers UK are concerned about the impact of cost of living increases on the already precarious position many unpaid carers face. Their research into the Cost of Living Crisis²⁵ has found that:

- Just under half (45%) of unpaid carers are currently unable to manage their monthly expenses.
- The number of people who are worried about how they will manage their bills over the next few months to September 2022 has more than doubled from 21% to 55%.
- The proportion of carers who were stressed and anxious about their finances has risen by about half from 52% to 75%.
- Nearly 6 out of 10 (58%) are cutting back on heating to manage their finances and 14% have already fallen into arrears with their utility bills.
- 45% of carers are relying on their savings, 26% are using credit cards, and 14% are using bank overdrafts.
- 89% of carers have seen their energy bill increase and three quarters of carers (75%) are also spending more on food and drink.
- Carers have seen increases in the cost of products and services they need for the person they are caring for 35% of carers are spending more on supplies such as incontinence pads, 34% are spending more on supplies to keep the

²⁵ Under Pressure: Caring and the cost of living crisis, Carers UK, March 2022
[Carers UK research briefing - Under Pressure - Caring and the cost of living crisis.pdf \(carersuk.org\)](https://carersuk.org/research/briefing/under-pressure-caring-and-the-cost-of-living-crisis.pdf)

person safe such as PPE, and 20% are spending more on equipment such as adaptations or medical devices.

- 83% of carers were worried or extremely worried about how they will manage their monthly expenses if costs keep increasing. Three quarters were worried they would have to cut back on heating. Almost a third (32%) were worried they would have to use a foodbank.
- Almost half of carers (48%) were worried that the increases in energy bills would lead to significant financial hardship, this rose to three quarters (75%) of carers who receive Carer's Allowance or Carer Element with Universal Credit.
- 46% of carers thought the increases in energy bills would negatively affect their health or the health of the person they care for and 42% thought they would not be able to heat their home to a safe level.

In relation to carers receiving Carer's Allowance or the Carer Element of Universal Credit the Carers UK research findings²⁶ are even more concerning:

- Two thirds of carers (67%) say they are currently unable to meet their monthly expenses.
- A quarter (24%) are using foodbanks to manage and nearly six out of ten (58%) are worried that they will have to use them.
- Nearly two thirds (64%) are cutting back on heating and a third (33%) have already fallen into arrears with their utility bills.
- Nine out of ten (87%) are stressed and anxious about their finances.
- Six out of ten (59%) are worried about increased energy bills affecting the health of the person being cared for or their own health.
- Six out of ten (56%) were worried about not being able to heat their home to a safe level.
- Over half (55%) are worried about increased energy bills will mean they have to cut back on food.

²⁶ Ibid

2.5 Financial Support for Carers

Despite their enormous contribution to society, too many carers continue to struggle financially often with serious repercussions for their mental and physical wellbeing. Providing care has the potential to result in a reduction in income as many carers will be forced to reduce their working hours and face extra costs associated with caring. Research from 2016²⁷ shows that overall 1.2 million informal carers were in poverty. The Covid pandemic has exacerbated the financial struggles that many unpaid carers face. Many have experienced increased costs because of the crisis combined with living on a limited income to meet these costs.

Carers NI survey data²⁸ has found that many carers face precarious financial situations. Many carers face additional costs associated with providing care, eg, equipment, increased food, energy and transport costs and many have had to reduce their working hours or leave work as a result of providing care. The survey found that:

- 29% of carers said they were struggling to make ends meet.
- A further 17% are in or have been in debt as a result of caring.
- More than 1 in 20 said that they cannot afford important bills like gas, electricity, rent/mortgage.
- More than 1 in 10 are cutting back on essentials like food and heating and a third are cutting back on seeing friends and family.
- For those on Carer's Allowance, almost half (46%) were struggling to make ends meet and more than a quarter (27%) are or have been in debt because of caring. Only a third (32%) of those in receipt of Carer's Allowance said that

²⁷ Informal carers & poverty in the UK, New Policy Institute, May 2016

https://www.npi.org.uk/files/2114/6411/1359/Carers_and_poverty_in_the_UK_-_full_report.pdf

²⁸ State of Caring 2021, A snapshot of unpaid care in Northern Ireland, Carers NI, October 2021

<https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2021-report>

they felt confident that they would be able to manage financially over the next 12 months.

- Over half (55%) of carers said they feel anxious or stressed when they think about their financial situation.
- Just over a third of respondents (35%) said that their financial situation had worsened since the start of the pandemic, with 70% saying they have had to spend more on household bills, shopping and everyday items. Almost a quarter of respondents (23%) said that they were spending more on equipment or products for the person they care for. For those on Carer's Allowance, the situation is even more stark, with almost a half (46%) saying their financial situation had worsened and more than three quarters (78%) spending more on necessities.

Carers UK and many other organisations representing unpaid carers have joined together to call on the Work and Pensions Secretary to recognise the financial impact that Covid19 has had on carers. An open letter²⁹ sent to the Work and Pensions Secretary, Rt Hon Therese Coffey MP and Chancellor, Rt Hon Rishi Sunak MP, calls for better financial support for unpaid carers who have faced rising costs during the pandemic.

Locally, the Women's Policy Group (WPG) in Northern Ireland³⁰ (the Women's Regional Consortium are represented on this Group) have called for an end to carer's financial hardship.³¹ The WPG have called for financial support for carers to be urgently improved as this would particularly benefit women who are more likely to be caring and providing higher levels of care.

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https://www.carersuk.org/images/FairerforCarers/Open_letter_re_level_of_Carers_Allowance_to_Work_and_Pensions_Secretary_-_vFINAL.pdf

³⁰ The Women's Policy Group Northern Ireland is made up of women from trade unions, grassroots women's organisations, women's networks, feminist campaigning organisations, LGBT+ organisations, support service providers, human rights and equality organisations and individuals

³¹ COVID-19 Feminist Recovery Plan, Women's Policy Group Northern Ireland, July 2020
<https://wrda.net/wp-content/uploads/2020/07/WPG-NI-Feminist-Recovery-Plan-2020.pdf>

A survey by Carers NI has found that 89% of the public in Northern Ireland think that local Government should provide additional support to unpaid carers, including increased financial support and investment in services so that unpaid carers can have a break.³²

Carer's Allowance, the main benefit for people providing unpaid care for family or friends, remains the lowest benefit of its kind at just £69.70 per week (2022/23 rates). Part of the eligibility for Carer's Allowance is an earnings limit of just £132 a week. These low values in terms of payment and earnings means that many carers struggle to make ends meet. Many organisations including Carers UK³³ have been calling for some time for the value of Carer's Allowance to be increased and for the earnings limit for claiming Carer's Allowance to be raised to ensure those juggling work and care on low pay also receive support.

Despite rising costs which sees the rate of inflation at a 40-year high Carer's Allowance rose by only 3.1% in April 2022 despite the actual rate of inflation being close to 10%. This is essentially a real term cut in the value of benefits for those on the lowest incomes. In Scotland, additional financial help is provided in the form of a Carer's Allowance Supplement which is paid through Carer's Allowance twice a year. Carers in Scotland also received a Coronavirus Carer's Allowance Supplement paid through Carer's Allowance to recognise the additional costs many faced as a result of the pandemic. Carers in England, Wales and Northern Ireland do not get this additional help available to carers in Scotland.

It has also been highlighted that for some people who need care there is a need for more than one person to provide that care. Due to the nature of certain disabilities some people need two carers providing care 24/7 to help with personal care, administering medications, etc. Despite this only one person is entitled to claim Carer's Allowance for this care. This seems grossly unfair given the already very low

³² <https://www.irishnews.com/news/northernirelandnews/2022/06/08/news/fifth-of-adults-in-north-working-as-unpaid-carers-report-shows-2736414/>

³³ <https://www.carersuk.org/news-and-campaigns/campaigns/fairer-for-carers>

level of Carer's Allowance and the intensity of care required for people with the most significant care needs.

"If you price what it costs for someone to go into care against what carers provide it would be very expensive. The Government are saving billions on this type of care. There really should be a little given back to carers."

"How much do women save the economy? If we priced it the figures would be scary. We need to value this unpaid care."

"The costs of have someone in a nursing home or in prison are extortionate, costing so many thousands. Yet how can they equate that with the level that Carer's Allowance is paid. If it costs that much to look after someone in those settings how come it is not recognised in another?"

"Everyone should be entitled to a basic living allowance whether they are a carer or disabled. The bottom line is that people should have a decent income."

"If you're a pensioner you get nothing for caring you are ruled out of Carers Allowance. It is not only people who are working that are discriminated against. It's not the case that if you turn 65 you're no longer a carer!"

"My aunt is paralysed from the neck down. Due to the nature of her disability she requires two full-time carers 24/7 so that they can lift her, provide personal care, administer medication, etc. Despite the fact that she needs two carers only one person can claim Carer's Allowance for looking after her which is very unfair."

2.6 Caring and Work

Working carers represent a significant proportion of the working population with figures showing that over a quarter (26%) of all workers are juggling work and unpaid care - one in four workers.³⁴ This illustrates the importance of providing a supportive working environment to these carers. If there is insufficient investment in carers and

³⁴ Carers Week 2020 Research Report: The rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak, Carers UK, June 2020
https://www.carersuk.org/images/CarersWeek2020/CW_2020_Research_Report_WEB.pdf

support from employers for those providing unpaid care then there is a risk they will be lost to the workforce and the economy as a whole.

Survey data from Carers UK found that female carers are more likely to be working carers with 43% of female carers aged 18-65 in employment, compared to 38% of male carers. This reflects the long-term trend that women are more likely to take on caring responsibilities over a decade earlier than men.³⁵

Local figures from Carers NI show that 1 in 7 of the Northern Ireland workforce is providing care and that more than 70,000 have quit their job to care for a loved one who is older, disabled or seriously ill.³⁶

Survey data from Carers NI³⁷ shows the struggles many carers face balancing work and care:

- 40% of working carers had passed on opportunities at work and 25% had moved roles to help them manage.
- 10% have had to reduce their working hours during the pandemic.
- 16% of working carers have had their employment situation negatively affected during the pandemic; by reducing their working hours, having their hours reduced by their employer, losing their job, losing business as a self-employed carer, or leaving their job due to concerns about catching Covid.

Given the disproportionate levels of unpaid caring responsibilities taken on by women and the negative impacts this can have on women's participation in paid work and earnings over their lifetimes this is a gendered issue which must be addressed in order to prevent further embedding of gender inequality.

³⁵ State of Caring 2021, A snapshot of unpaid care in the UK, Carers UK, October 2021

<https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2021-report>

³⁶ <https://www.carersuk.org/news-and-campaigns/news/research-70-000-people-in-northern-ireland-quit-work-to-care-unpaid-for-a-loved-one#:~:text=New%20research%20by%20Carers%20NI%20reveals%20that%20more,Ireland%20are%20juggling%20their%20paid%20job%20with%20caring.>

³⁷ State of Caring 2021, A snapshot of unpaid care in Northern Ireland, Carers NI, October 2021
<https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2021-report>

The Women's Regional Consortium fully supports calls by the Women's Policy Group in Northern Ireland³⁸ and Carers NI that more needs to be done by employers and by Government to ensure that there are carer-friendly policies in place that enable working carers to balance their caring responsibilities with work. The Women's Regional Consortium fully supports Government plans to introduce an entitlement to carer's leave for working carers but is also calling for this leave to be paid.

"I show up to my job every week, on time and do my job. Yet I feel like I'm begging for leave in relation to my caring role, it's like I owe them a favour if I am off. That emotional side of it plays a part too."

"Paid Carer's Leave would really come in handy for many carers."

"I would like to have my caring responsibility recognised at work and have a feeling that my job is secure."

"I cared for my mum for a number of years. It's hard trying to work full time and provide care. My sister and I took on the caring role but my brother only helped occasionally. Carers came to help. Each time she went into hospital there was a different social worker involved and you had to keep waiting on information to be transferred. Then when she came out of hospital there were new carers coming in. The system is a complete mess. I was burnt out."

³⁸ COVID-19 Feminist Recovery Plan, Women's Policy Group Northern Ireland, July 2020
<https://wrda.net/wp-content/uploads/2020/07/WPG-NI-Feminist-Recovery-Plan-2020.pdf>

3.0 Consultation questions

Are you responding as an individual (or on behalf of) or an organisation:

We are responding on behalf of the Women's Regional Consortium in Northern Ireland.

Organisation options: voluntary & community sector / health and social care trust/ HSC organisation/public organisation/ independent social care provider/ trade union / regulatory authority/ professional body / advocacy organisation / academic body /another NICS Departments/Arms Length Body/ and other)

Voluntary & Community sector.

If you are responding as an organisation, is it based in a rural/urban or both areas.

Both.

Format of the Consultation

The Women's Regional Consortium has concerns about the format of the consultation questions. It asks two questions within each chapter with a range of options followed by a space to expand the answer. As WRDA guidance on public consultations³⁹ states: "*the binary 'agree/disagree' nature of many questions hides the complexity of how people feel about different issues.*" We would urge extreme caution on using statistics on responses to these questions as the basis for making conclusions on the proposals.

The answer to these 'agree/disagree' questions needs careful analysis alongside the accompanying text. Careful consideration must be given to the fact that respondents

³⁹ Women at the Heart of Public Consultation, A guide for Public Authorities and Women's Organisations, WRDA, November 2017
https://wrda.net/wpcontent/uploads/2018/10/WRDA_WomenAtTheHeartOfPublicConsultation.pdf

may select one of these options but provide further clarification in the text. They may have several qualifications to their answer and if these are not addressed their answer may be different. The results from the 'agree/disagree' answers must not be considered in isolation or presented in such a way that they paint a misleading picture of responses. We would encourage the Department not to use results from these check box questions as the basis for any decision making. If they are to be used, they should not be used in isolation from any information given within the accompanying text.

Therefore, the Women's Regional Consortium has **not** provided answers to the check box questions asked within each chapter. The Consortium has provided our response under the further comments sections within each of the six chapter headings in the consultation following feedback provided at focus group sessions with local women. Our response addresses the issues on which we have received feedback from women and contains quotes from the women who took part.

Chapter 1: Sustainable Systems Building

Q1: Do you agree with the ethos and direction of travel set out under within this chapter?

- | | |
|----------------------------|--------------------------|
| Fully Agree | <input type="checkbox"/> |
| Mostly Agree | <input type="checkbox"/> |
| Neither Agree nor Disagree | <input type="checkbox"/> |
| Mostly Disagree | <input type="checkbox"/> |
| Fully Disagree | <input type="checkbox"/> |

Q2: Do you agree with the proposed actions within this chapter?

- | | |
|----------------------------|--------------------------|
| Fully Agree | <input type="checkbox"/> |
| Mostly Agree | <input type="checkbox"/> |
| Neither Agree nor Disagree | <input type="checkbox"/> |
| Mostly Disagree | <input type="checkbox"/> |
| Fully Disagree | <input type="checkbox"/> |

Please add any further comments you may have:

Vision for the Future

The Women's Regional Consortium is in agreement with the Vision for the Future set out in the consultation document. We want to see an adult social care system which is evidence-based, based on human rights and effectively supportive of those who both need care and those who provide care in whatever format that takes.

Legislative Provision

The Women's Regional Consortium is broadly supportive of Proposed Action 1 - The Department proposes the introduction of legislation to provide a cohesive legislative basis for adult social care provision.

We welcome the Department's assertion that any such new legislation "*would provide a cohesive, legislative basis for reform which could establish principles for adult social care services, confer rights to service provision and support the implementation of new policy direction.*" Many of the women felt that having legislative provision around care would provide important safeguarding and details of standards, rights and responsibilities.

However, discussions with women suggested that there is no point in having legislation if nothing changes. The women felt there needs to proper consequences for a failure to meet the law and the standards/responsibilities set out within it. Laws

need to be enforced and without this they will be largely ineffectual. In general, the women were disappointed at telling people in roles of responsibility their issues and nothing changing for the better. The women did not want to see any more processes developed that just resulted in the same, a failure to take action on the issues they were raising.

In addition, part of the success of legislation is that the law is known about and properly understood so that people know and understand their rights and how to enforce them. Effective training and information around new laws is essential to build knowledge and understanding of the rights, entitlements and responsibilities contained therein.

“We get promised that high standards of care will be set but nothing ever changes.”

“They create all these new laws but they never obey them.”

“I have so many meetings with people and the promises of change, yet still see no changes years later.”

“Where does the responsibility lie for the law? Who will be held responsible if the law is not met? It needs to be enforceable. Who will take responsibility if something doesn’t work out or something goes wrong – the Trust, the care companies, individuals?”

“Basic needs are just about being met for patients as it stands so what could be potentially changed so their needs would suddenly be being met - why does the law have to be changed in order for people to receive high quality care?”

“It’s one thing to have a law but you need people to act on it.”

“If there was a law at least there would be a safeguard for people.”

“The people we’re all looking after are lucky they have someone to look after them. The amount of people who have no one to look after them. If it was in law there would be something in place and there would be safeguards in place for these people.”

“Legislation is a good thing, at least that way you know what to expect.”

“Is the law going to set out just the basics or a higher standard of care?”

“I would support a new law - everybody deserves A+ standard but half the people are not getting the care they need.”

“A new law? We’ve seen it a hundred times before there are promises made and standards set and absolutely nothing changes on the ground.”

Funding for Adult Social Care

Funding for the provision of adult social care is a central issue within this consultation. Without adequate, sustainable funding it will simply be impossible to realise the vision for the future set out within the consultation document.

The consultation acknowledges that increased funding will be required to meet the rising demands for adult social care services created by demographic pressures. The ageing of the population has significant implications for funding for adult social care services. Given that older people are more intensive users of health services it is therefore inevitable that increased funding will be needed into the future.

First release of the results from the NI Census 2021 figures⁴⁰ show the likely future pressures on funding given the ageing of the Northern Ireland population:

- The 65+ population represents 17% of the total Northern Ireland population.
- Over the past 50 years the number of people aged 65+ has doubled but the working age population has only increased by 29% causing the old age dependency ratio to increase (up from 22% to 27% within the past decade alone).⁴¹
- For those aged 65+ females outnumbered males (54% compared to 46%).
- The 40 – 64 age group accounts for 32% of the Northern Ireland population an indication of future ageing of the population.

Social Care Workforce

The Consortium welcomes the recognition in the consultation of the need to improve the pay, terms and conditions for the social care workforce. We believe there is a

⁴⁰ <https://www.nisra.gov.uk/publications/census-2021-population-and-household-estimates-for-northern-ireland>

⁴¹ <https://twitter.com/MarkMagill1982/status/1529053547232477184>

real need to invest in the care sector and in care work so that it is seen as an attractive career with possibilities for advancement, training, professional development and promotion. This is particularly important for women who make up a significant proportion of the social care workforce.

The Women's Regional Consortium supports the need for a Caring Economy as proposed by the Commission on a Gender-Equal Economy. A 'Caring Economy'⁴² is based on gender equality, wellbeing and sustainability as a way to build back better after the Covid19 pandemic. A Caring Economy would prioritise care for each other and for the environment in which we live. Women's Budget Group research⁴³ found that a 2% GDP investment in care (for example, social care, childcare, parental leave and care leave) creates double the number of jobs for women and almost as many for men than the same investment in construction. Investment in free, universal childcare especially returns almost all of its initial investment.

As the Commission states a Caring Economy would prioritise care for each other and for the environment in which we live. *"A caring economy simultaneously ensures achievement of gender equality, sustainability and wellbeing. While these three objectives can, to some extent, be achieved separately, a caring economy allows them to be achieved together. For example, investment in paid care services improves wellbeing through ensuring that people's care needs are met; it improves gender equality because it raises the overall employment rate and reduces the gender employment gap (which are particularly crucial as we seek to counter the looming jobs crisis), and it is sustainable because care jobs are green."*

It is clear that investing in the care sector is a way for the Department to not only provide the necessary investment needed to address the crisis in the care sector with increasing demands due to an ageing population but also enables the

⁴² Creating a Caring Economy: A Call to Action, Commission on a Gender-Equal Economy, Women's Budget Group, October 2020

<https://wbg.org.uk/wp-content/uploads/2020/10/WBG-Report-v10.pdf>

⁴³ Investing in the Care Economy: A gender analysis of employment stimulus in seven OECD countries, International Trade Union Confederation, March 2016

[Investing in the Care Economy - International Trade Union Confederation \(ituc-csi.org\)](https://ituc-csi.org)

Department to invest in green jobs as care jobs are green at the same time as tackling gender inequality.

Chapter 2: A Valued Workforce

Q1: Do you agree with the ethos and direction of travel set out under within this chapter?

- | | |
|----------------------------|--------------------------|
| Fully Agree | <input type="checkbox"/> |
| Mostly Agree | <input type="checkbox"/> |
| Neither Agree nor Disagree | <input type="checkbox"/> |
| Mostly Disagree | <input type="checkbox"/> |
| Fully Disagree | <input type="checkbox"/> |

Q2: Do you agree with the proposed actions within this chapter?

- | | |
|----------------------------|--------------------------|
| Fully Agree | <input type="checkbox"/> |
| Mostly Agree | <input type="checkbox"/> |
| Neither Agree nor Disagree | <input type="checkbox"/> |
| Mostly Disagree | <input type="checkbox"/> |
| Fully Disagree | <input type="checkbox"/> |

Please add any further comments you may have:

The Women's Regional Consortium is fully supportive of the following proposed actions within this chapter:

Proposed Action 9 - The Department proposes to improve the pay, terms and conditions of the lowest paid in the social care workforce

Proposed Action 10 – The Department proposes to continue developing a Social Care Workforce Strategy. This will include actions to develop career pathways, supervision and support, training and education of the workforce and to raise the profile and recognition of the social care workforce.

Proposed Action 13 – The Department proposes that the NISCC will produce an annual social care workforce analysis report.

Proposed Action 16 – The Department proposes working with both the Department of Communities and the Department for the Economy to promote social care as a valuable and rewarding career choice.

The consultation acknowledges that the Covid19 pandemic has highlighted the vital contribution of the care workforce and acknowledged the increased pressures on the workforce as a result. It is vital that this goes beyond mere words and translates into actions to ensure that the care workforce is properly valued into the future. This will ensure benefits not only for those employed within the social care workforce but also for those who are receiving care.

While we are in agreement with Proposed Action 9 and that priority must be given to the lowest paid within the social care workforce we believe that improvements in the pay, terms and conditions must be extended to the entire social care workforce. We believe that cross-departmental working is essential in order to promote social care as a valuable and rewarding career choice. However, this cross-departmental working must be long-term, resourced and with a genuine commitment to promoting social care in order to achieve Proposed Action 16.

We are supportive of Proposed Action 13 and emphasise the need for gender disaggregated data on the social care workforce. It is vital that there is access to up to date data on the social care workforce by gender so that there is proper understanding of the gender equality issues at play within the sector.

Gender and Social Care

Many of the women who took part in focus groups acknowledged that most of those who work in care are dedicated to their job and provide high levels of care. They generally felt that this was not well recognised in terms of pay or conditions and that this needs to change. Many raised the point that this care work is often carried out by women and they felt that because it was seen as '*women's work*' it meant that it was generally undervalued and therefore not seen as a desirable career. Much more needs to be done to tackle the gender inequality inherent in care work with better pay, conditions and investment in the care sector.

We wish to highlight a number of issues raised in the Gender Equality Expert Panel report⁴⁴ in relation to adult social care and gender equality:

- There are 38,000 adult social care workers. This means that direct employment in the adult social care sector represents 5% of all jobs in NI, making it a critical area in terms of employment.
- Earnings in the adult social care sector represent 55% of average earnings.
- There is a predominance of unpaid training time, unpaid travel time and limited or no travel expenses.
- The social care workforce is predominantly female – in NI the figure is 87%. If only the HSC Trust domiciliary care workforce is considered, 98% is female and 43% of these staff are aged 55 or over.⁴⁵
- There is a high level of part-time working in NI and, as elsewhere in the UK, there are challenges recruiting and retaining staff.
- The Northern Ireland Social Care Council estimates that an additional 1,400 care workers were needed every year just to keep pace with demand.
- Levels of training in the care sector are low. A Northern Ireland Social Care Council (NISCC) survey of independent care providers on the qualifications levels of the domiciliary, residential and supported workforce found that only 48% held any relevant qualification.

⁴⁴ Gender Equality Strategy, Expert Advisory Panel Report, December 2020
<https://www.communities-ni.gov.uk/system/files/publications/communities/dfc-social-inclusion-strategy-gender-expert-advisory-panel-report.pdf>

⁴⁵ Department of Health (2016) Domiciliary Care Workforce Review 2016-2021

- The NI Health and Social Care Workforce Strategy noted that most (75%) adult social care workers work in the independent sector and acknowledged that there are considerable differences between the terms and conditions of employment for social care workers in statutory organisations and those employed in the independent sector. This includes lower pay, less favourable conditions and zero hour contracts.

As the Expert Panel report⁴⁶ states: *“it is clear that investment in care is needed to address the failings in adult social care and a better paid, better qualified social care workforce is critical to sustaining a social care system.”* The Women’s Regional Consortium supports the Expert Panel report recommendation that:

“There is an immediate need for increases in salaries of paid care workers. This should be linked to the professionalisation of training (within the development of a training and qualifications framework, including Higher Level Apprenticeship) for adult social care workers with opportunity for workplace progression and secure contracts for all care workers. These actions are critical to building a sustainable care system and will benefit the quality of care provided to users and the economy.”

As previously stated, the Women’s Regional Consortium supports the need for a Caring Economy based on gender equality, wellbeing and sustainability as outlined in Question 1.

“The people who work in care are amazing. There is the odd one who just wants to get in and out as quick as possible but most of them are amazing.”

“Care work is more like a vocation – they need to be paid accordingly – it’s a vocational job.”

“People who are passionate about care work can be pushed out of it because of the stress involved and because they are not treated well or what they are earning doesn’t cover their bills.”

⁴⁶ Gender Equality Strategy, Expert Advisory Panel Report, December 2020
<https://www.communities-ni.gov.uk/system/files/publications/communities/dfc-social-inclusion-strategy-gender-expert-advisory-panel-report.pdf>

“They need to make it worth your while for a person to work in care.”

“I used to work in a care home and I really enjoyed it. I would love to go back but I had kids and with the cost of childcare etc. I can’t afford to do it.”

“Low levels of pay is a big barrier for people going into social care.”

“There is nothing appealing about working in social care apart from the fact that you know you’re doing something good and helping someone.”

“Care jobs are not viewed as important. They are viewed as low skilled even though they are not.”

“These care jobs are often undervalued because it’s women who are doing them.”

“Carers are low paid and don’t get enough time to do their work.”

“Carers need paid more, then maybe more people will want to work in care.”

“People don’t want to be a carer as it is seen as a low skilled, low paid job – it is not seen as a high paid job.”

“Few people want to be a carer, not because it’s a bad job it’s just the amount of responsibility given to such such a low paid job just isn’t worth it.”

“Besides the personal satisfaction of knowing you’re helping someone, nothing attracts me to work in care.”

“I would love to work in care, but the pay is low, and I have no childcare.”

“Pay for caring is poor which reflects the attitude to this type of work.”

“There is no incentive to go into caring as a career. Staff turnover is high. We’ve had 9 different carers in a year.”

“Most carers are undervalued for their personality. They provide a bit of company and craic for my adult daughter and she gets so much out of them calling in. That part is so undervalued. The same is true for me as her carer I get so much out of them coming in – it’s a wee break and someone else to talk to.”

“I have yet to meet someone working in care who didn’t care about their job and genuinely want to help but there are just not enough of them and they are not being properly used. They are as disadvantaged by the system as everyone else.”

“Most people work 30-40 hours a week. Carers often work 24/7 and never stop and yet they are not paid for it.”

“More staff need hired to ensure everyone gets the care when and how they need it.”

Chapter 3: Individual Choice and Control

Q1: Do you agree with the ethos and direction of travel set out under within this chapter?

Fully Agree ☐

Mostly Agree ☐

Neither Agree nor Disagree ☐

Mostly Disagree ☐

Fully Disagree ☐

Q2: Do you agree with the proposed actions within this chapter?

Fully Agree ☐

Mostly Agree ☐

Neither Agree nor Disagree ☐

Mostly Disagree ☐

Fully Disagree ☐

Please add any further comments you may have:

Information and Advice

Most of the women agreed that individual choice and control over your own care was very important. In order to ensure choice and control there must be good communication with those needing care. They must also have access to

comprehensive and reliable sources of information and advice so that they have the necessary information with which to make informed decisions about their care needs. However, it was the general view of the women that information and advice around care options was very difficult to find and many people did not know where to go to find out this information.

The consultation states that *“people, families and family carers should be empowered to make meaningful and individualised choices about care and support through the provision of accessible information, advice and advocacy”* and that this would help them to make informed decisions. It goes on to say that HSCTs should put in place *“accessible systems which provide comprehensive information available to support people to make informed decisions about their own care. This will include web-based information, digital portals and printed information.”* We welcome the fact that the consultation highlights the need for accessible information, advice and advocacy so that people can make informed decisions about their care.

However, we caution about the focus being on mainly web-based or digital information. While this is an important means of finding out information for many people it is not for others and for them accessible and up to date information must be provided in other formats. Since 2010, government policy has assumed the majority of consumer interactions with government services will be carried out online. Online processes only make it more difficult for a range of citizens to find out information and claim their entitlements. For example, literacy difficulties, learning disabilities such as dyslexia and language issues, combined with patchy online access (particularly in rural areas), present very real challenges. In addition there are issues with cost with some people being unable to afford the extra costs associated with internet use.

The provision of internet access is not enough on its own and many people need ongoing support to get online and to use digital services. Marginalised citizens are least able to make effective use of e-Government services. They are least likely to be connected, to be aware of services, or have the necessary digital literacy to make meaningful use of such services. As government services become *“digital by default”* there

is growing evidence that the most marginalised are being left behind.⁴⁷ This will be problematic for many women including refugee and migrant women, for whom language and IT literacy are often major barriers, rural women, who rely more on public transport to access public services than men, older women and low-income women with limited access.

In discussions with women about accessing information about more complex issues such as social security many had not been able to access the information they needed, had missed out on rightful entitlements and generally did not know where to go to find out the information they needed. Where they had found out the information they needed this was often based on informal conversations with family members, friends, local charities such as Women's Centres, etc. Few had found out the information they needed from a Government website. This must be a consideration for the provision of accessible information as part of this consultation as care and decisions around care can be complex areas where people may need more intensive help to make the decisions which are truly right for them.

"It's vital to have choice."

"It would be better to have someone to go to instead of getting sent round the houses for help."

"There's a lack of information. You are so wrecked providing care and then the people who are supposed to help make it harder for you. You need to be internet savvy, you need to have a good level of education and understand all the language. I don't know how anyone does it alone, wrecked and with no support. How do they find the energy to find out information and fill out the forms? Nothing is simple – the forms are long and all asking you the same information."

"I see families who are very resourceful and have good support and know what to do. Others don't know anything, get no support and there's such a difference between the two."

⁴⁷ Leaving No One Behind in a Digital World, Hernandez and Roberts, K4D Emerging Issues Report, Institute of Development Studies, November 2018
https://assets.publishing.service.gov.uk/media/5c178371ed915d0b8a31a404/Emerging_Issues_LNOBDW_final.pdf#page16

“There’s no official person who says here’s what you need to do. You end up getting information and support from people in support groups or from friends/family.”

“I provide care for my 34-year-old daughter who has an acquired brain injury. I stated caring for her during Covid as she was vulnerable and we were worried about people coming into the house. I left work to care for her. She has two children aged 4 and 5. We help to look after them too. When Covid hit we stopped her carers and we had to learn an awful lot. We weren’t involved in any groups but then joined the Brain Injury Foundation and got a lot of help and information from them. We just had to find out one wee thing then find out another and we kind of found our way that way.”

“The effort it takes to find out the information you need – it’s hard work. It’s the energy that it takes and means you have no time for yourself.”

“You have to know what you’re looking for on a website. I find out about lots of things through the Women’s Centre. It’s amazing what I’ve learned and heard about here – I get knowledge on so many things that I try and pass on to others.”

“I find information from charities such as Chest, Heart and Stroke really helpful for me.”

“It should be easy to provide information to people and provide them with help with forms, etc. I was shaking with nerves when I contacted Make the Call. People really need this help.”

“When you register as a carer you should be given a package with all the information in it. Everything you and the person who needs care is entitled to and the contacts that you might need.”

“People should feel they have a sense of control and a say in the care and support they need and receive.”

Equity of Choice and Control

There was a perception among the women that if you had access to money that it was much easier to have choice and control over your care. They felt that this wasn’t fair and that those on the lowest incomes really had no choice or control over the care they received or the quality of it.

“It’s all down to money. People that have money have more choice. Everyone should have the same rights to the care they want/need.”

“Money always helps when you’re in this situation. If you don’t have money then you don’t have the luxury of paying for people to come in and help with care or to put someone in a better care home where they will be well looked after. You just don’t have the same choices.”

“It shouldn’t matter if you are able to pay for help or not it should be the same quality of care but it’s not. People are not all on the same playing field.”

Direct Payments

It is clear from discussions with women that there is insufficient information and support for people wishing to use Direct Payments. A lack of support and difficulty in understanding the processes involved meant that many women were put off using Direct Payments. Even when they were able to set up Direct Payments, women reported challenges in finding someone with the right skills to provide the care that was needed for their loved one.

“The Direct Payments scheme was very difficult, we struggled so much that by the time we understood what to do we no longer needed it.”

“Social workers are not approachable and they are very difficult to get hold of and they provided no support in helping me set up Direct Payments.”

“Too many family members caring for someone makes Direct Payments more difficult.”

“I found Direct Payments very difficult to sort out. I’m 58 and I care for my mother who has dementia. My daughter had to sort out the Direct Payments for me as I hadn’t a clue. It’s all online and it made no sense to me.”

“Direct Payments were very hard to set up. It was so difficult we didn’t end up doing it. I just remember it was a lot of hassle trying to get it sorted.”

“We couldn’t get hold of the social worker so we had no help with Direct Payments. There was no support or anyone to come out and help us with it, there was no one showing you the way.”

“There’s a lot of work in Direct Payments and finding the right person to employ is difficult. They told me I’ve a lot of family so they can help me.”

“It is difficult to find people with the right skills. There are only a few people I would leave my son with. They need to know him, his needs and medications and all the issues he has. Everyone with special needs is so different so even if you’ve had training in that area you won’t know the person.”

Chapter 4: Prevention and Early Intervention

Q1: Do you agree with the ethos and direction of travel set out under within this chapter?

Fully Agree ☐

Mostly Agree ☐

Neither Agree nor Disagree ☐

Mostly Disagree ☐

Fully Disagree ☐

Q2: Do you agree with the proposed actions within this chapter?

Fully Agree ☐

Mostly Agree ☐

Neither Agree nor Disagree ☐

Mostly Disagree ☐

Fully Disagree ☐

Please add any further comments you may have:

The Women's Regional Consortium is fully in agreement with the Power to the People report: *"there needs to be a shift from reactive to preventative."* We believe that if this was adequately resourced and implemented effectively it would benefit people's lives and reduce costs in the longer term.

We broadly agree with Proposed Action 26 to introduce the offer of preventive/support visits, however we are not in agreement with the age proposed in the consultation document.

Women at focus groups were broadly supportive of the benefits of prevention and early intervention but felt that 75 was too late in making these visits available. There was a general consensus that offering these visits at age 75 or older for many people could not be considered early intervention or preventative.

Some of the women raised the issue about resourcing for carrying out these visits. They were concerned about existing staff shortages and pressures on the health service which result in long delays. Women gave examples of equipment/adaptions that could really help with preventative work and help to improve people's quality of life but these were often hard to get or there were long delays leading to people having to wait or take action on their own. If these visits are not resourced adequately and there isn't the trained staff to carry them out, then they will fail to result in significant improvements in the areas of early intervention and prevention.

“Calling people at 75 is too late. You could start prevention/education work at primary school! For example, the prevention of long term illnesses such as diabetes, etc.”

“Is it OTs who would be doing this assessment? There aren't enough of them or other staff for that matter to do these.”

“Alzheimers/dementia often starts before 75 – there are few supports in place around this and 75 is too late to start this.”

“There are reports in the media of women needing to start help with the menopause earlier and that it would be a real benefit. For women, what good is it visiting them at 75 when they need the prevention/education help much earlier?”

“I think that a discussion with people at age 75 is maybe too old? It should be earlier in terms of prevention surely?”

“Bryson House provide a service where they go out to the house and check the electrics, nails, hazards, carpets sticking up, etc. to try and prevent accidents/falls. They also fitted a rail on the stairs. My mum heard about them from someone else she knew who had got it done.”

“The waiting list to see an OT is so long so people just end up getting worse.”

“Something as simple as a wheelchair can take ages. My mum is bad with arthritis. She can walk but it really wrecks her. Even walking from the house to the car is exhausting. If she had a wheelchair to help with this then she

wouldn't have to miss out on things. The wheelchair we had was falling apart and couldn't be used so I started phoning around. I was eventually told I could get one but it would be £150. That's a lot of money when you're on benefits. I put the word out I needed one and my sister's friend gave me one. It needed fixing up a bit. But it meant that we could take my mother out. We couldn't get one as my mum was not seen as needing it as she can walk a wee bit. She can but then she's exhausted."

"My sister is 66, she needed a downstairs loo or a chairlift. She got neither as it is a 2 year waiting list to see an OT. Our family got a loan from the Credit Union to get her a toilet built downstairs."

"My sister in law had a stroke at 50 and she still has no downstairs toilet she's still waiting. She ends up having to drag herself upstairs to the toilet, it's dangerous and she has lost some of her dignity as she ends up wetting herself on the stairs."

"If you're not the squeaky wheel you get nothing! If you're quiet about things you get nothing."

"75 is much too old for early intervention; people need support before then – information should at least be made available from 65."

"People need educated on how to prevent some illnesses before it's too late – instead of teaching them how to deal with them."

"Dementia support isn't made available until it's much too late."

"Advertising of support schemes in Women's Centres or home safety checks would be great for early intervention as it would prevent people from getting sick too soon or worsening."

Supporting Community

The Women's Regional Consortium welcomes the recognition in the consultation document that: *"the third sector and the community sector have much to offer in terms of an understanding of community need and flexibility and creativity in responding to that need"* and crucially the importance that: *"the relationship between the adult social care system and the community sector is that of a collaborative partnership."*

We stress the need for the work of the voluntary and community sector to be respected and valued in their work in support of the adult social care sector. The

voluntary and community sector have years of experience of providing information, support, advocacy work as well as vital experience of tackling poverty, disadvantage and inequality. They are skilled at reaching the most marginalised within communities and provide trusted spaces and skilled people to do this work.

The services delivered locally by voluntary and community organisations, such as Women's Centres, are vital to tackling disadvantage and promoting gender equality. These services which support statutory provision are the most cost effective way of ensuring that local needs are effectively met and ensures the best outcomes for the communities they serve. Much greater value and investment must be placed on these unique and trusted services. We believe that this work is undervalued and often unseen by Government and therefore grossly underfunded given its importance to people and communities.

Funding is a massive issue for the community and voluntary sector. Many of these organisations rely on short-term funding which does not allow for job security or the retention of knowledge and experience in the sector. Continuity of delivery is vitally important in that a need is generated when a project is set up and if it ends due to lack of funding it can leave those in need of help without the services they so desperately need and negatively impact on their wellbeing and quality of life.

While we would like to see the valuable services provided by the community and voluntary sector acknowledged and integrated into wider service delivery we would be concerned that responsibility is foisted on the community and voluntary sector without adequate funding and support to be able to do this important work.

We are therefore supportive of Proposed Action 27 to explore and promote improved support to the community sector through work being taken forward to develop a new approach to planning, managing and delivering services.

"I would be lost without Falls Women's Centre, they have dug me out of more holes than I care to remember. I've gone there in tears and they have helped and supported me."

“More funding is needed for Women’s Centres who do so much for so many and often it is not heard about or valued. They can get the help to where it needs to go as they see the need on a daily basis. Without them I don’t know where I would be. They are probably better than the doctors!”

“I wouldn’t be here today only for the counselling and training provided by Falls Women’s Centre.”

“It helps me to have a chat and to listen to what other people have to say and there’s no judgement in the Women’s Centre. Women need women! To understand and guide them. Sometimes someone else’s experience helps someone else – a problem shared is a problem halved.”

“My mental health is better even talking together helps. Some people may need more than coffee and a chat but getting together really helps me. Women’s Centres are so important as they help people get together and talk and can also signpost if there are more serious issues and further help is needed.”

“The work of the women’s sector and women’s centres is not valued. We are just fed crumbs of funding. Yet the sector is constantly firefighting doing the work on the ground but the funding always goes elsewhere.”

“We are working in partnership with the local Council on a project but they have no sense of what is required on the ground to make it work. They just don’t understand how it works at community level.”

“The community needs to have a bigger role in this – there’s trust at community level.”

“It needs people working at grass roots level. There needs to be a bottom-up approach so that everyone’s voices will be heard.”

“Healthcare support responsibilities have been made charities responsibilities now.”

“I had a bad experience of Day Centres, I felt like I was sent there to sit until I was ready to die. Footprints Women’s Centre is the only place that helped me to cope. The Day Centre wasn’t the right place for me but I came to the Women’s Centre and I feel more confident every day. They nudge me to do things by providing classes that I am interested in and I feel more confident every day.”

“Footprints Women’s Centre has been getting me out of bed recently. I’ve been forcing myself to get up and out to the Centre and take part in things. They care about how I’m feeling. This means I’m not having to go to my GP

about depression, having to go to CPN or needing treatment at hospital. The Centre is helping to nip it in the bud before it gets too bad and I need all that additional help and the cost of it too.”

“Women’s Centres stop people from getting worse in terms of mental health, etc. and needing more care and intervention. It would cost the health service even more if they didn’t exist as you would end up feeling even more depressed and maybe in hospital.”

“They need to have an easy system where people can find out information. The advice sector are good but they are understaffed and under resourced for this work.”

“We get help from Praxis for my husband who suffers from dementia. This input is really good for both him and I as his carer. He wasn’t feeling well the other day and I was able to have a chat with the Praxis person about it and he thought it might be a kidney infection. With everything else you have going on you don’t sometimes pick up on things. He suggested I ring the GP and that input was really helpful to me. You don’t want to be torturing the health service all the time but sometimes that wee bit of input can really help you make the right decision.”

The Women’s Regional Consortium broadly welcomes Proposed Action 28 that HSCTs include the needs of adult social care services and service users in their engagement in community planning processes. However, we stress that this needs to be genuine engagement and consultation and not merely a tick box exercise.

Co-design and co-production are increasingly being put forward by Government when reforms/new approaches are being developed. While this is to be welcomed unless there is a high level of genuine participation including from the most marginalised this will not be effective and will simply lead to a lack of trust/engagement in the process.

New Decade, New Approach included a commitment to put civic engagement and public consultation at the heart of policy-making but this needs to be done in a way which is meaningful. We refer the Department to the guidance on consulting with women produced by Women’s Regional Consortium members WRDA.⁴⁸ This

⁴⁸ Women at the Heart of Public Consultation, A guide for Public Authorities and Women’s Organisations, WRDA, November 2017
https://wrda.net/wpcontent/uploads/2018/10/WRDA_WomenAtTheHeartOfPublicConsultation.pdf

guidance contains five top tips based on the many years of experience that women's groups have in promoting women's participation in public policy making. These include the need to work together with the women's community and voluntary sector, making time for accessible face to face engagement, keeping language accessible and relevant, listening to the stories from women and making women visible in the product as well as the process.

As the Gender Equality Strategy Expert Panel report recommends: *"Participation in the policy process should be supported by the adoption of a meaningful approach to co-design, including realistic time periods for consulting and the resourcing of organisations."*⁴⁹

We agree with Proposed Action 29 to strengthen the capacity of the social work profession to support community focussed practice.

It is clear from comments from the women who took part in focus group sessions that there are resourcing issues with social work and pressure of demand for social work services has resulted in delays and long waiting times. In order to address this issue and to ensure that social workers can effectively support community focussed practice there is a real need to invest in social work to alleviate current and ongoing pressures on the profession.

"I never go to the social worker or OT because they are never available. It has fallen on charities and friends/family/support groups to help people."

"The Health Service is not joined up. It doesn't make sense. I'm disappointed in social services, the social worker should be able to tell you where the services are but they don't. There is no joined up working between these services and the Trusts in relation to care."

"They don't have a senior social worker anymore like they did in my day. Now there is a team leader who is an OT and she is very nice when you talk to her but she doesn't understand a lot of the issues. Things just get passed from one person to another. You need one person to answer your questions and

⁴⁹ Gender Equality Strategy, Expert Advisory Panel Report, December 2020
<https://www.communities-ni.gov.uk/system/files/publications/communities/dfc-social-inclusion-strategy-gender-expert-advisory-panel-report.pdf>

help you. There just isn't enough staff so they're not meeting anyone's needs."

"I haven't seen our social worker since December."

"My mum had a great social worker but she went off to get married and they put someone else in her place, they went off sick fairly quickly and they were trying to get the position filled. If you phoned they were just taking your details but saying they couldn't do anything about it until someone was in place. That was 2 years ago."

Chapter 5: Supporting Carers

Q1: Do you agree with the ethos and direction of travel set out under within this chapter?

- Fully Agree ☐
- Mostly Agree ☐
- Neither Agree nor Disagree ☐
- Mostly Disagree ☐
- Fully Disagree ☐

Q2: Do you agree with the proposed actions within this chapter?

- Fully Agree ☐
- Mostly Agree ☐
- Neither Agree nor Disagree ☐
- Mostly Disagree ☐
- Fully Disagree ☐

Q3: Please add any further comments you may have:

The Women's Regional Consortium is welcoming of the fact that carers have been identified as a strategic priority within the adult social care reform consultation.

Gendered nature of Care

As previously stated, care is a significant issue for women and an acknowledgement of the gendered issues around care is crucially important in taking action to support carers. In July 2020 the Women's Policy Group produced a Feminist Recovery Plan for Northern Ireland.⁵⁰ This comprehensive plan highlights the gendered issues around care and calls on decision-makers to take action to ensure a gender-sensitive response in the transition from the Covid crisis to recovery.

We endorse the following statement in the Feminist Recovery Plan and urge the Department to take note of the issues highlighted within the Carers Key Briefing from the plan⁵¹:

"It is clear that both the UK government and the Northern Ireland Assembly need to urgently address unpaid caring responsibilities in any recovery planning and longer-term economic modelling and recovery planning. Given the disproportionate levels of unpaid caring responsibilities taken on by women, and the drastic impact this can have on women's participation in paid work and lifetime earnings, a gendered lens is needed in addressing the segregation of care work to prevent further embedding gender inequality."

In addition, the Women's Regional Consortium endorses the following statement from the Gender Equality Strategy Expert Panel report⁵²:

⁵⁰ Covid-19 Feminist Recovery Plan: Relaunch – One Year On, Women's Policy Group NI, July 2021 <https://wrda.net/wp-content/uploads/2021/07/WPG-COVID-19-Feminist-Recovery-Plan-Relaunch-One-Year-On.pdf>

⁵¹ Covid-19 Feminist Recovery Plan, Carers Key Briefing, Women's Policy Group, March 2021 <https://wrda.net/wp-content/uploads/2021/04/WPG-FRP-Carers-Key-Briefing.pdf>

⁵² Gender Equality Strategy, Expert Advisory Panel Report, December 2020 <https://www.communities-ni.gov.uk/system/files/publications/communities/dfc-social-inclusion-strategy-gender-expert-advisory-panel-report.pdf>

“The contributions of those in managing home and family commitments should not be considered to have no economic value; the COVID-19 pandemic exposed the essential nature of care work, and this should be valued. It is crucial to recognise the economic value of unpaid work and challenge terms such as “economic inactivity” as they perpetuate the undervaluing of women’s domestic work. This has been estimated of being equivalent to 56% of GDP for the UK, with unpaid childcare alone being equivalent to 18% of GDP and long-term care being equivalent to 3% of GDP.”

Feedback from Focus Groups on Supporting Carers

Focus group attendees were most vocal about the issue of Supporting Carers. Many of the women who attended the focus groups had provided or were providing care and detailed a range of personal experiences in relation to this. There was an overwhelming sense of feeling unsupported, undervalued and forgotten while carrying out this important work. A summary of the issues discussed shows the extent to which action is necessary to better support carers:

- Unpaid care is not recognised or valued and is often invisible with carers just expected to get on with it without support despite the amount of money it saves the Government.
- Women are still more expected to provide care and there is the assumption that a woman will do this work when it is needed.
- The pandemic has shone a light on the importance of unpaid care but this must be translated into proper support for unpaid carers which has not been evident yet.
- It is only right that carer’s should have a decent income to live on but the current levels of help are far too low and it is too little for carer’s to live on particularly as we face into the Cost of Living crisis. Carer’s Allowance is one of the lowest paid social security benefits which shows the extent to which care is not valued by Government.
- Often carers face problems getting equipment, transport, adaptations to homes, other help that would really make a difference to them and the person they care for but they are unable to access it due to long waiting times, lack of resources, etc. This sometimes means that the carers to fund these things

themselves and in some cases means they are forced to get into debt to do so.

- There is a lack of transparency in care systems so that it is not easy for carers to find out how the system works so they can access the help they need with their caring responsibilities. It is not clear where to go for help and how to access simple information in a format which is easy to understand.
- Carers were frustrated about the bureaucracy and the length of time it can take to sort out the help they need. They talked about the mental capacity and the time needed to deal with all this while they are already really busy with their caring role.
- There is a lack of joined up services and continuity of service provision in relation to care which makes it harder for carers and the person they are caring for and often lengthens the time it takes to sort out issues around care.
- Women talked about the need to always have to fight to get the care they need for those they care for and for the support they need. It is a constant fight all the time to get help with their caring responsibilities. They feel like you have to be in the worst case scenario before you can access help.
- There is a 'cliff edge' when a child turns 18. Many of the support services in place for children stop when they turn 18 and this leaves a vacuum for both carers and those who require care. This places the onus back on carers to fill these gaps in service provision.
- Carers spoke often about the physical and mental health toll of providing care with little support. They talked about feeling isolated, not being able to get out, to attend family events and to socialise outside their caring responsibilities. This meant they often missed family events and they felt like they had no life of their own. This had impacts on family life and relationships. Supporting carers to share their views and experiences means acknowledging that they often have to make arrangements to have their caring responsibilities carried out by someone else and in many cases this can be difficult to arrange.
- Some of the carers who attended focus group sessions had been encouraged by other family members to attend as they felt it would be good for them to get

out and talk about their issues. To be able to leave many had to arrange for someone else to look after the person they cared for.

- It is often difficult to work and provide care as there is little or no support for carers in this situation. This has meant that some women have had to give up their job to provide care leading to reductions in income, loneliness and isolation. For those who can remain in work they are having to use all their leave for care and many would like more flexible leave specific to carers and that this leave should be paid as they cannot afford to take reduced pay or unpaid leave for caring.
- Many of the carers felt like they were beating their heads against a wall in relation to their caring work and recognition and support for it. They felt that they had shared their issues many times but that no one is listening especially after the pandemic. Carers felt strongly that the system needed to change and that action was needed immediately but were concerned that with no NI Executive progress would not be made. Carers were tired airing their concerns but with no discernible change to their situation.

The Women's Regional Consortium urges the Department to consider the range of issues identified above (and the quotes from the women which follow) as these illustrate the areas where the support of carers is failing and where action is needed.

“The country relies on full time carers. They are not appreciated the way they should be.”

“One of the greatest pressures in being a carer is that the authorities do not respect your time. I’ve had to spend hours and hours on forms and red tape. Hours that I do not have!”

“You are always having to fight for the things you need to care for someone. You get a different reaction when you ask for things as a woman compared to a man.”

“As a carer you are trying to keep people at home and help the system but you are left with no backup. I asked for equipment to help me care for my father and was left waiting 6 weeks to get it.”

“I have concerns once kids get to 18. There is a duty of care to these kids until they are 18 but after that where do you go? There needs to be more done around that to protect children with conditions/disabilities after they turn 18.”

“I eventually had to leave work to care for my autistic son. After he turned 18 he did a course with the Princes Trust but that ended. Things always end for kids like him. He is not able to care for himself or get a job or do things his peers can do. There are no services available to him – there is no autistic centre. When he was under 18 he had access to services/help but after 18 there is no help there, there are no services.”

“If you need support or help where is it? You always end up having to go back to family for support/help.”

“There is often a focus rightly on kids with health conditions and mental health but what happens to them when they become adults? Where do they go when they are older? Where are the services for them?”

“My sister was a carer for my parents and ended up looking after my dad and her own grandchildren. Her GP described it to her as the ‘sandwich generation’ whose parents are living longer so women are looking after their own parents as well as their grandchildren. That has just become acceptable yet the services haven’t risen to support these women.”

“I am a carer for my son and they were expecting me to buy all the equipment he needed but it was expensive as I am on benefits. It would be good if parents weren’t forced to buy expensive equipment that their children need to help them. If you worked in an office environment they would have to provide you with equipment through health and safety.”

“There’s not enough financial support or working rights for carers which really disadvantages them.”

“There is no support for us families that care, we have to give up our jobs to care and income support is just too low.”

“They just assume family will care not only do we have no support, but we have to give up our family time with each other to provide the care that’s needed.”

“It’s always the female siblings that are to care for their parents when they’re old and need care.”

“I’m so tired from caring already and the people who are supposed to help me make it easier in fact make it more difficult.”

“Sometimes you feel like you have to play games to get help. You have to look rough and under pressure and look like you haven’t slept in order for them to believe you’re struggling or for them to take any notice of you.”

“If you appear to be coping you’re just left to get on with it.”

“My adult daughter loves swimming but there is no support to help her do that. I can’t get in the water with her and there’s no support to help her do what she enjoys doing. Having support to do things like this would make a big difference. It’s a nice idea but there are too many hurdles.”

“I get 3 hours support a week – my friend comes and cares for my adult son, it’s so little but feels like so much when I get it.”

“I’m angry my husband had a stroke and because of Covid his services got taken away, but they have never returned.”

“Caring for family is soul destroying – seeing how much they can no longer do.”

“I don’t know where to go for support.”

“We just get what crumbs are thrown at us for support and we’re expected to say thanks when actually we aren’t really thankful because its next to nothing and so much more could be done. It’s not person centred it’s just whatever they have at the time.”

“Once children turn 18 their social care support is like jumping off a cliff. There is such a lack of support. My son is still disabled - what’s changed despite his age he still needs the help.”

“I feel like I’m always being palmed off when I look for help and support.”

“Caring is a 24/7 job yet we’re only being paid for between 7-10 hours a week. It’s a disgrace.”

“We’re the forgotten ones – because we care for our family. They don’t see or hear from us, they don’t care about us – out of sight out of mind.”

“I was the only able-bodied female with time in the family, the responsibility to care for my aunt was left down to me.”

“Lifting and laying my adult daughter without support or education has really strained my back and caused my physical health to deteriorate.”

“Being a carer for my aunt and granny caused my own health to deteriorate, I had no support.”

“Carers don’t know where to look for help, they just struggle on until it’s too late.”

“I lost my Carer’s Allowance because my husband works. I had to give up my job to care for my adult son who is autistic. They have you over a barrel as they know you’re not going to abandon your kids.”

“I look after my husband who is 75 and who had a stroke. I have carers coming in four times a day and they are great. My problem is that I can’t get transport to get him to the hospital for appointments. The Trust just keep telling me they don’t have the staff – how do you deal with that?”

“It’s just assumed that the family have the skills required to care from home, they don’t get trained on how to use equipment they way nurses do.”

“Someone needs to step in and provide information to us carers, so we don’t have to spend so much time trying to find out the information we need. We want access to information without having to search high and low for it.”

“When you’re caring you often don’t have the mental capability for doing lots of these things, finding out information, chasing up things when you are caring. All that should be taken off you when you need help – someone should be able to advise you.”

“Carers are just left on their own!”

“More leave from work is needed for carers and it needs to be flexible. You need to be able to get extra time off if needed.”

“There used to be special leave but it very much depends on the manager. When I asked for it there were a lot of questions and my manager said to me would you not just put your mother in a home!”

“My mum needed a lot of care and I applied for special leave. My boss asked me loads of questions and it was as if do you really need this leave?”

“Many carers can’t afford to take unpaid leave or reduced wages to provide care.”

“As a carer it would be nice to know you could have some kind of leave if you need it and there should be access to some kind of fund for income during this leave especially for those who are on low incomes.”

“When you’re a carer for someone it’s not just about the time you spend caring and the lack of money but you miss out on things like family events and celebrations because you still need to provide care.”

“They just assume that family will provide care and we have the skills to do it. They know you are not going to abandon your family.”

“They mostly assume women will provide care. I care for my husband who is 75 so I’m caring for someone who is a grown man and you need to be physically strong. The older I get the more I struggle with this.”

“If someone has to give up work to provide care it is normally the woman who earns less so she ends up giving up work to care.”

“The isolation of caring is soul destroying.”

“Very few families are able to manage work with providing care so normally someone has to give up work to care. It is nearly impossible to work and manage care. There are issues with getting childcare and access to carers to allow you to juggle work and care.”

“I would like someone to take my daughter shopping for an hour. It would really help her to get out and about. It’s constantly me doing this and it’s the physical part of folding the wheelchair and helping her. If we do anything we always need another pair of hands. Sometimes I’d just like someone else to do it. Instead they ask you is there no one in your family to help you.”

“The impact of caring on families is huge. It can lead to family breakdowns. If there is a family event like a wedding or funeral only one of us can go. It’s not good for personal relationships.”

“Carers feel like they are beating their head against a wall after coming through a horrendous two years of a pandemic. Carers have crumbled and they don’t know how to come back up again. And now there’s no one at Stormont to do anything about it.”

“Carers can’t get the help they need, waiting lists are getting longer, they can’t get the equipment they need anywhere. They feel lost and they are getting nowhere, the system needs to change.”

Respite Care

Women stressed the importance of being able to access respite care and how much of a difference it made to their lives in being able to have a break from their caring role. They spoke of respite being an essential and not a luxury. Often they had to fight really hard to get respite and sometimes the respite care offered was not suitable. Many were unable to access respite care and this was a particular issue for rural women. Being unable to access respite care had negative implications for their

mental health and family relationships. Many carers felt that Covid was being used as an excuse not to reinstate respite arrangements for carers.

“We get a break for three hours a week. Three hours a week with no autism! Some weeks those three hours is all that keeps us sane, we live for those three hours. I know lots of other friends who are caring who don’t even have this support.”

“They need to provide respite for carers, they need that break. They need to be able to recharge so they can go back to their caring role. They save the NHS so much money.”

“Day care and respite care are massive issues. They can’t keep using lack of resources as an excuse. I have two adult sons who had respite care before Covid but it has never been reinstated. They are telling me they haven’t enough staff to provide it again. They are using the pandemic as an excuse not to give services back.”

“There is no respite available so we can get a break. My son was offered respite in an old people’s home that was really far away. Respite is seen as a luxury when it is an essential.”

“Day care or respite would give me my life back.”

“I want to get some of my own life back. I don’t have a life. If I do go out I end up getting a phone call.”

“Respite is the biggest thing. Anyone who did get it by God they fought to get it. Some people ended up going to their MLA to get respite – you have to know what to do and who to push for it.”

“I asked for emergency respite to go to my mum’s funeral. They offered me an old people’s home which was miles and miles away for three nights for my adult sons. It was so far away and totally unsuitable for my sons who are in their 20s.”

“I tried to get respite for my daughter so that I could get away for a few days. There was no place suitable for someone with a brain injury and she’s a younger woman in her 30s. She was going to end up in an old people’s home and I just couldn’t do that to her.”

“I got the chance to get some respite from caring for my mum for three days. When I got the break I literally just sat there I couldn’t do anything I was mentally, physically and emotionally exhausted but at least I could just sit.”

“We live in Derry and the only respite they were able to offer was in Belfast. We used to get a weekend of respite care every 8-10 weeks but that stopped because of Covid and I’m not sure it’s ever going to come back now.”

Day Centres

Many of the women were very positive about Day Centres and the difference they were able to make to the life of the person they cared for as well as helping them get a break. However, many of the women complained about not being able to access Day Centres or long waiting lists to access them.

“There are times that I wish it wasn’t like this, that I wasn’t caring for my husband who has dementia. He has a mental health nurse who is amazing and helped me get in contact with some other organisations/charities that work in mental health and do things around engaging people. This has been really good for my husband. In the house I’m just there to answer questions, I’m like a domestic appliance, I’m just there to problem solve. But getting help through Day Centres is great for him, they get him to do things and make things and it helps him so much.”

“Day Centres are great. A lot of the people I work with are very isolated in their homes and could really benefit from a Day Centre.”

“It was a year since it was first mentioned by the social worker that we got access to the Day Centre. We had to wait a year.”

“My daughter goes to a Day Centre and it’s great. It was organised through the Brain Injury People. You need to be very lucky to get in there. The social and family impact of being able to go there is huge.”

“My husband gets his self-worth from doing things at the Day Centre, these things are very important.”

Support for Carers through the Benefits System

The Women’s Regional Consortium would also like to add the importance of support provided through the social security system for unpaid carers. We refer the Department to the issues we have raised about the inadequacy of Carer’s Allowance in Section 2.5. The low value of this benefit in terms of both the payment and earnings limit means that many carers struggle to make ends meet. It seems particularly cruel that the main benefit for people providing unpaid care for family or friends is the lowest benefit of its kind. Added to this the impact of the Cost of Living Crisis which has effectively seen a cut in the value of benefits which have not risen in

line with inflation. This leaves many carers in severe financial hardship and is something which urgently needs addressed in order to effectively provide support for carers.

We also wish to raise concerns about Discretionary Support which is designed to provide emergency loans and grants to claimants who find themselves in extreme, exceptional or crisis circumstances. Problems with accessing Discretionary Support due to problems with the telephone application and restrictive eligibility conditions including an income threshold and limits on the number and amount of debts a person can have has meant fewer awards have been made through this scheme. Some of the women carers we spoke to in focus group sessions had needed to use the scheme due to low income and had negative experiences.

An independent Review into Discretionary Support⁵³ found that it is critically important and should be protected stating: *“the need for Discretionary Support is likely to increase because too many individuals are unable to meet their essential needs from the income they receive through social security benefits or employment and so they remain at high risk of destitution.”*

The Women’s Regional Consortium wants to see greater investment in Discretionary Support in Northern Ireland and the urgent implementation of the recommendations from the Independent Review of Discretionary Support⁵⁴ to improve the current service. We would also like to see greater support for carers in accessing help through the benefits system more generally.

“I contacted Discretionary Support about replacing our 27-year-old washing machine that had broken down. I was changing my mother’s bed several times a night sometimes and I needed a washing machine. They still haven’t got back to me weeks later so we had to get a loan to buy a washing machine.”

⁵³ Independent Review of Discretionary Support, Department for Communities, February 2022 <https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-independent-review-of-discretionary-support-22.pdf>

⁵⁴ Independent Review of Discretionary Support, Department for Communities, February 2022 <https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-independent-review-of-discretionary-support-22.pdf>

“Discretionary Support is awful – it’s a dreadful system and the people on the phones are horrible. My friend is severely disabled and moved home and needed help with white goods but their attitude was disgusting. She was so upset after trying to apply. You’re already stressed in these situations and they just make you worse.”

“They treat you like you are trying to steal from them like it’s their money.”

“They don’t tell you things that you are entitled to, it’s like they’re trying to keep it secret. The Make the Call system is good although I even felt guilty for having to ring them.”

“During lockdown I was caring 24/7 and was in the house for two years. I didn’t get the extra £20/week those on Universal Credit got yet I could have really done with it especially as I had to pay someone to deliver our groceries.”

“The value placed on care and on the person you care for is low and the value of Carer’s Allowance shows that.”

“Carer’s Allowance is peanuts, it’s an insult.”

“The rate Carer’s Allowance is paid at is disgusting. I live in poverty to be able to look after my mother who has dementia.”

“My aunt is paraplegic and it takes two people to look after her. My two aunts care for her and have done since she was aged 15. But only one of them can claim Carer’s Allowance and the other one is not recognised in any way for this work. She has given her life to help care for her. Yet if my aunt was put in residential care it would cost a fortune to look after her. Carers are saving the Government millions yet they can’t give them a decent amount to live on. Even if they doubled what carers are getting the Government are still saving millions by having carers do this work.”

“The money you get on Carer’s Allowance doesn’t pay you for the emotional, mental and physical stress of caring.”

Co-production and Co-design

We are pleased to see the consultation include plans to “fully embed co-production with family carers as an integral part of the design process and implementation of adult health and social care services” and also “to fully embed Personal and Public Involvement with family carers as an integral part of the design process and implementation of adult health and social care services.”

We echo the call from our colleagues in Carers NI that this must include firm commitments to treating carers as strategic partners in care and ensuring that they are properly listened to when decisions are being made. Carers NI have raised their disappointment at the number of carers who recounted experiences of not being listened to and having their advice ignored.

We once again wish to stress the importance of genuine co-production and co-design in the reform of adult social care services. As previously stated unless there is a high level of genuine participation including from the most marginalised then this will not be effective. Resourcing organisations to do this work and providing realistic timeframes to do this work is essential. We again refer the Department to the guidance on consulting with women produced by Women's Regional Consortium members WRDA.⁵⁵

“There is no proper co-production, they are not coming to ask me what I think. The Trust have employed two consultants to do this work but they are not coming near me or meeting carers on the ground.”

Like our colleagues in Carers NI we do not agree with Proposed Action 30 to conduct an evaluation of the current 2006 Caring for Carers strategy to inform a new strategic approach. We do not believe it is necessary to carry out an evaluation of the Caring for Carers Strategy. We agree with Carers NI that carers have grown frustrated in the slow pace of change in social care reform and the case for a new strategic approach is well known so carrying out another review is only likely to lead to further delays. We therefore support Carers NI that a more favourable approach would be the immediate development of a new Carers Strategy for Northern Ireland.

The Women's Regional Consortium is generally supportive of Proposed Action 32 – the introduction of an independent Carers' Champion role.

⁵⁵ Women at the Heart of Public Consultation, A guide for Public Authorities and Women's Organisations, WRDA, November 2017
https://wrda.net/wpcontent/uploads/2018/10/WRDA_WomenAtTheHeartOfPublicConsultation.pdf

Women were mostly supportive of a Carers' Champion so that carer's issues can be kept to the fore. However, some of the women felt that the Carers' Champion role needed to have the power and resources to effect change and if this wasn't the case then it could just be a tokenistic role that fails to achieve anything. The Women's Regional Consortium supports Carers NI in its call for any Carers' Champion to be properly resourced and to have a fully funded policy, research and communications team to support their work.

"A Carers' Champion sounds like a good idea if they push for the improvements needed to carer's lives and keep these things at the forefront."

"A Carers' Champion – what kind of powers would they have? If they have no powers what is the point?"

"Creating a Champion role seems like one of those token things they put into consultations – like that will pacify them. They need to actually listen to carers and pay people providing care properly and they'll find that the care improves tenfold."

"If the Carers' Champion is only talking to the carers who are coming forward what about all the ones who are just getting on with their job and not saying anything? There are so many people you never hear from, people who are slipping through the net and doing this all on their own. There is so little help to signpost people to now."

"I would support a Carers' Champion as long as it's not a token gesture and nothing changes."

"The issue with these roles is that they can talk to you and never come back to you again so you tell them your views and after that you never hear anything."

"Caring is going to become more and more of an issue and these issues need raised so a Champion could be useful and a benefit to carers."

Chapter 6: Primacy of Home

Q1: Do you agree with the ethos and direction of travel set out under within this chapter?

Fully Agree ☐

Mostly Agree ☐

Neither Agree nor Disagree ☐

Mostly Disagree ☐

Fully Disagree ☐

Q2: Do you agree with the proposed actions within this chapter?

Fully Agree ☐

Mostly Agree ☐

Neither Agree nor Disagree ☐

Mostly Disagree ☐

Fully Disagree ☐

Please add any further comments you may have:

Carer's Assessments

Research by Carers NI⁵⁶ has highlighted how many carers do not feel that their holistic needs are being fully considered when they go through a Carer's Assessment:

- 63% did not feel their need to have regular breaks from caring was thoroughly considered in the assessment.

⁵⁶ State of Caring 2021, A snapshot of unpaid care in Northern Ireland, Carers NI, March 2022
[State of Caring in Northern Ireland - Carers UK](#)

- 37% felt their ability to have time to themselves was poorly considered.
- 75% felt that demands linked to the other responsibilities they faced alongside caring, such as looking after children, were not sufficiently considered.
- Less than half felt that their assessment thoroughly considered what needed to be put in place to support the person they care for in the event of an emergency.
- 70% felt the impact of caring on their employment/prospects of employment was not thoroughly considered.

Despite legislation directing Trusts to consider whether carers have needs in relation to the care they provide the number of carers receiving support as a result of a Carer's Assessment remains low relative to the number of carers. This issue was highlighted by the Gender Equality Strategy Expert Panel report⁵⁷ which looked at Department of Health statistics which showed that in the quarter ending June 2019, 2,007 assessments were completed and 2,153 declined. The most common reason given (by over a quarter of carers) was that they did not need support but almost a quarter did not give a reason.

The Expert Panel recommended that a review of Carer's Assessments should be conducted to establish the reasons for the relatively low level of assessments, the reasons why a significant number of assessment offers are declined and reasons for the variations across Health Trusts. The panel also called for assessment data to be gender disaggregated on the offer of assessment, request for assessment, acceptances and declines of assessment and services and support provided.

The Women's Regional Consortium supports Proposed Action 33 - a review of the NISAT and of the application of the NISAT. We support our colleagues in Carers NI who advocate for a dedicated work stream within that Review to look

⁵⁷ Gender Equality Strategy, Expert Advisory Panel Report, December 2020
<https://www.communities-ni.gov.uk/system/files/publications/communities/dfc-social-inclusion-strategy-gender-expert-advisory-panel-report.pdf>

at the use of the tool for Carer's Assessments and whether it is fit for purpose for these assessments.

"The only right carers have in NI is the right to have a Carer's Assessment. There is no statutory duty on the Trust to deliver on what is in the Carer's Assessment so it is of absolutely no use to me."

"I've been waiting 3 years for a Carer's Assessment that I begged for and was promised pre-Covid."

"They constantly reassess you but it's never to give you more help and support its always to give you less."

"Sometimes you come away from a Carer's Assessment thinking what is the point? You feel so deflated."

"In the Southern Trust I have been told they are not doing Carer's Assessments anymore they are doing a Carer's Conversation Wheel. This was thrown at me at the door as I was leaving and I was told to fill it in. It didn't capture the care I was giving (for four people then – my mother, father and 2 adult sons). The Southern Trust are piloting it. It didn't capture anything. I'm still waiting for a Carer's Assessment, I don't want the Conversation Wheel."

"They are doing Reviews over the phone now. I said no way come and talk to me. They told me they had reviewed my assessment – they did it behind my back and used Covid as an excuse to do it this way."

"What earthly use is a Conversation Wheel? It doesn't capture in depth what we feel."

"At your 3-year Review all they are interested in is if you can go out to work! Even getting out to the Review can be hard as you have to get someone in to look after the person you're caring for."

"Reviews are supposed to be about seeing what your needs are after 3 years – usually things have got worse. It would be great if Reviews were really about this but instead they are just a paper exercise."

"It's about getting a package that suits the person – there needs to be a person-centred approach. This is often not the reality. They need to talk to the carer and the person who needs the care."

Domiciliary Care

The Gender Equality Strategy Expert Panel report⁵⁸ highlighted a number of areas of concern in relation to paid adult social care which evidence low pay and poor working conditions of paid care staff:

“Analysis by ICF Consulting in 2018 shows that average earnings for a worker in the regulated social care sector (ie, those registered with NISCC and employed by the statutory or independent sector) is about £16,600 for a FTE; average FTE earnings in NI are £30,200. So, earnings in the adult social care sector represent 55% of average earnings. The Department of Health’s Domiciliary Care Workforce Review (2016-21) acknowledged the challenges within this sector and the variable salary and working conditions of paid care staff. In the statutory sector staff are employed under Agenda for Change Programme terms and conditions, though most are employed at Band 2. In the independent sector, terms and conditions vary from employer to employer, many workers are employed on ‘as and when’ contracts, workers are paid an hourly rate – to include contact time only, there is a predominance of unpaid training time, unpaid travel time and limited or no travel expenses.”

Added to this the fact that the social care workforce is mainly female. As previously stated in NI the figure is 87%. If only the HSC Trust domiciliary care workforce is considered, 98% is female and 43% of these staff are aged 55 or over.⁵⁹ There are clear gendered issues with pay, terms and conditions within this sector which need urgently addressed. Women at focus group sessions noted the poor pay and conditions of domiciliary care workers and many felt that their work should have a much higher value through increased pay and improved working conditions especially in the independent sector.

⁵⁸ Gender Equality Strategy, Expert Advisory Panel Report, December 2020
<https://www.communities-ni.gov.uk/system/files/publications/communities/dfc-social-inclusion-strategy-gender-expert-advisory-panel-report.pdf>

⁵⁹ Department of Health (2016) Domiciliary Care Workforce Review 2016-2021

We again refer to the Gender Equality Strategy Expert Panel report⁶⁰ recommendation that:

“There is an immediate need for increases in salaries of paid care workers. This should be linked to the professionalisation of training (within the development of a training and qualifications framework, including Higher Level Apprenticeship) for adult social care workers with opportunity for workplace progression and secure contracts for all care workers. These actions are critical to building a sustainable care system and will benefit the quality of care provided to users and the economy.”

Most of the women at focus group sessions wanted to acknowledge the commitment, passion and dedication of the domiciliary care workers they had known despite their often challenging working conditions. They spoke about how good carers made a real difference to the lives of those they provide care for as well as providing much needed support and respite for unpaid carers.

However, the women also noted a number of stresses within domiciliary care including insufficient time for care visits, irregular visiting times, unsuitable visiting times and issues around the provision of personal care. It is clear that domiciliary care services are under pressure and in some cases there is not enough time for visits leaving people with inadequate care or care which is not suited to their individual needs.

There is a need for investment in the social care infrastructure to fund high quality care services, reduce levels of unmet need and provide genuine choice for those who need care and their families.

“Good carers are a godsend. Good carers, if they have been coming in over a long period, nearly become part of the family. You need continuity of care, that’s essential.”

⁶⁰ Gender Equality Strategy, Expert Advisory Panel Report, December 2020
<https://www.communities-ni.gov.uk/system/files/publications/communities/dfc-social-inclusion-strategy-gender-expert-advisory-panel-report.pdf>

“Some carers are in and out in 5 minutes.”

“I cared for my aunt and sometimes the carers were only in a few minutes and didn’t even have time to make a cup of tea just do her tablets. Sometimes they didn’t call at all – what happens if no one turns up then it’s all on the family and what happens if someone has no family?”

“The carers were coming at 6pm for bed time, it was too early to go to bed. Sometimes the morning call was not until 11am/12pm. It’s not so much about the person then more about the company and when they can fit the care in.”

“In terms of domiciliary care my mum really hated men coming out to visit her.”

“Domiciliary carers from private companies are leaving for higher paid jobs in the health trusts.”

“The domiciliary carers are great, they create bonds with clients - they make my daughter feel sane.”

“Women who provide care are totally undervalued, the training is so basic, there is no career path and they are not classed as important as the elderly and disabled are not important. Women who provide care are not seen as important – we need to start to value these women. They really need valued and paid properly.”

“When I cared for my aunt sometimes the carers just didn’t turn up.”

“When there is no routine of regular carers it makes it difficult.”

“Community carers were coming out at 12pm for the morning call which is far too late as half the day had passed – as well as coming at 6pm for bedtime, even kids stay up later than 6pm.”

“Community carers provide no routine, different carers come at different times, it’s difficult to stick to a medicine schedule when they come and go like that.”

“My Granny didn’t like male carers washing and changing her.”

“A couple of my family members (all women) were involved in care to try and keep my mum out of a care home. We had carers coming in but they were turning up at different times and sometimes not at all. As a family we couldn’t relax and let them take over. We just ended up doing it with family carers being around as the outside carers were not reliable.”

“Carers were coming into our house four times a day and my mum felt it wasn’t her house anymore. She needed them coming in but the timings were bad – often it was already too late by the time they got there.”

“Domiciliary carers should be able to be flexible about the care they provide. Although how to make this work is very difficult in practice. If they stay longer with someone because they need it what impact will this have on the next person on the list?”

“It’s alright saying about the importance of home but you need the services to support this. I have carers for 10 hours a month as a sitting service. It’s nowhere near enough but the carers are great and my sons like them. However, it’s still a real invasion of privacy in your own home. You never know who is coming, they never tell you and my sons get upset if it is someone different.”

“The carers we have cover an area which is not huge but it’s the numbers. There are just not enough of them. Sometimes they come out at 7am and other times it’s 9am and this depends on the need in different areas – I know it’s hard to control this. We tend to be first or last on their list.”

“Carers need to be paid more and have more control over where they go and what they can do. The way petrol prices have risen recently is hard for them too – they are having to pay the extra.”

“I can say nothing bad about the carers we have, they are fabulous. They always start with care for the person and they help me out too.”

“I have carers who come in four times a day and they are my salvation. The girls are lovely. A lot of them have left and gone to the Trust because there are better wages there. A lot of time they are not getting paid enough for travel, they don’t get paid enough per mile so they’re having to subsidise it themselves. They need to try and keep these carers and not always have to be looking for new people.”

“Carers need to be given longer with each person. They come at all hours with no real routine. They were coming at 6.30pm to put my adult daughter to bed. She was going to bed before her children!”

“If someone is off on holidays it would be good to know who is coming – they don’t realise the impact this type of thing has on people. My sons get very upset with changes in their routine.”

“Half the time the carers don’t have time to make people proper meals they just go and get them a sandwich or something. I know someone with carers who is just living on sandwiches, that’s not right.”

“We were offered a carers visit at 7.30/8 in the morning for my brother who has Downs Syndrome and has care needs. There’s no way we could take an appointment at that time, he just wouldn’t get up. It doesn’t work for him or for us.”

Care Homes

We received limited feedback from women on care homes. However, there was a general acknowledgement that good quality care homes could make a real difference to some people especially those who are lonely and isolated and who have no one to help with their care. Some of the women felt there was a lot of guilt associated with putting someone in a care home and that this shouldn’t be the case if it is the right decision for them.

Most of the women raised issues with the cost of care homes and it was generally accepted that care home fees were very expensive. This meant that many people did not see this as a choice for their care and they felt priced out of good quality care homes. In terms of management of care homes there was support

“The cost of care homes is ridiculous; no one could afford them. Do only those who have money receive the best care?”

“It seems sensible that two people should be in charge of a care home.”

“If a care home is well run and the staff are good it makes a real difference to people needing care.”

“People are scared to go into care homes because of how expensive it is. They need to sell their house.”

“You shouldn’t have to feel guilty if you have to put someone into a care home.”

“My husband’s mum needed care after a fall and her two sons tried to look after her but it wasn’t easy as they were working. She eventually had to go into a care home and within two weeks they had her on her feet again. It was the best thing for her but my husband said you never get rid of the guilt. They wouldn’t have been able to provide the same care she got in the care home but they still felt guilty about not being able to do it.”

Supported Living

There was limited feedback from the women on Supported Living. Women were supportive of the benefits of these type of living arrangements where people were enabled to be independent as long as possible. They stressed the need for there to be more options for this type of care so that it is a realistic choice for people.

“There needs to be more independent living folds - this way people receive care, feel safe and can live with a sense of independence as long as possible.”

“My granny is in a Fold – they all have their own flats. They play bingo and do activities and get their meals. Her rent is paid. It’s a type of independent living. She is 83 and this really suits her well. Carers come in to people who live there too. There should be more places like that where people have their own space and where they can also take part in things. They have a women’s group and bingo, etc. These places help people be independent as long as possible.”

Impact Assessments/Screenings

Do you agree with the outcome of the Impact Assessment screenings?

- | | |
|----------------------------|--------------------------|
| Fully Agree | <input type="checkbox"/> |
| Mostly Agree | <input type="checkbox"/> |
| Neither Agree nor Disagree | <input type="checkbox"/> |
| Mostly Disagree | <input type="checkbox"/> |
| Fully Disagree | <input type="checkbox"/> |

Please add any further comments you may have:

Equality Screening

Care is a highly gendered issue in terms of the composition of both paid and unpaid carers and the fact that women are more likely to need care due to longer life expectancy for women.

Gender norms mean that women are expected to take on caring responsibilities and this is often even more expected in rural areas and among those from ethnic minorities.

We have outlined in our consultation response that the gendered issues around care disproportionately impacts on the quality of life for women. It means that many are forced into part time work, reducing their working hours or giving up work altogether. This has implications for their incomes, their quality of life, their ability to take part in community and society and impacts on their pensions.

We do not see these gendered issues reflected effectively within the Equality Screening and therefore have concerns that the gender issues at play within adult social care will not be tracked through to policy development in the resulting Strategy.

Section 75 and Carers

We support our colleagues in Carers NI in their call for more explicit recognition of carers. As they point out carers are sometimes considered under the protected group of *persons with dependents* but this tends to focus on parent carers only. We support the Carers NI recommendation for Section 75 of the Northern Ireland Act to be amended to explicitly recognise all unpaid carers as a protected group.

Rural Needs Assessment

The Rural Needs Assessment clearly identifies a good range of information sources to identify the social and economic needs of people in rural areas and the same for the social and economic needs of people in rural areas. These are desk based, research briefings, papers, plans, etc. As these are all a snapshot in time and we live in an ever changing environment; particularly in relation to socio economics it would be advisable to hold specific focus groups for rural dwellers so their current views and lived experiences could be taken into account in the new Strategy. This level of good practice should be the sole remit of third sector organisations like NIRWN to conduct.

The Rural Needs Assessment recognises '*there can be barriers to overcome in the rural areas, such as a smaller pool of labour, which can require social care workforce to travel distances to provide social care services to service users, or service users having limited access to social care services within their locality*'. This concurs with our members' views and experiences however, it is not clear from the consultation paper how a new Strategy proposes to address these barriers.

Recommendations:

- **Host a specific rural focus group on the proposed Strategy to ensure current rural needs are reflected.**
- **Specifically a rural recruitment drive should be resourced to increase the labour pool.**
- **A travel reimbursement rate, commensurate with changing fuel costs for the social care workforce.**

- **Clear identification of ‘gap’ areas that is updated with a budget and plan to address localities that are under served.**

The Rural Impact Assessment identifies many of the challenges and lays down opportunities for a fit for purpose workforce with adequate supply of staff:

Opportunities to maximise the supply of staff in rural areas:

- Realising the status and attractiveness of the HSC as a large employer in rural areas (especially in areas where there are few other large employers).
- This means highlighting the varied job roles and opportunities for career development in rural areas.
- This requires developing innovative solutions to service delivery and staff recruitment and retention.
- This may provide opportunities for people who need or want a ‘second chance’ – perhaps because the educational system has failed them, or because they want to change direction; their ‘life experiences’ should be seen as an asset.
- Finding new ways to inspire young people about possible job roles and careers in health and social care.
- Using technology so face-to-face staff resources are concentrated where they are most effective and needed.’

We cannot however, identify where this has been included in the proposed Strategy.

Recommendation

- **The opportunities identified in the Rural Needs Assessment are included in the Strategy and resourced and actioned.**

We know that ‘Life expectancy is much higher in rural areas’ so long-term rural dwellers are more likely to be impacted by this Strategy and the Strategy must take account of current and projected need; particularly in light of the already reduced workforce in rural areas now. We know too that ‘people living in rural areas on average wait much longer for emergency services than those living in towns and cities’. This

is unacceptable and endangers life and long-term quality of life. This Strategy must align with others and ensure that centralisation and rationalisation of services where deemed medically advantageous have the infrastructure in place first to ensure those living furthest away can have timely access.

Recommendations:

- **Short term, medium term and long-term plans for a trained workforce for rural areas.**
- **Actions across the Departmental Strategies which ensure that people in rural areas are not waiting much longer for emergency services than those living in towns and cities.**

The Rural Needs Assessment states that ‘plans (for the reform of adult social care) are intended to have the same impact across a region and consideration to be given to potential local circumstances which result in different outcomes’. We don’t believe that in its present iteration that the Strategy does include recommendations to address the specific rural needs and impacts outlined in the Rural Needs Assessment to ensure that the plan will have the same impact across the region. The Rural Needs Assessment clearly outlines the process of plan development from 2016 but neither this paper nor the Strategy include recommendations and implementations that take account of rural need.

The specific rural barriers and historic lack of access must be actively addressed to ensure equity of service and experience for all citizens across the region.