

Integrated Care System NI Draft Framework Consultation Response Document

Please note that responses can also be submitted directly online via Citizen Space which can be accessed via the following link should this be a preferable option: https://www.health-ni.gov.uk/consultations/future-planning-model-targeted-stakeholder-consultation

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Are you responding on behalf of an organisation?		Yes			
Organisation (if applicable)	Women's Resource and Development Agency				

The questions set out on the following pages are to help gather views and guide responses in certain areas. General comments can also be left at the end of this document on any aspect of the framework.

Please note: the boxes provided for additional comments in each question can be expanded.

Q1. Section 3 describes and defines what an Integrated Care System (ICS) model is which provides the blueprint for how we will plan, manage and deliver services in NI moving forward.

Do you agree that this is the right approach to adopt in NI?

Agree

(delete as applicable)

Additional comments:

An Integrated Care System is defined as:

'A collaborative partnership between organisations and individuals with a responsibility for planning, managing, and delivering sustainable care, services and interventions to meet the health and wellbeing needs of the local population. Through taking collective action, partnerships will deliver improved outcomes for individuals and communities, and reduce inequalities.'

WRDA agrees that it is essential to address the waiting list backlog and to reform services to ensure future sustainability. However, in the absence of adequate funding commitments, we also recognise the need to utilise the existing funding available in order to attempt to maximise the outcomes for Northern Ireland. We also agree that it is necessary to address the whole life-course of conditions, from prevention through to intervention and recovery where possible, through a more joined up approach with all relevant partners, including those beyond health and social care, such as the women's sector. WRDA agrees that an ICS in theory should enable collaborative working across the HSC sector and beyond to reduce health inequalities and deliver improved health and social wellbeing outcomes for our population. We also welcome that this model would be underpinned by the identification of the needs of individuals and communities and enable collaboration, integration and partnership which reaches beyond the health and social care sector in NI.

WRDA also supports the principle of local level decision making underpinned by the population health approach with a focus on improving outcomes. An ICS model should ensure that local providers and local communities (including women's organisations) are enabled to come together and plan care and services for their area based on needs. We welcome that this model over time would ensure greater autonomy, decision-making and control over funding to be devolved to these local partnerships with the expertise on how to best support people in the area.

Within the equality screening of the Future Planning Model Project Model for Northern Ireland, it is stated that 'the delivery of the model aims to improve the health and well-being of the people of Northern Ireland and reduce health inequalities, through collaboration and partnership working in the design, delivery and management of health, social and community services'¹. Further, under the section relating to evidence on 'Men & Women Generally', the following evidence is given:

¹ Department of Health Future Planning Model Equality Screening Document, p.2

'Various reports are referenced in the draft Framework Document including the Health Inequalities Annual Report 2021 which identifies that the healthy life expectancy inequality gap in 2017-19 was 13.5 years for males and 15.4 years for females and the rate of emergency attendances in 19/20 for the most deprived areas was more than one and a half times that of the least deprived.'

While we support the overarching aim to address health inequalities through collaboration and partnership working within this future planning model, WRDA is concerned that many health inequalities facing women have not been considered within this model or consultation. Further, as an organisation with experience in partnership working to address health inequalities, there are significant concerns in relation to adequately and sustainably funding partnership organisations within the voluntary and community sector.

WRDA fully appreciates that the health and social care system in Northern Ireland has been under immense and growing pressure for some time, particularly in relation to the waiting lists crisis and constrained financial environment. WRDA and the broader women's sector actively works in partnerships to try and address health inequalities faced by women in Northern Ireland.

One example of a partnership project to address health inequalities includes the Mas project (Maternal Advocacy and Support) which is delivered across 8 women's centres, all are located in areas of disadvantage and aims to remove or at least reduce the barriers to participation by providing perinatal mental health support within the community, providing childcare, lunch and additional support.

Women attending the Mas groups have talked about how they have felt let down with the breast-feeding support that they received, and this should be considered when assessing health inequalities. Some said that this had impacted on their mental health, and it was felt that the support was inconsistent. Public Health agency Heath Intelligence Briefing, Breastfeeding in Northern Ireland, September 2018 highlights health inequalities in relation to breast-feeding. In relation to 2017 statistics 45.8% of women from the most deprived areas compared to 74.2% from the least deprived. On discharge the percentage was 32.1% from the least deprived areas and 63.4% from the least deprived. At 6 weeks this was 18.9% from the most deprived areas and 44.3% from the least deprived. At 6 months the difference was 10% from the most deprived areas and 25.8% from the least.

The health inequalities in relation to breast-feeding and correspond with experiences of women on the Mas project, many who did not feel that they had received guidance and support to continue breast-feeding. It is worth noting that Northern Ireland has the lowest level of breast-feeding in the world and some women in the Mas groups have said that they felt that they had stopped before they were ready to.

Another example of a partnership to address health inequalities is through the work WRDA does in partnership with the PHA and has a contract with the PHA to deliver cancer screening awareness sessions to disadvantaged women in the community. The PHA carried out extensive regional research using deprivation and geography data to determine levels of uptake. The Big Data Analytics 2018 highlighted that uptake of breast screening using the Most Recent Invite Episode was substantially lower in areas of deprivation; and in many cases these communities are the most difficult to reach. Screening programmes have an important role to play in addressing health inequalities and WRDA work to address these health inequalities by targeting these hard-to-reach communities.

Some of the barriers to partnership working which need to be considered as policy enablers within any framework for an Integrated Care System include:

- Long-term, adequate and sustainable funding; WRDA has been in receipt of DoH for at least 30 years which contributes to core salaries & costs. This funding compliments our funding through PHA and enables the agency to train up Community Facilitators who in turn deliver Breast, Cervical & Bowel-BC&B cancer awareness raising workshops which importantly provide information on screening services.
- Recognition of the expertise among community groups, such as those within the women's sector, and the need to adequately invest in these partnerships,
- Early signposting Many of the women on the Mas project have expressed a belief that they could have been sign-posted by health care professionals to the community and voluntary sector at an earlier stage and have stated that they felt that healthcare professionals were often not knowledgeable in provision in their own area. There is a real opportunity to improve partnership working and acknowledge the expertise of the voluntary and community sector and refer women to services that can support their mental health. Early intervention is key and this can be supported by our sector.
- The disproportionate impact the COVID-19 pandemic has had on women, socially, economically and in terms of health, and how this may impact women in the longterm without a gendered response to recovery.
- Address the existing barriers to integration caused through unsustainable funding models which can prevent full integration between health services such as GPs in referring to community led partnership programmes due to uncertainty around future funding.
- Addressing the unequal distribution of care between men and women the need for a caring economy and adequately investing in the care sector while addressing the unequal levels of caring responsibilities women face.
- Measures to address potential resistance to change from the existing model of Health and Social Care.

WRDA has also undertaken a vast amount of work in addressing inequalities in our society, including through health inequalities and the impact of social deprivation on women. WRDA is the secretariat of the Women's Policy Group Northern Ireland, and the WPG has published two extremely extensive COVID-19 Feminist Recovery Plans² specifically highlighting many of the policy failures (including failures within the health and social care system) that have led to pre-existing inequalities faced by women to exacerbate greatly throughout this pandemic. As highlighted within the Future Planning Model, health outcomes are impacted by various factors including socio-economic factors (40%), health behaviours (30%), health care (20%) and physical environment (10%).

Therefore, it is crucial that all of these factors are incorporated into an integrated care model, and in doing so, there must be recognition of the vast evidence of how women have been disproportionately impacted by COVID-19 economically, socially and in terms of health, with many pre-existing inequalities being exacerbated due to the pandemic. In any ICS, these factors and the impact on health and social care (which is predominantly undertaken by women) must be considered as evidence beyond the measurement of life expectancy between men and women.

² WPG NI (2020) COVID-19 Feminist Recovery Plan: https://wrda.net/wp-content/uploads/2020/07/WPG-NI-Plan-2020-.pdf; WPG NI COVID-19 (2021) Feminist Recovery Plan Relaunch: One Year On: https://wrda.net/wp-content/uploads/2021/07/WPG-COVID-19-Feminist-Recovery-Plan-Relaunch-One-Year-On.pdf; WPG NI (2021), 'COVID-19 Feminist Recovery Plan - Department of Health Bespoke Report': https://wrda.net/wp-content/uploads/2021/02/Department-of-Health-WPG-FRP-Summary.pdf

Within the WPG COVID-19 Feminist Recovery Plan, some of these inequalities are expanded upon with several evidence-led policy recommendations that are relevant to this ICS consultation. This includes, but is not limited to:

- The impact of poverty and austerity on women's health and wellbeing,
- The impact of disproportionate levels of caring responsibilities on women's health and wellbeing,
- Issues relating to the implementation of Personal Independence Payment on women,
- Food insecurity and food bank use which disproportionately impacts women and single parents (91% of whom are women in NI),
- Destitution.
- The need for adequate investment in Social Security,
- The impact of financial insecurity and debt on women,
- The lack of an executive childcare strategy in Northern Ireland, or sustainable funding for the Women's Centres Childcare Fund (WCCF),
- Rural access poverty and distinct issues relating to rural mental health,
- The social determinants of health,
- Specific issues relating to women's mental health and mental health among marginalised groups,
- Women's centres' work on mental health,
- Ramifications of cancelled cancer screenings,
- Increased waiting lists,
- Access to abortion services and other forms of reproductive healthcare such as IVF across all of Northern Ireland,
- Maternal Mental Health improved services
- Maternal death rates among ethnic minorities and women in poverty,
- Trans healthcare,
- Support for disabled women,
- The impact of growing levels of domestic and sexual violence and abuse on women and girls and,
- Cuts to funding for community-based education and training for women.

We would urge the DOH accounts for the vast amounts of evidence provided within the Feminist Recovery Plans under the areas listed above when assessing the health inequalities between men and women. In addition, the Feminist Recovery Plans provide various recommendations in relation to addressing the gender segregated care sector, and how both paid and unpaid care (which is predominantly undertaken by women) must be prioritised in any recovery from COVID-19. In particular, we would urge the DOH to become familiar with the recommendations on creating a caring economy which are embedded throughout the Feminist Recovery Plans, as a potential solution to many of the issues facing our carers. These recommendations should be incorporated into any new ICS model for Northern Ireland.

Further, within the WPG COVID-19 Feminist Recovery Plan Relaunch: One Year On, a supplementary report on 'Putting Women's Voices at the Core'³ was developed based on primary research with over 150 women across Northern Ireland. Some of the key findings that need to be considered by any ICS in relation to health inequalities include:

• 82.1% of women said that their mental health had declined during the pandemic,

³ WPG NI (2021), 'WPG COVID-19 Feminist Recovery Plan: Supplementary Report - Putting Women's Voices at the Core': https://wrda.net/wp-content/uploads/2021/07/WPG-Feminist-Recovery-Plan-Research-Report-Womens-Voices-at-the-Core.pdf

- 57.9% of women said that their physical health had declined during the pandemic,
- 81.1% of women who designated as carers said that their caring responsibilities increased during the pandemic,
- 50% of respondents from an ethnic minority community said that they had experienced issues in attempting to access health care services,
- 34.2% of respondents living in a rural area struggled to access healthcare during the pandemic,
- 55.3% of rural respondents felt isolated from support networks,
- 38.1% of women said they had been impacted by increased waiting lists,
- 15.9% accessed or attempted to access healthcare services relating to maternity, pregnancy, perinatal mental health and birth-giving during the pandemic.

In addition to the quantitative data above, the WPG gathered several case studies of women impacted by the pandemic and several told us about their distressing stories throughout the pandemic in relation to healthcare, with many describing extremely challenging circumstances with attempting to access perinatal mental health support, lack of support throughout maternity care (including miscarriage support), access to an abortion, the impact of being a victim of a gender-based crime and more.

WRDA also welcomes the vision and objective for ICS NI outlined in Section 4, particularly the commitments that ICS NI will:

- Put the needs of people at the heart,
- Ensuring communities are involved in the planning of services,
- Delivering care within the community,
- Supporting people in managing multiple or life-long conditions and disabilities.

We note also within section 4, that the vision is highlighted as broadly ensuring:

- 1. Specialist care in hospital or clinics where needed (managed and delivered centrally).
- 2. Primary care in community to support general health,
- 3. Support for self-care and personal wellbeing (delivered by communities, partners and individuals working together) and,
- 4. Improved outcomes (for individuals, communities and wider population)

It is worth highlighting that there are issues with centralised specialist care for women, particularly rural women, due to unreliable public transport networks. Any centralisation of care cannot be to the detriment of rural access, particularly as women rely on public transport and public services at a higher rate than men. Further, some of the health inequalities that women face due to the disproportionate impact of poverty, austerity, caring responsibilities and more, will not be addressed within this vision and must be accounted for in any ICS for NI, and these factors must be embedded in any future planning model.

Therefore, WRDA supports the premise of an ICS model, but would like to see greater consideration and recognition for the additional health inequalities women face and the vast funding barriers the voluntary and community sector has long faced in delivering partnership work.

Q2. Section 5 sets out the Values and Principles that all partners will be expected to adhere to.

If applicable, please comment on anything else you think should be included.

Comments:

Within the model, it is highlighted that all partners will adopt the following values and principles:

 Ensure the person is at the centre of the model, with services planned and delivered in line with their needs with the aim of achieving improved outcomes for individuals and communities;

This is a value and principle at the core of the work of WRDA and the broader women's sector already. We are led by women's lived experience and recognise the expertise of women based on their lived experiences and understanding of what is needed to achieve the best outcomes for women and their communities.

• Demonstrate collective and shared leadership to overcome challenges and engage across organisational boundaries;

The women's sector has a strong history of collaborative and shared leadership spanning over several decades. For instance, WRDA was founded in 1983 and since then has worked collectively with women's organisations and other voluntary and community sector organisations to coordinate effective partnership projects.

An example of this is the Mas Project, whereby WRDA is the lead partner of a project on Maternal Advocacy and Support which links eight women's centres across Northern Ireland. The project provides peer support groups for women who are experiencing perinatal mental health problems and delivers a range of well-being initiatives. The project also provides an opportunity for women to talk about their experiences in the healthcare system and advise on areas that could be improved for women in Northern Ireland. The women have identified key areas that they wish to be changed and improved:

- Training on PMH for Health care professionals
- Permanent Mother and Baby Unit NI
- Long- term funding for Perinatal Mental Health Programmes such as Mas
- Healing Garden linked to baby loss for all Trusts (we welcome the development of the Snowdrop Garden in Belfast)
- A proper check out when leaving hospital
- More access to counselling
- Consistent Guidelines and Information
- A leaflet with local support services in every area so that healthcare professionals can make referrals
- Concerted effort to have the same staff member with the same women that would help to build relationships, trust and improve quality of care.

We would welcome Department of Health and health care professionals to attend our Mas Lived Experience conference in November to listen to the lived experience of women who must be at the heart of service improvement.

Adhere to the principles of parity and inclusion between partners;
 acknowledging the skills, experience and value that each partner can bring;

Again, WRDA and the broader women's sector has a strong track record of embodying this principle and value in our work. For instance, WRDA is a member of the Women's Regional Consortium. 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.

Further, WRDA is the secretariat of the Women's Policy Group NI, which provides a clear example of adhering to the principles of parity and inclusion between partners; acknowledging the skills, experience and value that each partner can bring. The Women's Policy Group Northern Ireland (WPG) is a platform for women working in policy and advocacy roles in 30+ organisations to share their work and speak with a collective voice on key issues. It is made up of women from trade unions, grassroots women's organisations, women's networks, feminist campaigning organisations, LGBT+ organisations, migrant groups, support service providers, NGOs, human rights and equality organisations and individuals.

Over the years this important network has ensured there is good communication between politicians, policy makers and women's organisations on the ground. The WPG is endorsed as a group that represents all women of Northern Ireland on a policy level and we use our group expertise to lobby to influence the development and implementation of policies affecting women.

The value of mutual respect and understanding across fields, disciplines and sectors of different ways of working and a commitment to consensus and shared working. We can learn from each other and supporting and appreciating different outlooks is enriching and can enhance service provision. It is also essential that a person-centred approach is applied to patient care. The broader women's sector has a strong history of applying this value to our work and we welcome this value within the ICS for NI.

 Agree clear and transparent ways of working together, having a mutual understanding of each other's existing governance arrangements and structures;

As stated before, this is a principle that is crucial to the work of the women's sector and we would agree this should be necessary for all partners in the ICS NI.

As highlighted above, WRDA is lead partner in the Mas project and we partner with 8 separate organisations. Clarity and transparency are essential in the running of the project. Effective communication, flexibility is essential in working together to deliver a new project, establishing ways of working that co-exist with the existing structures in the women's centres. We have found that a reflective approach is helpful, identifying issues and challenges at an early stage, communicating with partner organisations and remaining focused on service delivery and developing best practice.

 Commit to the gathering, analysis, sharing and use of population level data along with known evidence-based interventions to inform decision making and evaluation. This includes the 'lived' experiences of individuals and communities; Again, this is an area that WRDA has extensive experience in, for example, through the work of the WPG, and the broader work of our women's sector colleagues. The WPG for instance, is a group that has collective expertise on protected characteristics and focus on identifying the intersectional needs of all women. Some recent examples of collective work between partners includes the WPG COVID-19 Feminist Recovery Plan, which combined the expertise from 36 women working in policy and research roles across 27 organisations, to develop a 300+ page policy recommendation report that is completely evidence led. This project also involved collaboratively undertaking primary research with 150+ women across Northern Ireland through interviews, case studies, surveys and focus groups, to connect their lived experiences to the wider economic, social and health data available on the impact of COVID-19 on women in Northern Ireland.

In addition, the WPG Evidence Submission to the Justice Committee on the Protection from Stalking Bill, was a combined evidence submission with primary research from 11 different organisations with different areas of expertise. Each organisation worked in different areas (for instance, domestic violence support, campaigns on sexual harassment, LGBTQ+ organisations, migrant groups with expertise on factors to consider and more) to collate existing evidence on different aspects that needed to be included to strengthen the bill and meet the needs of victims and survivors. Further, we then worked collectively to gather testimonies from 41 victims of stalking in Northern Ireland, as primary data at a Northern Ireland level did not exist.

The Women's Regional Consortium is another example of women's sector partners conducting research amongst our own respective membership bases to inform responses and positions in relation to a range of public decisions on matters relating to debt, welfare reform, austerity, assessments of processes such as Personal Independence Payment, responses to government proposals such as the Skills Strategy for Northern Ireland and more. Lived experience and the expertise of women is at the core of our work and we would welcome this principle within the ICS.

• Foster a culture of openness, transparency and trust between partners and the wider population they support;

We agree that this principle is crucial to any ICS for NI as this is something that is central to the work of the women's sector and allows for the strong history of partnership and collaborative working that has been outlined.

• Work collectively to remove or avoid duplication, ensuring the most efficient use of available resources and deliver value for money;

This is also a principle that WRDA would agree with. The women's sector in Northern Ireland is vast, and each organisation is unique in their own areas of expertise or in the membership and women they support. We regularly work together to identify the appropriate women's organisation to take the lead on various projects depending on the area of work at hand. That said, the women's sector and wider voluntary and community sector has faced vast funding cuts in recent years, and in any ICS for NI, it is crucial that this principle of value for money is not placed above the interests of the communities we represent. It is imperative that adequate funding is provided to support the organisations working in partnership to implement the ICS and that each community group is recognised for the unique contributions they make to their own local communities.

 Identify and promote best practice and learning between partners, encouraging flexibility, agility and innovation to collectively meet and

address challenges. Use evidence and outcomes to shape local services based on a quality improvement approach. - p.13

Cancer Screening programmes and early intervention save lives, improve health and enable choice. WRDA works in partnership with the PHA and other organisations and supports the health system to reduce inequalities in the uptake in screening. Collaborative working is at the heart of our cancer screening awareness programmes and this partnership working helps us to ensure disadvantaged communities are reached. WRDA also works to promote best practice and learning between partners. For example, recently working with the British Deaf Association to ensure service delivery is accessible for those with a hearing impairment; working with Deaf/Blind UK / NI to ensure services accessible for deaf/blind participants; offering interpreters for cancer awareness sessions for the BAME community and offering bespoke sessions for participants with additional support needs.

The Mas project also works closely with Aware NI and access training and support for staff and participants. Further, we are part of a perinatal mental health partnership NI and work together with others in the area to develop referral pathways and support each other's work and services to avoid duplication and deliver value for money. We are strong advocates of collaborative working and believe that supportive partnerships are beneficial to organisations and service users. It is important to be knowledgeable in community, voluntary and statutory provision so we can create partnerships and refer participants to a service they can benefit from.

Some of the Mas participants attend multi-disciplinary team GP surgeries. It has been indicated that this system is providing an improved support for women with a direct mental health service provided by the mental health practitioner who can then liaise with health visitor and doctor and provide follow ups with the women. This inhouse partnership working seems to be providing an improved service for women and a reflective and gradual rollout across Northern Ireland with a commitment to identify learning is helpful. The Mas project has been in contact with West Belfast MDT Social work who has been keen to link in with the Mas projects in the area which we are pleased to see, indicating a willingness to shape local service by lived experience.

WRDA agrees with the following comments highlighted in section 6.1 in relation to Population Health planning:

"The health and social care system, irrespective of how effective and efficient it is, can only ever address a limited dimension of health and wellbeing. The 'system' needs to have communities and other stakeholders outside of HSC at the heart of planning processes in order to identify and address need, whilst at the same time strengthening cross-government efforts to address the wider determinants of health and wellbeing."

Many organisations across the women's sector have spent decades identifying and addressing the needs of women across Northern Ireland. The Women's Sector in Northern Ireland also has a strong history in partnership working, led by women's lived experiences and with women at the core, to improve the lives of women. The women's sector also has a strong history in many of the other values and principles, as highlighted above, and would stress that in order to continue meeting the above values and principles under an ICS for NI, adequate and long-term funding is necessary to ensure sustainability and longevity of these practices.

Any co-production to implement population health planning must be meaningful and ensure that voluntary and community sector stakeholder organisations are given

autonomy in decision-making rather than lip service. The four main themes of population health planning (Focus on improving the health and wellbeing of a defined population; Empower individual communities to take control of their health and wellbeing; Explicitly address the determinants of ill health and their interactions; Intelligent actions and impact) certainly are worthy areas of work to focus on within the ICS NI.

In practice though, many women's sector organisations have spent years trying to be actively involved in work that already exists within these themes, but the evidence we have raised on the disproportionate impact of certain policy decisions on women have been ignored. In any future planning model, the evidence from experts across the women's sector on how to improve the health and wellbeing outcomes for women must be taken seriously and acted upon.

Finally, for this partnership to work, it is crucial that healthcare professionals also advocate and support this new system. The partnership must be genuine and meaningful so that it can be built upon for years to come and address health inequalities and the pressures the HSC system is facing.

Q3. In line with the detail set out in Section 7 do you agree that the Minister and the Department's role in the model should focus on setting the overarching strategic direction and the expected outcomes to be achieved, whilst holding the system to account?

Unsure

(delete as applicable)

Additional comments:

Strategic Direction as highlighted in Section 7:

To inform the overall model, the Minister and the Department will set the overarching strategic direction for health and social care in Northern Ireland, and will set the expected outcomes to be achieved. This will inform the work at each level of the system. It is the Department's mission to improve the health and social wellbeing of the people of Northern Ireland by:

- Leading a major programme of cross-government action to improve the health and wellbeing of the population and reduce health inequalities.
- Supporting interventions on health promotion and education to encourage people to adopt activities, behaviours and attitudes which lead to better health and wellbeing.
- Supporting the population to become more engaged in ensuring its own health and wellbeing.
- Ensuring the provision of appropriate health and social care services, both in clinical settings such as hospitals and GPs' surgeries, and in the community through nursing, pharmacy, social work and other professional services.

Whilst it makes sense for the Department to implement the strategic direction of the overall model through the four points highlighted above, WRDA would welcome more information on how the Ministerial and Departmental priorities are identified and whether

clarity could be given on how these priorities are chosen and whether they will be adaptable over time based on the needs of different areas.

We note that the health and wellbeing profile for Northern Ireland will be built using a wide variety of quantitative and qualitative data and that these will help define health and social care needs, health inequalities and by extension, shape the Ministerial and Departmental priorities.

However, WRDA would have concerns over how the health inequalities of marginalised groups in particular can often become politicised in Northern Ireland and how vast levels of qualitative and quantitative data on the disproportionate harm gender neutral policy making has harmed women, for instance, has largely been ignored by the NI Executive for several decades.

In particular, given the political landscape in Northern Ireland and instability around Ministerial positions and parties in the Executive, WRDA would believe that priorities should be identified by health professionals alongside the groups working together in coproduction at a community level and that a bottom-up approach is adopted and that the Ministerial and Departmental roles should be to support the implementation of the priority areas highlighted by those working in collaboration across the ICS NI.

While sections 7.4-7.7 highlight the process for the Strategic Outcomes Framework, and states that this will be developed with key representative groups and will be subject to its own specific engagement activities, greater clarity is needed then on how this would overlap with any Ministerial and Departmental priorities and who these key representatives would be.

Further, it is important to note that the past few years has led to an unprecedented amount of public consultations, calls for evidence, stakeholder engagement groups and more on a vast range of legislation and public duties. Often, these forms of engagement with key representative groups (such as the women's sector) have been done with very little notice or acknowledgement of the underfunding and overcapacity working level of the sector throughout the global pandemic. This will continue to be a barrier in voluntary and community sector engagement and participation in the future if funding levels aren't addressed and if consultative and evaluative work is not done with good practice timelines.

Crucially, good practice would indicate that a public consultation should be open for at least 12 weeks, and this consultation (which has been open for 8 weeks rather than the minimum good practice guidelines of 12 weeks) and several other crucial consultations throughout 2020-2021 have fallen short of this (including the four days of notice to respond to the TEO COVID-19 Recovery Plan). If the Strategic Direction of the ICS NI is to be determined by the Minister and Department, and engagement with key representatives only follows after this, it is likely the existing challenges and barriers towards meaningful engagement with stakeholders such as women will prevail.

WRDA has produced guidelines for public authorities on 'Putting Women at the Heart of Public Consultation' that we would highly recommend the Department engages with in any future meetings with key representatives or attempts to enable stakeholder participation⁴.

⁴ WRDA (2018) 'Putting Women at the Heart of Public Consultations: Guidelines for Public Authorities': https://wrda.net/wp-content/uploads/2018/10/WRDA WomenAtTheHeartOfPublicConsultation.pdf

Q4. Section 8 sets out what the ICS model will look like when applied to NI. It is based on the principles of local level decision making which will see a shift of autonomy and accountability to local ICS arrangements. Do you agree with this approach?

Agree

(delete as applicable)

Additional comments:

ICS Model:

Regional level – A Regional Group will provide an oversight, co-ordination and support role for the wider model. The Group will hold responsibility for the associated governance and accountability functions, and the coordination of the planning and delivery of regional and specialised services.

Area level – 5 Area Integrated Partnership Boards, 1 per HSC Trust area, with overall responsibility for strategic area planning and local delivery to meet local population needs, guided by a regional strategic outcomes framework.

Locality level – covering GP Federation and Integrated Care Partnership areas, and aligning with other relevant areas, such as local councils, where possible. These groups will work to deliver interventions and programmes in each locality as agreed by Area Integrated Partnership Boards.

Community level – focusing on individual towns/local districts, GP practices / MDTs (where established), and community pharmacies, with the potential to align with existing areas such as District Electoral Areas (DEAs) where possible and appropriate. The exact size and number of communities in each Area will be for each Area Integrated Partnership Board to determine.

WRDA would support this ICS model, particularly as it is in line with other forms of ICS models worldwide and follows best practice. Clarity would be welcome on where the community organisations fit in within this model, particularly regional organisations such as WRDA, who may not neatly fit into the local or community level elements of this model based on the definitions above.

Further, clarity would be welcome on the terms of reference for both the Regional Level and the five Integrated Partnership Boards in the Area levels and how the regional strategic outcomes frameworks are developed. WRDA does agree that local communities are the best placed to identify the needs of their areas, and that specific sectors are best placed to identify the needs of the groups they support; for instance, the women's sector is crucial in identifying the needs of women across the region and within communities and areas of locality. Therefore, we would welcome clarification and more detail on who would be involved at each level of this ICS model.

Some examples of the regional, local and community-based health partnerships between WRDA and other women's sector organisations and health professionals include:

 WRDA's flagship cancer screening awareness programme is delivered by a network of NI wide Community Facilitators, providing employment for the community facilitators whilst building community capacity. Community Facilitators are locally recruited women, qualified to a level 3 in Training and Development, delivering the sessions to their peers. This model of peer education is highly successful and has proved to overcome barriers to attending screening. Therefore, whilst working at the community level, we work in partnership at the local level with GP surgeries, pharmacies and Trusts. Clarity would be welcome on where partnership programmes such as this would fit across the new ICS model.

• Further, the Mas project recognises the unique role of the women's centres, and the project was developed due to the needs of women as the centres were already providing mental health support to women in the absence of adequate statutory provision. It is essential that their role is adequately involved and recognised in the community level model at community level. One of the key strengths of the Mas project is that it is located within the women's sector and is trusted by women. The centres not only provide maternal advocacy and support, but the women can receive counselling, complementary therapies and progress to personal development and adult education courses providing progression and empowerment for women in communities. We believe that their invaluable but under-resourced role must be adequately acknowledged in the ICS model.

Overall, WRDA agrees with this ICS model and the principles of local decision making. If the principles and values are applied, this model is certainly achievable. Women's organisations have vast experience in local decision making to support their communities and they should be involved in planning services to improve efficiency and capacity, make the best use of available resources and support the sustainability of services and the wider system.

Q5. As detailed in Sections 8 and 9, a Regional Group will be established to undertake an oversight, co-ordination and support function for the ICS. Do you agree with this approach?

Agree

(delete as applicable)

Additional comments:

The Regional Group will be established under the direction of the Department of Health, and in partnership with the PHA, will undertake the below objectives.

- To provide support to the Area Integrated Partnership Boards in their initial establishment and ongoing operation;
- Put in place clear and robust governance and accountability arrangements with the Area Integrated Partnership Boards:
- Plan, manage and co-ordinate the delivery of regional and specialist services;
- Provide an oversight function in relation to equity of access to services and quality of care across the system, working to remove regional variation and duplication where appropriate and beneficial; and

 Lead the co-ordination and sharing of best practice between and across areas, sectors, organisations and partners, ensuring there is clear mechanisms in place to do so
 p.20

(NOTE - the Regional Partnership will be set up in 2021 ahead of closure of HSCB on 31st March 2022 and the PHA will have a lead role in the development, implementation and operation on the model)

As stated in response to Question 4, more clarity is needed on where regional and local voluntary and community sector groups, such as the women's sector, would fit within this model before specific comments can be given. WRDA would agree that a regional board would be a welcome way to coordinate the 5 IAPBs, but again, more clarity is needed on the Terms of Reference for both before a detailed comment on the appropriateness of these within a model can be given.

In section 9.2, it is stated that the Regional Group will assist in the establishment of the relevant partnerships between organisations and sectors. WRDA would welcome detail on how organisations and sectors will be prioritised and how the specific membership of the Regional Group making these decisions. It is also stated that the Regional Group will produce an annual Regional Population Health and Wellbeing Plan in response to the strategic direction set by the Minister and Department which is informed by local intelligence and population needs. As stated in response to Question 3, we believe the strategic priorities for the model should be bottom-up and informed by all partners equally to overcome political challenges that may arise in relation to priority setting. WRDA does welcome that this plan will be informed by local intelligence and would stress that lived experiences of groups and qualitative data should be included within this intelligence gathering process.

WRDA agrees that it is appropriate for the Regional Group to oversee the monitoring of the overall performance of each AIPB against work plans and agreed outcomes, indicators, measurements, in line with the OBA approach, and targets (where appropriate). This monitoring and evaluative framework should be open and transparent to the public and communities involved in the partnerships in relation to timescales for monitoring and evaluation findings.

In the coordination and delivery of regional and specialised services, we welcome the provision for clear guidance on/or criteria on what falls under the regional remit, and therefore, what can or cannot be delivered or delivered by the AIPBs autonomously. WRDA would stress that this clarity must be provided ASAP, and that consideration is given to the impact of these decisions and any centralisation of care on women, particularly rural women.

WRDA would also urge the Department to meet the responsibilities outlined in the Rural Needs Act and undertake a Rural Needs Impact Assessment on any policy decision taken in relation to the planning and delivery of regional and specialised services.

Q6. As detailed in Sections 8 and 10, do you agree that the establishment of Area Integrated Partnership Boards (AIPBs) is the right approach to deliver improved outcomes at a local level?

Agree

(delete as applicable)

Additional comments:

The overarching aim of each Area Integrated Partnership Board is to deliver improved health and social care outcomes and reduce health inequalities for their local population areas based on a population health approach and through improved integrated working across sectors and boundaries in the planning, delivery and management of services. This will be undertaken in line with the agreed strategic direction and priorities.

This will include:

- Building relationships and trust between leaders; encouraging shared responsibility and accountability for collective gains and risks;
- Providing clear leadership for the area on the direction of travel and priorities to be addressed, supporting and enabling partners to deliver against agreed outcomes; and
- Encouraging genuine partnership working at Locality and Community levels and across all partner organisations.

WRDA agrees that the approach of developing five Area Integrated Partnership Boards is the right approach. As the HSCB will no longer exist, and the AIPBs is not an HSC Trust Grouping, it will be important to make this clear as the ICS is rolled out to avoid confusion and to ensure issues from the HSCB Trust areas are not carried over into this new model. Further, as the IAPBs will be based on the familiar geographical breakup of the population, it will be crucial to highlight that this does not preclude cross-boundary working or initiatives where it may be deemed appropriate or necessary for two or more areas to collaborate.

For instance, in the commissioning of abortion services, the failure for the DOH and the Health Minister to fully commission services has led to gaps across Trust areas where women and pregnant people have been unable to access abortion services in their area. Cross-boundary collaboration is crucial in time sensitive areas of healthcare such as abortion to ensure the gaps in access to provisions does not happen again in the future.

Further, we particularly welcome the aim of the AIPBs to encourage genuine partnership working at *Locality* and *Community* levels and across all partner organisations. Adequate support to enable partners to identify and meet the needs of local communities is crucial in order to reduce health inequalities.

It is crucial that the establishment of AIPBs represents the needs of each area and population in order to deliver the improved health and social care outcomes and to reduce health inequalities in each of the five areas.

Q7. Section 10 of the framework provides further detail on the local levels of the model, including the role of AIPBs.

Do you agree that AIPBs should have responsibility for the planning and delivery of services within their area?

Agree

(delete as applicable)

Additional comments:

Each area will consist of the following (there will be 5 areas):

- An 'Area' level Integrated Partnership Board (AIPB) –with responsibility for overseeing the work of the integrated care partnership in its area and the governance of all affiliated structures. Each AIPB will provide the local direction and priorities for its area, in line with the strategic outcomes set by the Minister and the Department. The AIPB will take into account the identified needs of its local population. The AIPB will have wide representation from constituent organisations (see paragraph 10.6) and will be accountable to the Regional Group in terms of the development, delivery and monitoring against an agreed work plan.
- <u>'Locality' level structures</u> to support the work of the AIPB. The exact number and role of the groups at this level will be determined by the AIPB. However, they should be based around existing GP Federations and Integrated Care Partnership areas, and should also align and integrate with local Council structures (Community Planning Partnerships) and boundaries wherever possible. AIPBs must utilise the knowledge and expertise already in operation within each area. This approach will provide consistency across the region and will ensure the most efficient use of existing resources.
- <u>'Community' level structures</u> are also to be determined by each AIPB. The number, size, and area(s) covered should reflect the most appropriate structure for each Locality. For example, it may be useful to base these around local or individual GP practices and MDTs (where established), community pharmacies or local community groups or organisations. The key is to ensure that any groups at this level contribute effectively to and assist with the work of the AIPB.

WRDA broadly agrees that the AIPBs should have responsibility for the planning and delivery of services within their area. We would like to highlight again our responses to the previous questions in this consultation where concerns have been raised about the need for detail on the TOR of these AIPBs, who is represented on them, and where sectors with local and regional organisations (such as the women's sector) would fit within this model.

WRDA supports the involvement of local and community level structures as this can increase flexibility so that new models can emerge; support local areas in their own priorities and plans for integrated care and ensure that health professionals support the local and community groups in efforts to deliver care in an integrated way.

However, more detail is needed on the local level structures and community level structures and how representation at each level is decided.

Q8. Do you agree that AIPBs should ultimately have control over a budget for the delivery of care and services within their area?

Agree

(delete as applicable)

Additional comments:

WRDA agrees that AIPBs should ultimately have control over a budget for the delivery of care and services within their area. Autonomy over budgets is crucial to ensuring local areas have the flexibility to meet the specific needs of those in that population. There should be clarity on the amount of say the local and community level structures have in terms of identifying budget priorities in each area outside of the AIPB proposed in Section 10. Further, openness and transparency is crucial to ensuring all areas and partners are considered equal partners. We support the aim highlighted in 11.4.4 to 'improve efficiency and optimise capacity, making the best use of available resources and support sustainability of services and the wider system'. However, it is crucial that budgetary decisions are not purely driven by cost effectiveness and efficiency, and that the needs of certain groups are not deprioritised or centralised at a regional level in order to ease financial strains in the AIPBs.

Full equality screenings and rural needs assessments should accompany budget allocation to each area and each AIPB should be fully transparent on budgetary decisions with all local level and community level supporting structures.

Finally, the WPG has made several recommendations in relation to gender budgeting and specifically on the investment into the care sector throughout the COVID-19 Feminist Recovery Plan (for instance, research shows that a 2% GDP investment into care provides twice as many jobs for women and almost as many jobs for men as the same investment into construction), which we would like to urge the DOH and the AIPBs to fully consider in relation to allocations of budgets.

If all values and principles of the model are applied to the memberships of the AIPBs and partnership structures, the AIPBs should be in tune with grassroots intelligence on health and social care needs within each area.

Q9. As set out in Section 10, do you agree with the proposed minimum membership of the AIPBs?

Agree

(delete as applicable)

Additional comments:

The proposed minimum membership for each AIPB is:

- HSC Trust Chief Executive
- 3-4 GP Leads 1 Federation Support Unit lead, 1 GP Medical lead, 1-2 Local Medical Committee leads
- 4 Trust Directors covering Planning, Nursing & AHPs, Social Services, and Medical
- 1 Lead from Community sector
- 1 Lead from Voluntary sector
- 1 Lead from each Community Planning Partnership within the AIPB area
- 1 Carer representative
- 1 Service User
- 1 Community Pharmacist Lead
- 1 Regional Group Lead (specific to each AIPB) 1 PHA Director / Assistant Director (specific to each AIPB)
- 2-4 Locality Partnership chairs (depending on area and make-up of Locality structures)

We also welcome that each AIPB may consider additional membership, either permanent or on an ad-hoc basis as they deem appropriate, for example from specific specialisms, professional bodies or local bodies, but core membership must include the above. This would be important for the introduction of new services for instance, such as the development and implementation of specialist perinatal mental health services, increased access to IVF treatment or the roll out of abortion services. There are expert organisations supporting women and pregnant people within the women's sector on all of the above issues and we would hope that additional membership, either on a permanent or an adhoc basis, would be available to groups with expertise on these areas.

WRDA also agrees that for efficiency and to enable each AIPB to function effectively, each core member should ideally be in a position to provide a collegiate viewpoint for their relevant profession, area or sector, and be of sufficient seniority to contribute to decision making at meetings and enable successful implementation of agreed system wide changes.

WRDA would also like to recommend that each AIPB membership should be gender balanced with women accounting for at least 50% of membership, particularly as 79% of the Health and Social Care workforce in Northern Ireland are women and 70% of the Voluntary and Community Sector workforce are women. Too often, women account for the greatest proportion of workers but are vastly underrepresented in decision-making levels and we would highly recommend gender balanced AIPBs as a way to prevent the underrepresentation of women in the new Integrated Care System for Northern Ireland.

Further, it would be work considering additional membership from the Voluntary and Community Sector at the AIPBs given the vast amount of work the women's sector and other VCS organisations are already doing to address health inequalities for the most marginalised people in our society. We note that section 12.10 suggests that 'a Partnership Forum or Partnership Board for a given profession or sector could be used to sit alongside the structures. Such a forum would be responsible for collating and securing the views of their sector, and be able to provide one or 2 nominated individuals as formal members of the Area level AIPB'. This is certainly an approach we would welcome in order to ensure the women's sector has adequate representation across the area AIPB.

Finally, we would like to acknowledge the below community level aims to:

'to involve individuals and community leaders in the process of helping people manage their own health and wellbeing with appropriate support; and to access health and care services within their own community. It also helps to coordinate and maximise community and voluntary support for its own citizens. It seeks to ensure that plans and initiatives from Regional and Area levels are delivered locally with fairness and efficiency.

This includes:

- Promotion of a "community ethos" for health and wellbeing by aiming to join up care at this level and recognise local representatives and champions for that community;
- Valuing the assets of the community including organisations, networks, resources etc. and building with them by supporting their capacity and sustainability; and
- Empowering grassroots initiatives and projects where suitable; and with resources if possible.
- Optimising the utility of all commissioned family practitioner services
 pp.27-28'

WRDA agrees with these aims for the Community level and agrees with point 12.13, that is it important that the right support and structures are in place to foster this level of engagement to the benefit of the model, the local population and community. In particular, it is important to identify, build on and utilise existing local or regional resources and structures and adequately invest financially in the many voluntary and community sector organisations undertaking this work both now and in the future.

Q10. As set out in Section 10 of the framework (and noting the additional context
provided in Annex A of the document), do you agree that initially each AIPB should
be co-chaired by the HSC Trust and GPs?

Agree - initially	then open t	o all members	shin	

(delete as applicable)

Additional comments:

WRDA welcomes the fact that, in the first instance and to enable implementation, each AIPB must be co-chaired by the Chief Executive of the relevant HSC Trust and a nominated lead representative of General Practice in the area; but that the chairmanship should be for each AIPB to determine moving forward and will be open to all members. Opening up the chair position to all members is an important step in recognising the equal voice of all members and partner organisations and to enable all members to utilise their skills and expertise to provide a sound foundation on which to build progress within this model.

Q11. The framework allows local areas the flexibility to develop according to their particular needs and circumstances.

As set out in Section 10, do you agree that the membership and arrangements for groups at the Locality and Community levels should be the responsibility of the AIPBs to develop, determine and support?

Agree - if adequately resourced.

(delete as applicable)

Additional comments:

We agree that it is necessary for this framework to allow local areas the flexibility to develop according to their particular needs and circumstances. WRDA also agrees that the membership arrangements for groups at the Locality and Community levels should be the responsibility for the AIPBs to develop, determine and support. However, this must be done by clearly defining the links between the Community, Locality and Area level structures (as highlighted in Sections 10.9 and 10.10). To achieve this, local communities must be given adequate opportunity to meaningfully engage in this process in order to highlight the needs of the Locality and Community groups. This must involve meaningful stakeholder engagement at each level to ensure the groups that should be involved can be identified. WRDA would like to highlight the Guidelines we have developed for Public Authorities on Putting Women at the Heart of Public Consultation which may assist in this process⁵.

If AIPBs have the responsibility to develop, determine and support the membership and arrangements for groups at the Locality and Community levels there needs to be flexibility to develop according to the particular needs and circumstances which will allow for the aim of improving the health and wellbeing of the local population. Any plans and initiatives from Regional and Area levels are delivered locally with fairness and efficiency. This includes: 'Empowering grassroots initiatives and projects where suitable; and with resources if possible.' It is not enough to state 'if possible' there should be enough resources to fulfil this action.

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⁵ WRDA (2018), 'Putting Women at the Heart of Public Consultations: Guidelines for Public Authorities'; https://wrda.net/wp-content/uploads/2018/10/WRDA WomenAtTheHeartOfPublicConsultation.pdf

General Comments

Please add any further comments you may have:

This is a very high-level consultation, and it is difficult to know how a lot of these proposals will work in practice. We would also encourage that in the future, the DOH abides by good practice guidelines for public consultations to encourage meaningful engagement with stakeholders and ensure that consultations are open for a minimum of 12 weeks (rather than 8 weeks, as was the case with this consultation). A short consultation timeframe with a complex and high-level policy consultation, such as this one, makes it difficult to gather the views of women in order to fully highlight their voices.

WRDA has developed a guide on putting Women at the Heart of Public Consultations to ensure evaluations and consultations are more accessible and to ensure the voices of those who are marginalised are heard and meaningful engagement has taken place.

Further, we would like to note that this consultation response is from WRDA, but that many of the recommendations and concerns we have raised are issues that impact the wider women's sector. We would highly recommend that the DOH engages further with our women's sector colleagues to gather further views on this ICS model, particularly given the breadth of work across women's centres, rural community groups and women's organisations in addressing gender inequality and health inequalities.

The examples of partnership working on matters relating to health inequalities within this response included WRDA, Women's Centres, the Women's Policy Group, Women's Regional Consortium and more. We highly recommend that the DOH further engages with women's centres and the border women's sector to gain a better understanding of the existing structures at a locality and community level, the challenges they face and how these models can be built upon within this ICS.

There are many other women's organisations who would need to be consulted on this new model and we would particularly encourage that the DOH engages with groups such as Northern Ireland Rural Women's Network, who have vast expertise on the needs of rural women, as well as other women's organisations that are based outside of Belfast and will have strong levels of expertise on the needs of those within their local communities. This is of particular importance given the lack of Rural Needs impact Assessment to support this future planning model.

In addition, WRDA works closely with organisations supporting Black, Asian and minority ethnic women, migrant women, LGBTQ+ women, women in areas of social deprivation, disabled women and more. We would highly recommend that the DOH further engages with organisations such as Migrant Centre NI, HERe NI, Transgender NI, CARA Friend, Women's Aid, Alliance for Choice, North West Migrant Forum, Belfast Multicultural Association, Anaka Women's Collective, PPR (and their 123 GP campaign in particular) and more. This is certainly not an exhaustive list, but it is crucial that effective stakeholder engagement is undertaken before this new model is rolled out in March 2022.

We briefly highlighted some of the health inequalities that women face which have not been considered within this consultation. We would urge the Department to undertake a much deeper assessment of the health inequalities women face before rolling out this model in order to prevent pre-existing inequalities under current health and social care models being carried forward into this new integrated care system. The additional health inequalities faced by disabled women, black women, traveller women, ethnic minority

women, migrant women, LGBTQ+ women, rural women, women living in poverty, single mothers and more must be accounted for within this model.

The additional health impacts women will face due to the disproportionate impact of the pandemic, for example the long-term impacts of maternity restrictions, increased domestic and sexual abuse, food poverty, welfare reform and austerity, perinatal mental health, inability to access reproductive healthcare, the backlog of cancer screenings and waiting lists, greater likelihood to suffering from chronic pain conditions and more *must* be incorporated into this model. The WPG has provided a comprehensive evidence base of the impact the pandemic has had on women's health in Northern Ireland throughout the COVID-19 pandemic and we would again urge the DOH to become familiar with this evidence base and recommendations and use this local intelligence in this future planning model.

This is not an exhaustive list of the women who face additional health inequalities, or the inequalities they have faced, but rather an example to highlight the vast amount of research the Department must consider beyond metrics such as life expectancy between men and women in any Equality Screening.

WRDA would also like to stress the importance of effective participation with stakeholders beyond membership on partnership boards. Local intelligence and lived experience is crucial to tackling the issues we are facing as a society in terms of health inequalities through the existing HSCB. There must be robust mechanisms in place to ensure meaningful stakeholder engagement and input for organisations supporting grassroots groups on a daily basis; particularly given the funding and capacity issues many of these groups face which can be a barrier to engagement.

Further, it is stated throughout the supplementary consultation documents that lessons must be learned from recent years within the HSCB; but no clarity is given on what these lessons are. This information should be provided alongside clear examples of the best practice used elsewhere that is informing this model.

Greater clarity is needed on what the transition between the HSCB to the ICS NI will look like and how service providers and stakeholder groups will be consulted throughout. This will ensure policy enablers can be put into place ahead of the model being delivered and enable implementation. The women's sector has a long history of working to highlight women's health inequalities through local intelligence and lived experience, but often this is not acted upon at a regional level. Further, the women's sector and particularly the women's centres across Northern Ireland have a long history of partnership working on early intervention and prevention initiatives to address health inequalities but have been faced with a funding crisis for the sector for many years. Lessons must be learned from these existing partnerships and what is currently working well, what needs to be improved and how.

Finally, WRDA would like to highlight some extracts of evidence and recommendations from the WPG COVID-19 Feminist Recovery Plan Relaunch: One Year On that are relevant to this future planning model. Please note, the section numbers relate to how they appear in the Feminist Recovery Plan. We would like this evidence and the subsequent recommendations to be considered when determining health inequalities for women in the Integrated Care System for NI.

For any questions or queries regarding this response, please contact Rachel Powell, Women's Sector Lobbyist, Women's Resource and Development Agency rachel.powell@wrda.net

1. Extracts from the Economic Justice Pillar:

1.3.3.3 Unequal Distribution of Caring Responsibilities

Women are more likely than men to be forced out of the labour market by unpaid, domestic work or caring responsibilities and 69% of carers are women. Women in NI also have a 70% chance of providing care in their adult life, compared to 60% for men and by the age of 46, half of all women have been a carer (11 years before men)⁶. Research from Carers NI shows that Northern Ireland's carers save the economy £4.6 billion per year⁷; whilst unpaid carers across all the UK provide social care worth £57 billion per year⁸. What women have always known, and what has now been more unavoidable as the world tries to cope with the pandemic, is that care work, which is predominantly undertaken by women and girls, is central to the functions of every economy; yet it is still treated as a private issue and undervalued as contributors to economies.

Research on the rise of unpaid carers in the UK during COVID-19 highlights that the pandemic has led to an increase of 4.5 million people providing unpaid care; which is an almost 50% increase in the number of unpaid carers since the crisis began⁹. Many new unpaid carers are drawn from the working population, as 26% of all workers are now juggling work and unpaid care; an increase from one in six to one in four¹⁰. Significantly, this highlights where future carers may come from if there is not sufficient investment in carer and support and significant investment into the redistribution of care work, and supporting unpaid carers, is needed urgently. The losses of a failure to invest in care will not only be felt by carers and their families, but to the employers and Northern Ireland economy alike.

⁶ WRDA (February 2020), 'Gender Inequality in Northern Ireland: Where are we in 2020?', Bold Women Blogging, (available online): https://bit.ly/3zS2WET

⁷ Carers NI (2015), 'NI Carers save government £4.6 billion a year', https://bit.ly/3d88Mbz; see also: Carers NI (2017) 'State of Caring 2017': https://bit.ly/3j79KbO.

⁸ Office for National Statistics (2017), 'Unpaid carers provide social care worth £57 billion' (2017): https://bit.lv/35PpKYl

⁹ Carers Week (2020), 'Carers Week 2020 Research Report: The rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak', *Making Caring Visible*, https://bit.ly/3giOrFQ p.4.

¹⁰ ibid.

Research from carers Week 2020 found that in Northern Ireland¹¹:

- 15% of respondents said they were already providing care before the COVID-19 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,
- 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 NI 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 NI do not believe that unpaid carers have been supported by the Government during the COVID-19 pandemic,
- 74% of NI respondents also 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.

More recent research from the Carers Week 2021 Report found that out of 2,850 carers surveyed in the UK¹²:

- 81% have had to provide more care during the pandemic,
- 63% are worried about continuing to care without a break,
- 74% are exhausted as a result of caring,
- 72% have not had any breaks throughout the pandemic,
- 71% are stressed and anxious as a result of caring,
- 35% feel unable to manage their caring role,
- 65% feel lonely and isolated,
- 55% felt overwhelmed by their caring role,
- Only 14% felt confident support will continue into the future,

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¹¹ Ibid, pp.27-28.

¹² Carers Week Report 2021: https://bit.ly/2SixOqG

- Carers lost 25 hours of support every month during the pandemic or 425 hours throughout the pandemic,
- 64% reported relying on family and friends to take a break,
- 21% chose not to take any breaks because they were worried about catching COVID-19,
- 66% of carers who did receive a break said they had not enough breaks to protect their health and wellbeing or had fewer breaks than before the pandemic,
- 33% used their breaks to complete practical tasks such as housework,
- 26% used any breaks they had to attend medical appointments,
- 25% used a break to catch up on sleep,
- 63% have not been able to look after their own health and wellbeing during the pandemic,
- 69% of carers said their mental health worsened during the pandemic,
- Women carers were more likely to say their mental health had been impacted (71%) compared to men carers (64%),
- 64% of carers said their physical health worsened during the pandemic,
- Women carers were more likely to say their physical health had been impacted (66%) compared to men carers (61%),
- 65% felt lonelier and more isolated than before the pandemic,
- 70% of parent carers reported being lonelier and more isolated,
- 49% of carers reported not being able to maintain their relationships and this rose to 55% for those who haven't had a break during the pandemic,
- 44% highlighted they were not getting enough support before the pandemic,
- Just 11% of carers said they were getting the same level of support they had before the pandemic,
- 28% of carers said they needed more support than before the pandemic.

Some of the Carers Week Report 2021 findings specific to Northern Ireland included:

 In Northern Ireland, many carers cited worries and uncertainty about Health and Social Care Trusts budgets and social care funding being cut after the pandemic,

- Before the pandemic, 44% of carers were unable to access the breaks they needed, and this increased to 79% of carers being unable to take a break.
- A further 11% have had fewer or insufficient breaks,
- Of the 28% able to take a break, 30% used breaks for their own medical appointments and 29% used their breaks for practical tasks such as housework,
- 72% of carers in NI say their mental health has worsened because of the lack of breaks,
- 67% said their physical health had deteriorated during the pandemic,
- 78% reposted feeling exhausted and worn out as a result of caring,
- 69% are worried about continuing care without a break,
- 33% feel unable to manage their caring role,
- Just 9% were confident that the support they relied on would continue in the future,
- 29% of carers reported needing more support than before the pandemic, either due to the needs of the person they care for increasing or due to their own health deteriorating.

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.

Recommendations:

WPG recommendations to address gender segregation and the unequal distribution of care include:

- Analyse the economic value of putting money into caring, which may help carers get back into paid employment and thus improve their health and financial wellbeing and consequently reducing pressure on the health and benefits systems in the long-run.
- For a better, more resilient economy, it is essential that we value and recognise care work. It needs to be a valued job that is paid well,

attracts investment in education and training, provides opportunities for promotion and is seen as a valued career.

The WPG also supports the below medium-term and longer-term recommendations from the UK Women's Budget Group¹³:

- Do not turn to austerity measures to pay for the cost of the crisis.
- Invest in social infrastructure, including health, care and education.
- Design a sustainable and stable social care system so that no-one has unmet needs, free to the point of use with well paid, well trained permanent staff and funded via general taxation.
- Reform the social security system so that it protects all people, including migrants, against risk, poverty and destitution.
- Sustainably funding the women's sector so that no woman is left in danger.
- Introduce policies to encourage sharing of care and unpaid work between women and men.

Recommendations from Carers Week Report which we endorse include 14:

- There is a significant role for information and advice for carers, forward planning, but also better support so that people can rely on what they need.
- In the longer term, the Government needs to build a better future for carers that tackles the underlying issues that they face.
- Increase awareness of the role of caring and unpaid carers the NI Assembly should promote awareness of the important role of unpaid carers and caring and introduce more concrete support so that value is recognised practically.
- Fund and rebuild social care and health services the NI Assembly needs to recognise the amount of pressure the system has been under during the coronavirus outbreak, and the funding shortages that were widely recognised for many years before the crisis. There needs to be a significant increase in funding levels to allow the social services and the NHS to rebuild after the crisis, alongside bringing

¹³ UKWBG (May 2020), 'Briefing from the UK Women's Budget Group: Easing Lockdown: Potential Problems for Women', (available online): https://bit.ly/3ghxzPW

¹⁴ See (n38).

forward plans for long-term reform of social care. Greater investment in care will lead to a healthier and happier population that is better able to balance important aspects of their lives, including personal relationships, work and family.

- End carers' financial hardship Financial support for carers must be urgently improved, which would particularly benefit women who are more likely to be caring and providing higher levels of care. The UK Government and NI Assembly should immediately increase the basic level of Carer's Allowance and introduce a £20 per week increase to match the rise in Universal Credit.
- Greater consistency is needed in connecting carers to support available to look after their own mental and physical health and wellbeing. Support for carers to take part in physical activity, for example, can be hugely beneficial in preventing them developing health problems in later life as well as reducing isolation.
- Support working carers more through employers and by Government - Employers, and the NI Assembly, should ensure that there are carer-friendly policies in place that enable working carers to balance their caring responsibilities with work. We fully support the Government's plans to introduce an entitlement to take care leave for working carers; our preference would be for this to be paid.
- Schools, colleges, and universities should be encouraged to introduce policies and programmes that support carers and improve their experience of education,
- Increase funding for carers breaks, better funding for social care, develop a supportive healthcare system, end carers' financial hardship, create a carer-friendly work environment and introduce paid carers leave.

1.7.7 Covid-19 and Rural Mental Health

There is no doubt that the Covid-19 pandemic has impacted mental health; bereavement, social isolation, uncertainty and financial insecurity have all impacted on wellbeing. It is also well known that early intervention is important as it can help prevent the escalation of presenting mental health issues. We do not have data on the specific rural mental health impacts yet however we do know that rural areas are much less likely to have access to the relevant support at their local GP e.g., 40%

of GP Practices across west Tyrone offer in-house counselling compared to 100% in East Antrim¹⁵.

Those in need of mental health support should have quick and easy access to counselling and it should not be determined by your post code or your socio-economic status. The number of sessions should also be determined by the need of the patient and not determined by economics.

Scottish research¹⁶ indicated that stigma related to mental health issues is also particularly problematic. Rural areas are known to have strong communities and whilst this can act as a protective factor for people with mental health issues it can also be a barrier to them seeking and accessing services due to the perceived stigma of their circumstances. It was noted that decision makers do not have the same level of information and evidence regarding rural areas and this makes it harder to come up with solutions. We would argue that data to support a Mental Health Strategy in its development and delivery requires quality data that is both gender-disaggregated and takes account of rural and urban experiences.

Recommendations:

- The Programme for Government, Budgets and future policies take account of rural women's needs.
- Ensure that all GP practices are adequately resourced to provide timely access to counselling for everyone who needs it.
- Ensure that nobody waits longer than 28 days for a routine appointment and no longer than 2 days for an urgent one.
- Provide people with options for accessing counselling in their local
 GP practice or through the Talking Therapy Hubs run by the Trusts.
- Mental Health data that is both gender-disaggregated and takes account of rural and urban experiences.

1.9.2 Care Work: A Key Sustainable Industry

The WPG would also like to endorse the following evidence and recommendations from the Feminist Green New Deal:

"WBG research indicates that a 2% GDP investment in care (social care, childcare, parental leave etc.), creates double the amount of jobs for

¹⁵ PPR #123GP map (2020), 'FOI Data Reveals a Postcode Lottery When it Comes to Counselling Through GP Practices', https://bit.ly/3jyuU37

¹⁶ Voluntary Health Scotland (February 2020), 'Mental Wellbeing in Rural Scotland', https://bit.ly/3jrNhGl

women and almost as many for men than the same investment in construction.¹⁷ Investment in free universal childcare especially, returns almost all of its initial investment."¹⁸

"The care industry is 30% less polluting (in terms of greenhouse gas emissions) than the construction industry and, the education industry is 62% less polluting than the construction industry." ¹⁹

This is of particular importance to Northern Ireland given our calls for a universal, free and high quality childcare provision. If the Northern Ireland Assembly, and the Department of Education, introduce free universal childcare, statistics from the WBG submission to HM Treasury indicate that a full return would be made on this investment through additional tax revenue generated by the additional jobs created.²⁰

Recommendations from the WBG and WEN, which we have applied to Northern Ireland, include:

Sharing Care:

- Recognising the dual-benefit job creation and increased tax revenue through investing in paid care jobs that are already done in an unpaid capacity by majority women,
- Through increased investment in care jobs and the care sector, not only will women's employment and economic opportunities increase, but children from disadvantaged backgrounds will benefit from increasing qualities of childcare and education,
- Broaden definitions of 'green jobs' beyond construction and technology to incorporate the care sector as an already existing low carbon, high compense sector that is increasingly neglected,
- Ensure that all green jobs in Northern Ireland include a real living wage, are securely contracted, ethically procured and unionised,
- Implement a 30-hour paid work week in recognition of unavoidable unpaid care,
- Actively encourage and incentivise care leave and caring responsibilities being undertaken by men,

¹⁷ ITUC (2016), <u>'Investing in a Care Economy</u>: A gender analysis of employment stimulus in seven OECD countries', *ITUC*. <u>https://bit.ly/3zQsYIG</u>

¹⁸ Ibid, p.1.

¹⁹ WBG calculations from Eurostat data: https://bit.ly/3d5qUD9

²⁰ Women's Budget Group (2020) '<u>Budget Representation to HM Treasury</u>: Invest in *Social* Infrastructure', *UK Women's Budget Group*. https://bit.ly/2T2cPiK

- Establish a Universal Basic Income or Universal Basic Services to ensure minimum living standards and recognise and remunerate the £4.6 billion unpaid carers contribute to Northern Ireland each year,
- Balance recommendations for greater food self-reliance with recognition of the gendered, unpaid and low-paid labour involved in producing and providing food, particularly as Northern Ireland may be disproportionately impacted by different food standards to Great Britain post-Brexit,
- Supporting and developing sustainable small businesses that reduce domestic work through mass preparation and distribution of locally grown food.

2. Extracts from the Health Pillar:

2.1 Mental Health Concerns due to COVID-19

Along with the vital physical health considerations, one of the most concerning health implications from the COVID-19 lockdown is the impact on women's mental health. The Women's Policy Group is deeply concerned that out of a total £90 million health allocation, just £1.5 million was requested for the Mental Health Action Plan by Health Minister Robin Swann. The health foundation states that 'good mental health is an asset and is also linked to good physical health - both of which support positive social and economic outcomes for individuals and society'²¹. Northern Ireland has faced a mental health crisis for many years, and this is only likely to have worsened due to the lockdown. Urgent measures need to be taken to address this crisis and support the women impacted by poor mental health in Northern Ireland.

Research by the Office for National Statistics (ONS)²² provides an insight into the mental health of adults during the COVID-19 pandemic and highlighted that women were more likely than men to experience some form of depression across all age groups. It showed:

 Around 1 in 5 (21%) of adults experienced some form of depression in early 2021 (27 January to 7 March); this is an increase since November 2020 (19%) and more than double that observed before the COVID-19 pandemic (10%).

²¹ Marshall, L. et. al. The Health Foundation (June 2020), https://bit.ly/2TTWU6k

²² Office for National Statistics (May 2021) https://bit.ly/35JuiPQ

• Around 1 in 3 (35%) adults who reported being unable to afford an unexpected expense of £850 experienced depressive symptoms in early 2021, compared with 1 in 5 (21%) adults before the pandemic.

Over the period 27 January to 7 March 2021:

- Younger adults and women were more likely to experience some form of depression, with over 4 in 10 (43%) women aged 16 to 29 years experiencing depressive symptoms, compared with 26% of men of the same age.
- Disabled (39%) and clinically extremely vulnerable (CEV) adults (31%) were more likely to experience some form of depression than non-disabled (13%) and non-CEV adults (20%).
- A higher proportion of adults renting their home experienced some form of depression (31%) when compared with adults who own their home outright (13%).

An analysis of the impact of the pandemic on women by the Women's Budget Group²³ highlighted that:

- A large-scale study published in September 2020 found that being younger and female was associated with significantly greater levels of stress, anxiety and depression during the COVID-19 pandemic than for other groups,
- 44% of young women with a disability or long-term health condition said they are struggling during the COVID-19 pandemic (compared to 27% without a disability or long-term health condition),
- 43% of young women feel their mental health had become worse over the last 12 months (compared to 32% of young men) and over 50% said they were worried about their mental health,
- Lone parents (the vast majority of whom are women) were twice as likely to have poor mental health, compared with other family types, immediately before and in the early stages of the crisis.
 Overall, 51% of single parents reported having depression, bad nerves or anxiety compared with 27% of couple parents.

²³ Women's Budget Group, 'Lessons Learned: Where Women Stand in 2021' (January 2021) https://bit.ly/3vQ268K

The University of Essex²⁴ has identified that women are more likely to experience a negative impact on their mental wellbeing due to increased family responsibilities, financial worries and loneliness. Research evidence provided by the Women's Budget Group (WBG) shows this burden is even greater for single parents.²⁵ Some of the starkest differences in the WBG survey were in the rates of high anxiety among mothers compared with fathers, although both represent significant spikes compared to normal data. The WBG states that recovery from the pandemic will not only need to address economic harm but the damage done to the population's mental health and particularly to women's and mothers' mental health.

Cambridge University has also reported evidence²⁶ that the COVID-19 pandemic has had a larger adverse impact on the mental health and wellbeing of some groups than others. Young adults and women have been more likely to report worse mental health and wellbeing during the pandemic than older adults and men. Women reported a larger increase in loneliness during the pandemic, as well as a greater degree of family and caring responsibilities, which could partially account for their higher levels of poor mental health compared to men. This research also found that similar to pre-pandemic trends, adults with low household income or socio-economic position reported more anxiety and depression than adults with higher household income or socio-economic position.

Research on the impact of COVID-19 on unpaid care work and psychological distress in the UK²⁷ found that every week women spent 5 more hours on housework and 10 more hours on childcare than men during lockdown. This increased housework and childcare was associated with higher levels of psychological distress for women. One-third of parents adapted their work patterns because of childcare/homeschooling. Men and women who adapted their work patterns had on average higher GHQ scores (indicating a possible psychiatric disorder) than those who did not. This association was much stronger if he or she was the only member

²⁴ ISER (June 2020) The gender gap in mental well-being during the Covid-19 outbreak: evidence from the UK, Working Paper Series' https://bit.ly/3x3F9ju

²⁵ Women's Budget Group, Fawcett Society, The London School of Economics and Political Science and Queen Mary University of London (August 2020) Parenting and Covid-19 – Research evidence, https://bit.lv/3vOH2zq

²⁶ Chandola, T. et al, (December 2020) The mental health impact of COVID-19 and lockdown-related stressors among adults in the UK Cambridge University Press, https://bit.lv/35PCz4V

²⁷ Xue, B. and McMunn, A., (August 2020) Gender differences in the impact of the Covid-19 lockdown on unpaid care work and psychological distress in the UK, UCL Research Department of Epidemiology & Public Health, https://bit.ly/3vRshM0

in the household who adapted their work patterns or if she was a lone mother. Only 10% of fathers reduced work hours due to care work compared to 20% of mothers.

Combining employment with increased childcare, homeschooling and housework may have increased feelings of psychological distress through reduced time for sleep and leisure, and the stress of trying to meet competing demands. This research²⁸ suggests that lockdown has hit people with young families and lone mothers particularly hard in terms of mental health. Continued gender inequality in divisions of unpaid care work during lockdown may put women at a greater risk of psychological distress. Awareness of continued gender biases in divisions of labour and their impact on psychological health is an important consideration going forward.

A survey by Parentkind showed that 86% of children's and 84% of parents' mental health and well-being have been negatively affected by the disruption to schooling since the start of the first lockdown.²⁹ Interestingly this research noted that parents in Northern Ireland are far more likely to have been impacted negatively by the current arrangements for their child's schooling than their English counterparts: whilst 84% of parents in Northern Ireland said their mental health and well-being has been negatively impacted 45% of parents in England say the same.

In addition, prescribing statistics for anti-depressants are on the increase as a result of the pandemic. Anti-depressant prescription rates in the UK are among the highest in Western Europe with prescription rates in Northern Ireland significantly higher than the rest of the UK. Recent figures show that from January to December 2020 more than 2.75 million items were dispensed in Northern Ireland compared to 2.5 million in 2019 and 2.4 million in 2018.³⁰ During the year 2020/21 anti-depressants were dispensed to nearly 1 in 5 people in Northern Ireland (over 357,000 people) which is almost 19% of the population. 63.7% of those receiving anti-depressants were female with the highest proportion seen among females aged 45 to 64. These figures indicate that anti-depressants were

²⁸ Ibid

²⁹ Parentkind (March 2021) Coronavirus Parent Survey Results Northern Ireland, https://bit.ly/3vVbmrT

³⁰Madden, A. Belfast Telegraph (18th March 2021) Concern as amount of anti-depressants dispensed in NI rises, https://bit.ly/3vOHiOU

dispensed to 23.6% of Northern Ireland's female population compared to 13.8% for males.³¹

2.1.1. Social Determinants of Health

It is essential to recognise that poor mental health is strongly associated with social and economic circumstances, including living in poverty, low-quality work, unemployment and housing.³² Studies from past viral outbreaks show well-documented increases in mental health disorders. The drivers for this include social isolation, job and financial losses, housing insecurity and quality, working in a front-line service, loss of coping mechanisms and reduced access to mental health services. As previously stated in this document, women are disproportionately represented in poverty, social housing, and employment related to frontline services and care-giving.

Research shows that poverty increases the risk of mental health problems and that poverty can be both a cause of mental health problems as well as a result of them. Statistics from the Mental Health Foundation show that those living in lower socio-economic groups are more likely to experience chronic ill-health and those in the most deprived areas of Northern Ireland are twice as likely to show signs of a mental health problem (30%) than those in the least deprived areas (15%).³³ Austerity and public cuts have also hit Northern Ireland hardest as it relies more heavily on public spending for its output compared to the UK.

Research by the Trussell Trust shows that the population of people referred to food banks in their network during the pandemic saw an increase in the proportion of people reporting mental health problems from 51% in early 2020 to 72% in mid-2020.³⁴

Medical professionals have warned that existing health inequalities are likely to widen without urgent action to support the most vulnerable to

³¹ General Pharmaceutical Services (June 2021), Annual Statistics 2020/21, NIRSA, https://bit.ly/3vUkUn0

³² Marshall, L. et. al. The Health Foundation (June 2020), 'Emerging evidence on COVID-19's impact on mental health and health inequalities', https://bit.lv/2TTWU6k

³³ Mental Health Foundation (2016) Mental Health in Northern Ireland: Fundamental Facts, https://bit.ly/2TTWU6k

³⁴ The Trussell Trust (May 2021) State of Hunger, Building the evidence on poverty, destitution, and food insecurity in the UK, Year two main report, https://bit.ly/2TITCxH

the economic and other effects of social distancing measures³⁵. Action to address poor mental health and promote positive mental health can therefore not be achieved without addressing the broader social and economic determinants of ill health such as poverty, unemployment, low paid and low quality work.

Sir Michael Marmot who carried out a government review on health inequality has said that increasing out-of-work benefits and support for low-paid workers as the country emerges from the pandemic could have a big impact in curbing a mental health crisis and even save lives. He said in an interview that Government Ministers should not "fiddle around the edges" and instead should drastically reform the "uncaring" system in place. He said: "I have seen evidence that for some people in receipt of Universal Credit, there are mental health consequences. It is a brutalising system. Everyone should have at least the minimum income necessary for a healthy life." He went on to say that: "And in work, they should be paid a living wage. If they can't work, for whatever reason, then the welfare system should be sufficiently generous for their health not to be damaged by that experience. We know what needs to be done. Let's do it." 36

Northern Ireland's Interim Mental Health Champion, Professor Siobhán O'Neill has called for a "recovery plan" across society to deal with the impact of the pandemic on mental health.³⁷ Professor O'Neill has stressed that the budget for mental health services in Northern Ireland needs to be increased given the greater demand which is likely to be placed on mental health services in the aftermath of the pandemic. She also addressed the groups who are particularly vulnerable to mental health challenges as a result of the pandemic, including young people, women and people with children at home, as well as those with pre-existing medical conditions and those on low incomes. The plan includes interventions for those in socially deprived areas with Professor O'Neill stressing the benefits of targeting specific low-income locations and the benefit this has on mental health.

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³⁵ Margaret Douglas et. al. The British Medical Journal (April 2020), Mitigating the wider health effects of covid-19 pandemic response, https://bit.lv/2U0uvXZ

³⁶ Savage, M., The Guardian (March 2021) Raise benefits to curb UK crises in mental health, expert urges, https://bit.ly/3vQ3tEq

³⁷Leebody, C., Belfast Telegraph (March 2021) NI's mental health champion calls for 'recovery plan' in aftermath of pandemic, https://bit.ly/3gPTJWd

2.1.2. Mental Health among Marginalised Groups

We welcome the publication of the Mental Health Action Plan by the Department of Health and the recent consultation on a new Mental Health Strategy for Northern Ireland, although it is extremely disappointing to see that considerations have not been given towards the increased mental health difficulties faced by the LGBTQ+ community (particularly trans individuals), disabled women, black and minority ethnic women and other groups that face social isolation and vast health inequalities. A policy that applies to all is not enough to address the health inequalities faced by marginalised groups and much more nuanced, intersectional approaches are needed to support these groups.

Mental health care cannot ignore race, gender, sexuality, or disability, and mental health professionals must be culturally competent in the language and experiences of women in these communities in order to properly care for them. For the women in these communities, not only are there significant barriers to accessing these services as a result of lengthy waiting times and inaccessible referral pathways, but once having accessed the services, there is not a guarantee that their experiences will be understood or affirmed due to lack of training and experience. The Department of Health should specifically ring-fence funding for the development of cultural competency within mental health services in direct collaboration with community organisations that represent these women.

Some of the marginalised groups we recommend need urgent mental health support, through increased access to mental health services; specialised medical interventions; and higher levels of specialised support include:

2.1.2.1 Victims of Domestic and Sexual Violence and Abuse

The number of domestic abuse incidents recorded in 2019/20 is 31,817. This is the highest level since the data series was first compiled in 2004/05 and shows a 53% increase on the figure for 2004/05 which was 20,959. The latest figure of 31,817 incidents shows an increase of 135 and is 0.4% higher than 2018/19 which was 31,682. The number of domestic abuse crimes recorded was 18,640. This shows an increase of 2,476 (15.3%) compared to the previous twelve months and is the highest level recorded since these statistics started being collected in 2004/05 showing a 93% increase on the level of 9,647 recorded in 2004/05. In relation to gender breakdown of offenders 69% victims of all domestic abuse crimes were female and 30% were male. Of all offenders dealt with by police in 2019/20 in connection with domestic abuse crimes that resulted in an outcome, 86% were male

and 12% were female. The majority (94%) of offenders were aged 18 and over.

Our first lockdown in NI began on 23rd March 2020 and within this year, up until 23rd March 2021, eight women have lost their lives, murdered by a partner or a family member. We know the links between domestic homicide and high-risk indicators such as coercive and controlling behaviour, stalking and domestic violence.

Victims of domestic violence require specific and appropriate mental health services, including safety planning, therapy, and/or counseling. These services should be available to the victim regardless of whether or not she is currently in a relationship with the abuser. The services should be provided by people trained in the dynamics of domestic violence. Some of these services are currently being provided (for example through organisations such as Women's Aid), but should be expanded and funded as a matter of urgency due to the increased risk of domestic violence as a result of the COVID-19 pandemic.

Victims of sexual violence also require appropriate therapy and counselling services. Any person who self-identifies as a victim of sexual violence should be able to access services from therapists trained in trauma informed care and victim responses to sexual violence. These services should be provided within a timely manner and prioritised as a matter of urgency. There needs to be greater recognition of intimate partner sexual abuse and both the short and long term traumatic impacts on individuals, but this is not addressed adequately within the Gillen Review.

We recommend that specific funding is allocated for appropriate, safe and rapid therapeutic services to victims of domestic violence and sexual violence. Funding needs to be allocated to specialised services based on skills.

2.1.2.2 LGBTQ+ People

LGBTQ+ communities in Northern Ireland experience mental health issues at disproportionately high levels due to widespread social stigma, abuse, and institutionalised homophobia, biphobia and transphobia. Mental health issues within the community are exacerbated in a myriad of ways by statutory services which fail to meet their needs including: failure to adequately fund and competently advertise sexual & reproductive health services, leading to significant HIV/STI anxiety; failure to provide transition-related-care for trans individuals in a timely and culturally competent manner; failure to fund access to IVF for lesbian and bisexual couples; failure to enforce equality legislation in schools and

adequately clamp down on anti-LGBTQ+ bullying; failure to address poverty, homelessness, and criminalising drug use; among many others.

These issues, compounded with the chronic underfunding of mental health services and lack of cultural competency within such, has led to a mental health crisis within LGBTQ+ communities. This manifests itself in a variety of different mental health issues, such as depression, suicide, substance abuse, self-harm, unemployment and homelessness.

We must adequately fund mental health services and engage in meaningful co-development and coproduction of training and service provision with LGBTQ+ communities. Specifically, LGBTQ+ counselling and mental health services should be funded and delivered in collaboration with community organisations (including those already doing this work, i.e. Rainbow). Service providers need to be specifically trained on supporting LGBTQ+ people, with this training delivered by/developed with LGBTQ+ community orgs. For trans people, mental health support, community support, and access to gender affirming care should have clear and defined pathways between them and be integrated in such a way that improves access to all while not requiring access to mental health care as a prerequisite to other care.

We must also recognise that the disproportionate mental health issues within LGBTQ+ communities are not inevitable, and are contributed to significantly by the institutionalised issues explored above. In order to improve the mental health of LGBTQ+ communities, the conditions which led to that poor health must be addressed.

2.1.2.3 Carers

The COVID-19 pandemic has resulted in increases in the numbers of women with caring responsibilities and issues with a lack of support for carers. This has had an impact on the mental health of these carers. Across the UK almost two thirds of carers (64%) say that their mental health has worsened as a result of the pandemic. 65% of women said their mental health had suffered compared to 58% of men.³⁸

Before the crisis, carers in Northern Ireland were already providing substantial hours of care. In April 2020, 78% said they were providing more care than before. Six months on, this figure had increased to 85% of carers reporting they were providing more care.³⁹ 61% of carers in Northern Ireland have not been able to take any breaks from their caring role during

³⁸ Carers UK (October 2020) <u>Caring behind closed doors: six months on</u>

³⁹ Ibid

the COVID-19 pandemic, while 17% said that they had not been able to take as many breaks as they felt they needed. This has affected carers' health and wellbeing, with almost two thirds (65%) reporting that their mental health has worsened due to the COVID-19 pandemic.⁴⁰ Information on the impact of caring responsibilities will be expanded on in section 2.2.

2.1.3. Women's Centres work on Mental Health

Women's Centres across Northern Ireland carry out a range of work and programmes in relation to mental health in local communities. This important work has continued during lockdown and many have seen considerable increases in demand for their wellbeing and mindfulness classes as well as for one to one counselling as a result.

Some of the examples of the courses, programmes and services that the Centres provide include the Maternal Advocacy and Support (MAS) project (see section 2.5.2.) Mindfulness, 5 Steps to Wellbeing, Art as Therapy, Declutter Your Mind, Managing Stress, Mood Matters, Benefit Checker and Financial Support (to support women who have difficulties understanding the benefits system) and offering social spaces which are women-only safe spaces for women to meet, talk and make friends. The Centres also have close links with Women's Aid NI, social services, the Probation Board, PSNI, Health Trusts, Mental Health nurses, social workers, psychiatrists, local churches and community and voluntary organisations to provide holistic services to women and their families.

The range of services that Women's Centres can offer in relation to mental health can depend on funding. In some cases where funding is not available services can depend on the availability of trained volunteers to carry out this work. Some of the Women's Centres have funded provision for counselling but many operate this counselling on a voluntary basis. Many of the Centres have seen their counselling services grow considerably as a result of the pandemic.

Chrysalis Women's Centre in Craigavon does not get any specific funding and relies on trained volunteer counsellors. Demand is growing in the local area with the impacts of lockdown, COVID-19 and unemployment.

"I think we are just at the start. I think we are going to get a pandemic of mental health issues after the Covid pandemic."

⁴⁰ Ibid

- (Ruth McKeever, Manager of Chrysalis Women's Centre, Craigavon)

Atlas Women's Centre in Lisburn has also seen significant increases in demand for their counselling services from people of all ages. They receive many referrals from local GPs, Community Psychiatric Nurses, the Mental Health Team and health visitors. They have nine counsellors and they receive no set funding for any of them and are all voluntary.

The Centre has seen significant mental health issues for parents as a result of the COVID-19 pandemic including isolation, homeschooling and children out of their routines. Many of the women have had new babies and are suffering fear, anxiety, loneliness and isolation. There have been a lot of pregnancies in the area and the mental health of these women has really been impacted because they have not been able to access the same level of care and have not had continuity of care. Many women are experiencing financial worries and some have had small local beauty businesses which have been really affected by lockdowns. The Centre is also seeing a lot of relationship issues with separations and cases of domestic violence. They are seeing examples among the women they work with whose mental health has improved in the last number of years because of the services they provide, losing this progress as a result of lockdown and a reduced ability to access these important services.

Atlas Women's Centre has seen increasing demand for its range of programmes supporting mental health and isolation. Although prior to the pandemic they were able to accommodate 250 places per week, that will not be possible coming out of lockdown with social distancing and safety precautions impacting on the numbers of people who can access their services. They are concerned about how they will meet demand for their services, given the impact on mental health of the pandemic and lockdown.

"Atlas women's centre is so important to women in this area and the services we provide will be needed even more coming out of lockdown."

- (Gay Sherry-Bingham, Manager of Atlas Women's Centre, Lisburn)

Kilcooley Women's Centre recognises that health and wellbeing initiatives underpin everything they do in the Centre. The Centre believes it is important to provide low level wellbeing improvement opportunities on a regular basis. In addition, it is key to have good links with other community organisations in order to provide higher level wellbeing support when needed such as financial advice, domestic abuse support and counselling. Kilcooley Women's Centre offers a broad and varied

range of wellbeing support programmes alongside low-cost, affordable, onsite childcare to make all opportunities as accessible as possible.

"During lockdown many of our classes moved online via Zoom. In order to provide appropriate support we have been making regular weekly calls to all participants to ensure they are supported and can be directed to appropriate services during the pandemic. We also created a local 'lockdown' specific directory for all services across the Borough which was designed to help people by making it easier to avail of services and local support."

- (Alison Blayney, Manager of Kilcooley Women's Centre, Bangor)

Women's Centres play a crucial role in relation to mental health services in local communities and are often able to reach and engage with those who are the most marginalised. They provide trusted, local spaces where women and men can access help in relation to mental health issues. The services provided are holistic so that the full range of issues that are impacting on a person's mental health can be addressed. Early intervention is an important area of their work to ensure that mental health issues do not get the chance to take hold and cause even greater problems for those impacted.

The fact that the women's centres provide childcare to enable people to avail of courses and counselling is a major aspect of this work. It enables people to take advantage of help with their mental health without having to disclose to friends/family if they do not wish to do so and removes a significant barrier to access for these important services especially for women.

Despite the importance of the work of women's centres across Northern Ireland in relation to mental health, this work often goes unseen in the wider mental health structures and its value is untold and unrecognised. In fact, funding for the work of women's centres is being cut. Funding for the women's sector in Northern Ireland has been continually diminishing over the past ten years. In the last five years alone, the women's sector has faced cuts of 2 – 5% per year from budgets. Women's organisations have seen a shift from core funding to short-term project funding. This limits their ability to respond to emerging issues, retain key staff and develop any long-term planning to meet the needs of women. This lack of funding only serves to further compound the marginalisation of women and of those who are at the greatest risk of poverty, ill health and social isolation.

Recommendations:

- Increase the budget for mental health services as a result of greater demands arising from the pandemic.
- Developing pandemic-related mental health policies to take into account those who have been most impacted including women, young people, those on low incomes, BAME and LGBTQ+ people and carers. Government should devise policies that consider the mental health impacts on these groups and provide funding and services to specifically improve their mental health and economic wellbeing.
- Health and Social Care Trusts should ensure carers in Northern Ireland are informed of their right to a Carer's Assessment so that carers are alerted to the mental health supports available to them and to help ensure that those at most risk of poor wellbeing and burn out get the support they need.
- Identify carers as a priority group requiring emotional support services and develop agreed pathways for them to access mental health interventions.
- Reducing poverty through significant investment in welfare and debt prevention to ensure people have sufficient income to live on both during the crisis and into the future as society gradually emerges from the pandemic and its longer-term impacts see sections 1.4-1.5.
- Improving access to culturally competent sexual health services (reducing STI/HIV anxiety).
- Decommodifying housing and ensuring quick access to alternative accommodation in cases of DV/SV/homo- + trans-phobia from housemates and family.
- Improving cultural competency within drug cessation services, safe injection rooms, etc.
- Removing crisis/mental health response from PSNI duties, developing emergency community healthcare support for mental health crisis situations.
- Adequate long-term funding must be provided to the wider women's sector and to the network of women's centres across Northern Ireland for their work on mental health issues. Funding and support must be increased so that they can continue, develop and strengthen their work in relation to mental health which has seen increased demand as a result of the pandemic and which is unlikely to diminish for some considerable time.

2.2 Women with Caring Responsibilities and Dependents:

Information on the impact of caring throughout the pandemic has already been highlighted in detail in section 1. However, it is still worth analysing the impact of caring responsibilities on carers' health. The numbers of people with caring responsibilities in the UK increased dramatically throughout the COVID-19 pandemic. Urgent action is needed to address the increasing mental health concerns of carers. As the majority of carers are also in paid employment, if action is not taken to support this group, it is likely to have long-term detrimental impacts on the workforce. Some statistics on impact of increased caring responsibilities during COVID-19 from the Carers Week report includes⁴¹:

The top three most frequently chosen challenges by all unpaid carers:

- managing the stress and responsibility (71%)
- the negative impacts on their physical and mental health (70%)
- not being able to take time away from caring (66%).

These results closely matched what the public, who had never been unpaid carers, thought the challenges that unpaid carers face were:

- not being able to take time away from caring (72%)
- managing the stress and responsibility (70%)
- the negative impacts on their physical and mental health (69%).

There were other important challenges that were frequently chosen by unpaid carers:

- the impact it has on other personal relationships (e.g. with family, friends, partners etc.) (63%)
- the negative impact it has on their ability to do paid work (55%)
- the financial impact of the additional care costs (eg specialist care equipment, home adaptations (53%)
- not having anyone to talk to about the challenges of caring (50%).

⁴¹ Carers Week (2020), 'Carers Week 2020 Research Report: The rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak', Making Caring Visible, (available online): https://bit.ly/35MKMXC p.7.

The general public, who don't have a caring role, were asked what worries they would have if they took on an unpaid caring role. Their top three worries were:

- The negative impact on their own physical and mental health (56%)
- Not being able to cope financially, not being able to afford care services or equipment required (50%)
- Not knowing or understanding what help is available to carers (49%).

For too long, women and unpaid carers have provided social support that upholds the health and wellbeing of society whilst propping up the NI economy to the value of £4.6 billion per year. Earlier in this plan, statistics were given of the economic benefits of investing in care for both gender equality and in addressing climate change. The needs of carers' health should be a priority in any recovery planning in Northern Ireland.

2.3 Additional Health Concerns

In addition to the increased mental health implications of the various lockdowns throughout the COVID-19 pandemic, there are other concerning implications on women's physical health as a result of the pandemic. This includes the ramifications of cancelled cancer screenings, increased waiting lists, the ongoing health impacts of austerity cuts and poverty, and issues around accessing abortion and maternal health services, and how this impacts upon women's bodily autonomy. We also have specific concerns for the health of immigrant women, women of colour, trans women and disabled women.

2.3.1 Ramifications of Cancelled Cancer Screenings

In the initial FRP launched last July, data from Cancer Research UK showed the vast impact of just 10 weeks of lockdown on cancer screenings and the long-term impact on cancer services and individual health⁴². Based on the average number of people screened per week (210,000), just 10 weeks of lockdown created a backlog of 2,100,000 screening appointments, tests and treatments by the beginning of June 2020. As

⁴² Katie Roverts, (June 2020), 'Over 2 million people waiting for cancer screening, tests and treatments', Cancer Research UK, (available online): https://bit.ly/3qmxH0k

lockdowns continued for most of 2020 and into 2021, this has significantly worsened.

For every week that screenings were paused, Cancer Research UK estimated that 7,000 people weren't referred for further tests and 380 cancers were not diagnosed. While cancer screenings resumed across the UK after the first lockdown, recent data from The Lancet Oncology shows that:

"COVID-19 has had devastating effects on patients with cancer, with huge numbers of missed diagnoses and delayed treatments due to health systems under pressure and patient reluctance to seek medical care. Despite repeated reassurances from officials that the UK's National Health Service (NHS) remained open for urgent care, a study estimated that 45% of those with potential cancer symptoms did not contact their doctor during the UK's first wave of the pandemic (March-August, 2020), citing reasons including fear of contracting COVID-19 and avoiding placing extra strain on the NHS. Consequently, suspected cancer referrals fell by 350 000 compared with the same period in 2019. Combined with interruptions in cancer screening programmes and delays in scans and diagnostics, a spike in late cancer presentations and diagnoses is anticipated, making some previously curable tumours more difficult to treat and, unfortunately, further excess deaths unavoidable.43"

Organisations such as the Women's Resource and Development Agency (WRDA) travel across Northern Ireland to deliver sessions to increase awareness of the need for people to assess themselves and attend Breast, Cervical and Bowel cancer screenings; and these services must be prioritised as we move out of the lockdown.

2.3.2 Increased Waiting Lists

According to the Lancet Oncology, waiting lists are a growing concern across the UK:

"The UK's NHS currently has more than 4.6 million people on waiting lists for surgery and 300 000 people have been on

⁴³ The Lancet Oncology, (April 2021), 'COVID-19 and cancer: 1 year on', Vol.22, Issue 4: https://bit.ly/2TUHXAX

hold for more than 12 months—a wait time that is 100-times higher than before the pandemic.⁴⁴"

As a result of this, the NHS Confederation has continued calls for urgent emergency funding and long-term spending by the UK government⁴⁵. This is an issue that is drastically worse in Northern Ireland and should be an urgent priority for both the Northern Ireland Executive and the UK Government. Northern Ireland has the worst waiting lists across the UK and the Department of Health has stated what without significant and recurrent funding from the Executive, it could take up to 10 years to tackle Northern Ireland's current waiting lists⁴⁶.

In Northern Ireland, more than 335,000 people are waiting for a first consultant-led appointment, and more than half of those people (189,753) have been waiting longer than a year for this first appointment⁴⁷. People waiting more than a year on a waiting list increased by more than 20,000 compared to the end of December 2020 when 167,806 people had been waiting more than a year, and more than 70,000 compared to March 2020 when 117,066 had been waiting more than a year. On top of this, another 12,476 people were waiting for a first appointment for cataract treatment at a day procedure. The Department of Health target is that at least half of all patients should wait no longer than nine weeks for a first appointment and that no one should wait longer than a year. While more people were seen in the first quarter of 2021 (71,078) compared to quarter 4 of 2020 (66,055), there were still 34,190 fewer people seen compared to quarter 1 in 2020, where 105,268 people had their first appointment.

This is reflective of the significant backlog created due to both COVID-19, and insufficient funding to address the issue. A worrying development is in the impact this has on worsening inequalities. In the year April 2020 to April 2021, 5,200 procedures were undertaken by trust consultants in private and independent sector facilities, which helped time-critical cancer surgeries during the pandemic. However, private healthcare is unattainable for many in Northern Ireland and cannot be seen as a long term solution to increased waiting lists, as this drastically undermines the principle of universal, free healthcare and can create barriers to those

⁴⁴ Ibid.

⁴⁵ BBC News, 'Coronavirus: NHS waiting lists 'could hit 10 million this year', BBC News Health, (available online): https://bbc.in/2TZBMLP

⁴⁶ BBC News (April 2021), 'NI hospital waiting lists could take up to 10 years to tackle', https://bbc.in/3gPybZR

⁴⁷ BBC News (May 2021), 'NI Hospital Waiting Lists 'undermining' Free Health Service', https://bbc.in/3gQbEfz

unable to afford to go private. Given the information provided in section 2.1.1 on the social determinants of health, this is particularly concerning to the WPG.

In 2021, in the first case of its kind, two women have taken legal action to highlight Northern Ireland's lengthy waiting lists and have been granted leave for judicial review⁴⁸. It has been argued that the vast waiting lists in Northern Ireland are a "glaring breach of the duty to the public to provide basic healthcare"⁴⁹. Further, a 2019 review of Northern Ireland waiting lists found that a person in Northern Ireland is 48 times more likely as a person in Wales to wait more than a year for care. When compared to England and Scotland, where approximately 1 in 12 people were on elective waiting lists, 1 in 5 people in Northern Ireland were on waiting lists for more than a year. This is an issue that has inevitably been exacerbated by backlogs due to the pandemic. This situation is creating real risks to patients' quality of life and increases disease and preventable death.

A potential solution for this is to create elective care centres, which may be politically and financially easier than closing sites to centralise care; given huge problems with access poverty and public transport in Northern Ireland. More information on the health impacts of austerity on women will be outlined in the following section 2.4.

Recommendations:

- Introduce multi-year budgets to allow for measures to be implemented to address the waiting list crisis in Northern Ireland.
- Develop a 10-year strategy to address waiting lists in Northern Ireland and ensure private healthcare does not become the norm nor create further barriers for those unable to afford private healthcare.
- The NI Assembly should actively lobby against any steps towards the privatisation of the NHS by the UK Government.

⁴⁸ BBC News (January 2021), 'Waiting lists: Legal action over lengthy NI lists clears first hurdle', https://bbc.in/3qlUVnF

⁴⁹ Ibid, n198.

2.4 Health Impacts of Austerity on Women

In the past rising levels of government debt have led to austerity and welfare reform policies which prioritised rapid reductions in government spending through cuts to health and social services. As stated earlier in this plan, women in Northern Ireland were disproportionately and cruelly impacted by years of austerity and welfare reform policies introduced as a result of the 2008 financial crash. Not only does austerity have significant impacts on economic standing, it also has been proven to have profound health impacts. Research by the British Medical Association highlights:

'Austerity and welfare reform in the UK has resulted in substantial reductions in public spending, principally through budgetary cuts on departments and services. This has significantly affected local government funding and welfare support. The broad impact has been to hamper progress in reducing inequality and job prospects; a decrease in the number of households achieving a minimum income for healthy living; increases in relative child poverty; and increased levels of material deprivation. These factors can impact negatives on health and wellbeing in the absence of strong support systems.'50

Research has shown that economic crises and their countermeasures have pronounced and unintended effects on public health. It shows that austerity measures can exacerbate the short-term public health effect of economic crises, for example, through cost-cutting or increased cost-sharing in health care which reduce access and shift the financial burden to households. Strong social protection mechanisms (both formal and informal) can mitigate some negative effects of recession on health such as increasing suicides.⁵¹

Evidence from countries such as Iceland, Sweden, Canada and Norway highlights the importance of maintaining high levels of public spending on social welfare and health as important mechanisms for improving health outcomes and narrowing health inequalities, while supporting long-term, sustainable economic growth. In addition to the direct impacts of the Covid-19 pandemic on health there will be broader health impacts on mental health, the misuse of drugs and alcohol, suicidal behaviour and instances of domestic abuse. Austerity policies are only ever likely to worsen these impacts. A study on the impact of austerity measures on health reported that austerity policies were implicated in worsening mental health, increased suicide rates, heightened mortality in older age groups and greater unmet health care needs.⁵²

The Marmot Review into health inequality⁵³ showed that life expectancy in England has stalled. Among women particularly, life expectancy declined in the more deprived areas of the country. Sir Michael Marmot said in relation to the findings that while his report is concerned with England, in Scotland, Wales and Northern Ireland the damage to health and wellbeing is similarly unprecedented.⁵⁴ He said: "Austerity has taken a significant toll on equity and health, and it is likely to continue to do so. If you ask me if that is the reason for the worsening health picture, I'd say it is highly likely that is responsible for the life expectancy flat-lining, people's health deteriorating and the widening of health inequalities."⁵⁵

If the government uses austerity policies as a response to the Covid-19 crisis this has the potential to cause widespread damage to health. Policies that prioritise economic and social support as well as increasing access to care are more likely to reduce the health impacts of this economic crisis and should be the focus of government action.

In the context of an upcoming recession due to COVID-19, we support recommendations from the British Medical Association to:

- Increase investment in social protection systems such as unemployment programmes, housing support and income maintenance to counter the projected recession and austerity,
- Increase investment in healthcare and public health services in the short and long-term, including adequate funding for evidence based preventative and early intervention services.

Throughout this recovery plan, we have presented evidence of the extremely negative impact austerity has had on Northern Ireland. Suffering for women due to a decade of austerity was immense; socially,

⁵⁰ BMA (2016), 'Health in all policies: health, austerity and welfare reform: A briefing from the board of science', British Medical Association, (available online): https://bit.ly/3wV2Cng

⁵¹ Financial crisis, austerity, and health in Europe, The Lancet, March 2013, https://bit.ly/3vOIJwM

⁵² Austerity and health: the impact in the UK and Europe, The European Journal of Public Health, October 2017, https://bit.ly/3qiE4SC

⁵³ Health Equity in England: The Marmot Review 10 Years On, The Health Foundation, February 2020, https://bit.ly/3gVgnGh

⁵⁴ The Guardian (February 2020), 'Austerity Blamed for Life Expectancy Stalling for First Time in Century', https://bit.ly/3gPyFz4

⁵⁵ Ibid

economically and in terms of their health and wellbeing. In addressing the health crisis we currently face, tackling health inequalities for women and the unequal health ramifications of economic decision making needs to be a priority.

2.5 Abortion, Maternal Mental Health and Bodily Autonomy

2.5.1 Abortion and Bodily Autonomy

2.5.1.1 Abortion: Legislation, Access & Education

Since 22nd October 2019, new legislation decriminalised abortion in Northern Ireland. Instead of access becoming mainstreamed within the health service over a year after the regulations were laid the Minister for Health has failed to commission the services required by law. Alliance for Choice (AfC) have maintained public and political pressure to enact our legal access to abortion. While AfC are incredibly productive, often responding directly to abortion seekers, therefore we cannot reflect every achievement. Whilst the onset of COVID-19 presented challenges for AfC, we adapted creative ways to engage on abortion rights as an access and justice issue firmly on the political agenda. Without the support of the Joseph Rowntree Reform Trust (JRRT) we would not have been able to continue our push against an incalcitrant government, talk to religious groups or build a movement.

2.5.1.2 Access to Services

NI now has the most progressive law on these islands, especially with the recommendations from the CEDAW inquiry into Abortion in NI now enshrined in primary legislation. The WPG wish for the abortion legislation to be honoured to the letter and urgently. The NI Executive blockage of Health Trusts interim Early Medical Abortion (EMA) services initially, and their subsequent precarity, illustrates clearly how the Department of Health and one of the main political parties is governing against the best interests of people living in NI. It is testament to the public campaigns of AfC, Doctors for Choice NI, the work of individuals within the trusts and the Royal College of Obstetricians and Gynaecologists (RCOG) that the Executive relented and allowed the Trusts to provide abortions without

commissioning. AfC continues to signpost access to the online EMA pills and train ordinary people on how to self-manage pills safely for themselves. AfC provides these services because of an urgent need but they should not have to. The Health Trusts should have been supported with what the World Health Organisation (WHO) has classed as essential services.

There has been a 28% increase in NI requests to the Women on Web services since the law was changed. This is unacceptable. Though these services are safe and it is legal for women and pregnant people to use them, they have nominal fees and present no aftercare, which could be offered by a locally NHS run telemedicine service. Since the beginning of the outbreak WHO recommended that services related to reproductive health are considered part of essential services during COVID-19. In June 2020, WHO recommended that abortion provision in the global pandemic should:

"Minimise facility visits and provider-client contacts through the use of telemedicine and self-management approaches, when applicable, ensuring access to a trained provider if needed."

(World Health Organization (1 June 2020) 2.1.4 Sexual and reproductive health services, Maintaining essential health services: operational guidance for the COVID-19 context, Interim guidance (pp. 29))

Abortion telemedicine has been available throughout Ireland, England, Scotland and Wales since the onset of the pandemic. Northern Ireland remains the only place where a safe, cost effective and practical method of abortion care has been denied to individuals seeking abortions. Emma Campbell of AfC said: "There is no evidence-based reason for blocking these services, they have proven to be safe, effective and preferable to many people unable to travel even outside of a global Covid-19 outbreak."

In October 2020 an Open Letter was sent to the Health Minister for Northern Ireland, Robin Swann.⁵⁶ This letter included 76 organisational signatures calling on the Minister for Health to commission abortion services in line with the regulations and WHO recommendations. The letter highlighted:

⁵⁶ Open Letter to Robin Swann, Health Minister for Northern Ireland – 21st October 2020

"On Monday 5th October 2020, the Northern Health Trust reluctantly advised they are no longer in a position to provide early medical abortions due to lack of resources. This was as a direct result of a failure of the Department of Health to commission or fund ANY services. This is just as the confirmed cases of COVID-19 have surged in that same Trust, with risk of contagion amongst the highest across the UK and Ireland. The blocking of EMA services and a complete lack of telemedicine as a result of the DoH inaction, means those seeking abortions will have to travel to GB, which directly contravenes WHO guidance, placing service users and healthcare workers at increased risk of COVID-19 and adding unnecessary cost and pressure to NHS services...

Since April 2020, over 150 women and pregnant people from Northern Ireland have had to use the Central Booking system of the British Pregnancy Advisory Service (BPAS) and have been forced to travel to GB in order to access the care they require, more have used Women on Web and Women Help Women services when a straightforward pathway was unavailable to them."

The Secretary of State for Northern Ireland and the Department of Health led by Robin Swann need to do their jobs, uphold the law and deliver the services they were charged with implementing. Without this there will continue to be issues with the provision of abortion services across the Health Trusts as evidenced by the fact that there are now no longer EMA services available in the South Eastern Trust since January 2021.⁵⁷

Because abortion has been more heavily restricted in Northern Ireland it has fostered a society that is in many ways, decades behind on women's reproductive healthcare. In adolescence this manifests in our relationship and sex education (RSE) in schools. Roughly 70% of post-primary schools in NI use abstinence based RSE, provided from an evangelical Christian perspective. Many schools, utilise the ethical elements of religious studies to teach only a "Christian" perspective on abortion. Yet groups recently formed such as the Faith Voices for Reproductive Justice demonstrate there is no singular "Christian" perspective on abortion. Many people of faith require access to the full spectrum of reproductive healthcare.

⁵⁷ AfC statement on South Eastern Trust closure of services – 5th January 2021

Aspects of sexual pleasure, consent and LGBT+ relationships are ignored, within current RSE provision. As a consequence our young people are put at greater risk of STIs and an inability to recognise the red flags of abusive relationships. According to a survey by <u>Love to Know NI</u>, 96.8% of respondents wanted change in how RSE is delivered island-wide, with those responding describing their RSE experience as "inadequate", "terrible" and "useless".

Stigma continues around women's sexuality, resulting in barriers to contraception and abortion services. In January this year, over 700 women were contacted regarding poor placement of contraceptive implants between 2017 and 2020. A number became pregnant and many would have been unable to access abortion services at home or been at risk of prosecution for seeking telemedicine services from online providers. On top of these barriers, there are long waiting lists for long-acting reversible contraception and vasectomies, up to 2 years in some cases. Many people can become pregnant more than once in that time.

For those wishing to become pregnant, there is a shameful lack of funded access to fertility treatments in NI, with only one fresh and one frozen embryo transfer funded by the Health and Social Care Board. This is yet one more inequity between NI and the rest of the UK. There is even less access for those not in heterosexual relationships, or wishing to parent alone and there are no sperm banks.

Many women report high levels of satisfaction with maternal care during pregnancy and childbirth, however NI has one of the lowest rates of breastfeeding in the world, with 24% of women wanting more support in breastfeeding according to the Birth NI survey. Until 2021 there was zero funding for perinatal mental health treatment and no mother and baby psychiatric care unit. Thanks to brave campaigners like the Maternal Advocacy and Support Project and Linsday Robinson this has changed and funding for a unit for new mothers with postnatal mental illness will now be granted.

Lifelong issues for women, such as chronic menstrual pain are also, unsurprisingly, not treated well in Northern Ireland. With an 8 and a half year wait for women to be diagnosed with endometriosis, a condition that impacts on as many as 1 in 10 women, they are left in chronic monthly pain with no state-funded access to diagnosis or treatment. With only one specialist surgeon for endometriosis in NI, it is no surprise that so many women experience delays in surgery for debilitating pain.⁵⁸ These are

⁵⁸ Northern Ireland women with endometriosis in eight-year wait for diagnosis, Belfast Telegraph, April 2021, https://bit.ly/3vOgLkv

disgraceful examples of how women's healthcare is underserved, women's pain disbelieved, and women's experiences ignored.

Finally, the horrific experiences of people trying to access the care that is available needs to be ameliorated with the passing of the Private Members Bill on safe access zones and a detailed list of NHS sanctioned treatment needs to be published to avoid women being misled to the door of the likes of Stanton Healthcare.⁵⁹

Recommendations:

- Delivery of access to services to ensure we deliver on the current legislative framework which is in line with current minimum human rights recommendations from the UN without unnecessary delays from consultations and delivery design.
- Overcome institutional barriers to implementation of abortion legislation and regulations in institutions concerned with women's health, including health trusts, hospitals, schools, youth organisations and other statutory bodies via training, education and funding.
- De-stigmatisation of abortion to ensure media narratives reflect wider societal attitudes and the concerns of those most keenly impacted rather than those with strongly held beliefs but no direct impact.
- Telemedicine in line with the rest of the UK and Ireland.
- Equal access to fertility treatment.
- Adoption of preventive and timely strategies to deal with acute and chronic long term reproductive health conditions such as Polycystic Ovary Syndrome and endometriosis.
- Roll out RSE according to the CEDAW minimum recommendations as set out in our primary legislation.
- Enact buffer zones with haste to allow women and pregnant people safe access to abortion and contraception healthcare.
- End the Executive block on abortion by allowing the Secretary of State for NI to step in and fund, resource and commission services.
- Publish information on all current abortion services on the Public Health Agency, Department of Health and Trust websites.

Northern Ireland women with endometriosis in eight-year wait for diagnosis - BelfastTelegraph.co.uk

⁵⁹ Stanton Healthcare needs to answer for deliberately misleading abortion seekers in Belfast - Shado Magazine (shado-mag.com), April 2021, https://bit.ly/3gPRouB

- Investigation of false claims of service delivery by rogue pregnancy services.
- Proper funding of mental health services throughout pregnancy and early years parenting.

2.5.2 Maternal Mental Health

Maternal Mental Health provision in Northern Ireland has been extremely limited and it is great news that funding has been released to have specialist perinatal mental health services in all five trusts in Northern Ireland. This will mean that all five trusts in Northern Ireland will have adequate provision. Currently there is just a limited perinatal mental health service in the Belfast Trust. Plans for the services are currently underway and it is hoped that all provision will be in place by the end of 2021.

This is welcome news for campaigners who have worked tirelessly to make this happen and for the women who will now be able to access this service. The Everyone's Business Campaign has been instrumental in lobbying for equality and the end of the postcode lottery in maternal mental health services across the UK.⁶⁰ It is important to note that the specialist services criteria is aimed at women with severe or complex mental health illness. The majority of women with mild to moderate perinatal mental health illness would not meet the criteria for this service. It is essential that communication and co-operation, strengthening of primary care, universal services and co-design with the community voluntary sector is implemented and improved fully.

With plans for a mother and baby unit in Wales, Northern Ireland remains the only part of the UK with no Mother and Baby Unit (MBU) and women who need hospital care must be admitted to a general psychiatric ward and be separated from their babies. The business case for an MBU in Northern Ireland is still under development, we would urge that this is prioritised so that women who require the highest level of care can do so without separation from their babies. Northern Ireland has lagged behind the rest of the UK for too long with its perinatal mental health care, it is essential that women here receive the same equality of care.

WRDA's Maternal Advocacy and Support (Mas) project is a Big Lottery Community funded project and provides peer support across 8 women's

⁶⁰ The Everyone's Business Campaign | Maternal Mental Health Alliance

centres.⁶¹ The project also provides advocacy and engages the women in the journey of improving services. Projects such as Mas need to have long term statutory funding to provide support for women who may have been severely unwell in the past so that they can stay well and also as an early intervention tool to minimise the risk of deterioration for women who would be considered to have a mild to moderate perinatal mental health condition.

Women have indicated the difference that compassion, support and an appropriate response to the disclosure of low mood and poor mental health can make. So far, many participants on the Mas project have expressed how they have felt let down by health professionals and that lack of consistency in staff has been detrimental. There have also been examples of good practice that left women feeling hopeful and supported. The Mas project aims to provide the environment for women to express their lived experience with the aim of improving services in the future.

It is important to create an environment where women do not feel stigmatised or judged for accessing support for their mental health. It is also essential that women from lower socio-economic backgrounds do not feel that this is a further barrier to them accessing support.

The Mas project not only provides peer support for women but offers a real opportunity for change and primary care service improvement, led by women with lived experience. It is also important that peer support in the community secures long-term statutory funding demonstrating a real commitment to women with maternal mental health difficulties. The Women's Centres provide a safe, supported environment for the Mas project with family support, childcare and a range of holistic services on site. As well as many of the Women's Centres offering counselling and complementary therapies there are links and progression to adult education for women.

There is also a need for the Mental Health Strategy to include a commitment to promoting and improving infant mental health, improving care to the most vulnerable babies and young children as highlighted by the Association for Infant Mental Health Northern Ireland. 62 We also commend the NSPCC Fight for a Fair Start Campaign that urges governments across the UK to ensure that babies, parents and children

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⁶¹ Maternal Advocacy and Support Project (MAS) – Women's Resource and Development Agency (wrda.net)

⁶² AIMH(NI)| Home (aimhni.co.uk)

receive the mental health support they need.⁶³ PPR's #123GP campaign aims to end the current postcode lottery in relation to access to counselling in surgeries. The campaign highlights that the majority of maternal mental health patients receive support from primary care services that are in need of urgent funding and improvement.

The Maternal Mental Health Alliance report on the impact of the pandemic highlights that the pandemic has had a disproportionate impact on women compared to men as they are more vulnerable to socioeconomic inequalities, gender inequalities, domestic violence and economic insecurity. Further, women from specific communities have been more markedly affected than others. The report points to the fact that perinatal mental health services had worrying gaps before the pandemic but anxiety, reduced social and family support, changes to birth plans, reductions in support services for women and the change to virtual contact have exacerbated existing problems.⁶⁴

Recommendations:

- Urgent commitment to funding for a Mother and Baby Unit in Northern Ireland.
- Excellent communication and referral pathways established between specialist services, primary care and the community and voluntary sector.
- Long-term sustainability and funding provided for community and voluntary sector maternal mental health projects such as the Mas project.
- The views of women with lived experience are utilised to improve patient care provided by primary services.
- Commitment and funding for mental health prioritised for infants, children and families who need support including the provision of counselling services.

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⁶³ Fight for a Fair Start | NSPCC

⁶⁴ Maternal Mental Health Alliance (March 2021), 'Maternal mental health during a pandemic, A rapid evidence review of Covid-19's impact', https://bit.ly/3wRwJvL

2.5.3 Maternal Death Rates Among Ethnic Minorities and Women in Poverty

From 2016-2018, 217 women died during or up to six weeks after pregnancy from causes associated with their pregnancy, among 2,235,159 women giving birth in the UK⁶⁵. This equates to 9.7 women per 100,000 that died during pregnancy or up to six weeks after childbirth or the end of pregnancy. The most common reasons included cardiac disease (23%), blood clots (15%), epilepsy and stroke (13%), mental health condition (13%), sepsis (11%), bleeding (9%), other physical conditions (7%), cancer (3%), preeclampsia (2%) and other (4%)⁶⁶. Crucially, improvements in care which may have made a difference to the outcome were identified for 51% of women who died.

Within the UK, Black women are four times more likely to die in pregnancy or childbirth compared to white women, and Asian ethnic backgrounds face twice the risk⁶⁷. Urgent action is needed to tackle systemic biases contributing to the unequal mortality outcomes in ethnic minority women and women facing deprivation68. New research by Oxford University Department of Population Health say that the COVID-19 pandemic is likely to have worsened these disparities⁶⁹. In addition, women living in the most deprived areas of the UK are almost three times more likely to die than those in the most affluent areas and women experiencing multiple disadvantages when they died increased by a third since 2019 from 6% to 8%. In 2016-2018, 547 women died during or up to a year after pregnancy from causes associated with their pregnancy, among 2.2 million women who gave birth in the UK. Within this period, 34 Black women died among every 100,000 compared to 15 Asian women in every 100,000 and 8 white women in 100.000. The figures were fundamentally unchanged compared to previous reports and recommendations despite consistent campaigns to encourage responses from the NHS and government agencies to address racial and socio-economic disparities.

The disparity in maternal death rates simply due to a woman's ethnicity, socio-economic background or disability is wholly unacceptable and lower standards of care for these groups must be urgently addressed. The WRDA Consultation Response to the NICE Draft Guidelines on Inducing Labour for Black and Brown women, women over 35 and women with high BMIs and the WPG Endorsement Response submitted in July 2021 are available here.

Recommendations:

- Systemic biases leading to higher maternal death rates among Black women, Asian women, disabled women, and women from areas of deprivation must be urgently addressed, particularly as COVID-19 has amplified social and ethnic inequalities in the UK.
- Implement all recommendations highlighted by MBBRACE UK in relation to improving patient care for professional organisations, policymakers, service-planners, commissioners, service managers and health professionals⁷⁰,
- Improve implementation of maternal care recommendations by ensuring Maternity Networks work with their member organisations and professional groups to support all relevant healthcare professionals to deliver care for pregnant women in line with these recommendations,
- Increase and improve care for women with neurological complications, pre-existing health conditions, disability, medical or surgical disorders and infection.

2.6 Health Inequalities and Hostile Environment for Migrants and Black and Minority Ethic People

"Black, [Asian] and Minority Ethnic (BME) communities are generally considered to be at increased risk of poor mental health (Bhui and McKenzie, 2008; UK Department of Health, 2011; Fernando, 2012) and

⁶⁷ Hannah Summers (January 2021), 'Black women in the UK four times more likely to die in pregnancy or childbirth', https://bit.ly/3jsN1Y3

⁶⁵ MBRRACE-UK (December 2020), 'Saving Lives: Improving Mothers' Care', https://bit.ly/3dsKXvv

⁶⁶ ibid.

⁶⁸ British Medical Journal (January 2021), 'Disparity in maternal death rates because of ethnicity is "unacceptable", BMJ 2021;372:n152, https://bit.ly/2UUbq7h

⁶⁹ MBRRACE-UK (December 2020), 'Saving Lives: Improving Mothers' Care', https://bit.ly/3dsKXvv

⁷⁰ MBRRACE-UK (December 2020), 'Saving Lives: Improving Mothers' Care', https://bit.ly/3dsKXvv

frequently have less confidence using available services (Rooney, 2013)."⁷¹ Furthermore, Black, Asian and minority ethnic people living in Northern Ireland are at a heightened risk of discrimination and racist hate crimes in Northern Ireland.⁷² Prejudice and hate crimes impart a significant psychological toll on victims. Any attempt to address the mental health needs of the Black, Asian and minority ethnic community in Northern Ireland needs to encompass a strategy to combat racism, particularly institutional racism in the health care system.

Some of the identified challenges to minority ethnic and migrant communities accessing mental health services include language barriers, discrimination, difficulty with GP registration and other aspects of accessing care and the stigma associated with accessing mental health services.⁷³ Further, the culture and power dynamics of psychiatry - a field dominated by white men - can be off-putting to BME people attempting to access care.

A report commissioned by Migrant Centre NI and the Black and Minority Ethnic Women's Network found that a substantial minority (34.7%) of migrant women surveyed did not know or were unsure of what healthcare they were entitled to under their immigration status⁷⁴. Though there is interpreter provision available through the NHS, in practice some women report that they are not always provided with interpreter services even upon request and 16.6% of BAME women surveyed report being unable to adequately express their needs to their healthcare provider. Black African and Caribbean Women rated their experiences of healthcare among the most negative of all respondents.

These women, compared demographically to the rest of the group, represented a lower proportion of English speakers, a higher proportion of refugee and asylum seekers, higher rates of unemployment, lower household income and lower levels of educational attainment. This is illustrative of the impact of systemic racism and anti-Blackness to account

⁷¹ Institute for Conflict Research (December 2015)

^{&#}x27;Waking this thin line Report' Black and Minority Ethnic (BME) Experiences of Mental Health Wellbeing in N.Ireland (conflictresearch.org.uk), https://bit.lv/2TYhkei

⁷² BBC News Northern Ireland 12 June 2020 'Racism: More than 600 hate crimes reported to PSNI', https://bbc.in/3qkQrgK

⁷³ Institute for Conflict Research (December 2015) 'Walking this thin line Report: Black and Minority Ethnic (BME) Experiences of Mental Health Wellbeing in N.Ireland', https://bit.ly/2TYhkei

⁷⁴ Austin, J. (2017) Ethnic Minority Women's Access To Quality Healthcare In Northern Ireland, Migrant Centre NI and Black and Minority Ethnic Women's Network.

for even starker levels of health inequalities for Black African and Caribbean communities.

Refugee and asylum seekers reported additional health needs related to the trauma of persecution and fleeing their countries of origin which are not adequately addressed by local health providers due to lack of awareness, lack of resourcing, perceived discrimination, or the barriers outlined above. Women with no or low levels of formal education reported the highest levels of need compared to the group, particularly the need for interpreter provision, being able to communicate healthcare needs, comfort with exclusively seeing a female GP, comfort expressing women's health issues and unmet healthcare needs, in particular, gynaecological and sexual healthcare needs. Women who took part in the survey made specific reference to community organisations who helped them to access care including GP registration and assistance with appointment scheduling, highlighting the importance of adequate funding and resourcing for organisations doing this work.

Health outcomes for Traveller communities in Northern Ireland are among the worst in the country, illustrating severe disenfranchisement and systemic neglect. A report completed by Strabane Access Youth Engagement commissioned by Migrant Centre NI found that health outcomes in Traveller communities were not only lower than those in the general population but also compared to those in other socially deprived areas⁷⁵. 33.5% of all respondents surveyed reported their health as "poor" or "very poor". 89.5% of respondents indicated that at least one person in their household has a disability or limiting long-term illness. Irish Travellers are nearly seven times as likely to die by suicide than the general population. From a gendered perspective, there are severe inequalities in maternal healthcare, with Traveller women experiencing significantly higher rates of miscarriage, stillbirth, neonatal deaths as well as maternal deaths during and shortly after pregnancy.

A conservative estimate of life expectancy gaps between Traveller women and settled women shows that Traveller women's life expectancy is 12 years shorter. Barriers to healthcare include discrimination by GP surgeries to require proof of permanent address to register, inadequate or inappropriate public health outreach, awareness, and education to meet the needs of Traveller communities experiencing higher levels of illiteracy, anticipation of discrimination and a lack of cultural awareness on the part of healthcare providers. These barriers are embedded within broader

 $^{^{75}}$ Strabane Access Youth Engagement (2018) The Needs and Issues of the Traveller Community in Northern Ireland, , Migrant Centre NI

social frameworks of systemic discrimination and socio-economic disenfranchisement of Travellers.

It is also the case that, should an individual have a negative experience in accessing mental health care or any kind of health care, they will be unlikely to engage in the future. The lack of cultural competency on caring for BME people, widespread language barriers and the UK Government's hostile environment policy have ensured that these off-putting negative experiences happen more often to people of colour accessing services, to the detriment of community health.

Members of the migrant community, particularly those without secure immigration status may be put off from accessing healthcare for themselves or their families during COVID-19 because of the continued operation of 'hostile environment' measures which have the NHS sharing migrant data with the Home Office. This impacts some of the most vulnerable women in society such as pregnant women, victims of trafficking and domestic violence and persons living with HIV.

The history of data sharing between the Home Office and the NHS differs across the UK. In England a 2016 Memorandum between the NHS, English Department of Health and Social Care and the Home Office previously allowed the Home Office to request confidential patient information for immigration enforcement purposes, including for minor immigration infractions. This Memorandum was halted in November 2018 following condemnation from a Health & Social Care Select Committee inquiry and legal action taken by Migrant Rights Network, represented by Liberty. UK wide data sharing continues between the NHS and the Home Office regarding migrants who have incurred a debt to the NHS.

Migrant women and mothers are specifically targeted and harmed under the UK's hostile environment immigration policies. Utilisation of the NHS to document and report patients' immigration status discourages women to access care, important medical screenings and specialist services

⁷⁶ Memorandum of Understanding between Health and Social Care Information Centre and the Home Office and the Department of Health (came into effect January 2017, subsequently withdrawn)

⁷⁷ Liberty <u>press release</u>, Legal victory against Government's hostile environment (November 2018)

⁷⁸ Department of Health & Social Care (March 2019) Overseas chargeable patients, NHS debt and immigration rules, https://bit.ly/3gRZmn4

(including prenatal and antenatal care) or report domestic abuse⁷⁹. Women not considered "ordinarily resident" in the UK, including those who are undocumented or are awaiting an asylum decision, do not have their maternity care costs covered under the NHS. Reports exist of asylum seekers being told that debts incurred to the NHS for maternity services will be used against them in decisions on the outcome of their asylum claims⁸⁰. Xenophobic rhetoric targets migrant mothers specifically, with the UK government and media stoking fears of "heavily pregnant" migrant women using the NHS en masse despite no empirical evidence to support this. NISRA figures for 2019 show that just under 11 per cent of births were to mothers from outside Northern Ireland, the UK and Ireland; this figure has stayed relatively stable since recording began in 2009.⁸¹

NI legislation such as the Provision of Health Services to Persons not Ordinarily Resident Regulations (Northern Ireland) 2015 does not embed hostile environment practices in the same manner that equivalent English legislation does. However, data sharing related to migrants who have incurred debt to the NHS does apply to treatment received in Northern Ireland.

The Health Minister Robin Swann publicly said in a debate on 24 March 2020 that data on migrants/Asylum seekers accessing treatment for COVID-19 would not be passed on to the Home Office. At the same time, he also gave a (clearer) assurance that treatment would be free to everyone. This was later backed up by a response from the Minister to a written question from Gerry Carroll MLA (AQW 3899/17-22), which was answered in May 2020, almost two months after the question was first tabled. While these assurances are welcome, the atmosphere of fear created by the hostile environment policies means that this is not enough to ensure migrants will seek treatment. At no point has this information been widely publicised by the NI Executive or another public authority. A public information campaign would have allayed the fears of many migrants.

A different approach was taken in the Republic of Ireland where Simon Harris TD gave a clear, widely reported declaration at the start of the crisis that all people, documented or undocumented, could access health

⁷⁹ Equality and Human Rights Commission (2018) The lived experiences of access to healthcare for people seeking and refused asylum, https://bit.ly/2U1x5S4

⁸⁰Coddington, K. (2020) Incompatible With Life: Embodied Borders, Migrant Fertility, and the UK's 'Hostile Environment, , Politics and Space, 0 1-14. https://bit.ly/3vV6X8u

⁸¹ NISRA (December 2020) Registrar General Annual Report 2019, https://bit.lv/3wOLHSt

services in Ireland without their details being passed on the Department of Justice and Equality.

It is crucial that all persons in Northern Ireland, including migrants living here without immigration status, feel safe contacting health services to report COVID-19 symptoms and to seek advice. It is not enough to remove charging practices without also making it clear that no person's data will be shared with the Home Office during the crisis. With the statutory basis for data sharing practices in Northern Ireland unclear and healthcare a devolved competence, it is within the power of the NI Executive to take action to address this issue.

There has also been a lack of clarity regarding access to the vaccination programme for people living in Northern Ireland without status. It appears clear from the regulations that there are legal entitlements to all persons to receive health services – including vaccines – relating to COVID-19 for free (with the sole exception of persons travelling for vaccination).82 However, this is not always reflected in practice. There is evidence of individuals being informed that there are British citizenship requirements for vaccinations. This may be an isolated case but a systemic problem also relates to booking on the HSC COVID-19 online portal which asks questions regarding GP registration and place of residence.83 People who cannot answer yes to questions on GP and residence are then told that they are not eligible. Anyone who is told they are not eligible for the vaccine is then advised to email if they 'still think' they are eligible. The process is confusing and requiring people to follow up themselves is not appropriate. Online guidance on eligibility is also unclear stating the vaccine is available 'If you live in Northern Ireland and are entitled to treatment by the Health Service'.84 This statement is misleading as many migrants will not be eligible for all healthcare and others will pay fees, which may lead them to believe they aren't eligible for vaccination. Further, there does not appear to be guidance on vaccine eligibility available in languages other than English.

A lack of clarity on access to vaccines will prevent people accessing the programme and undermines public health. Clear messaging is particularly essential for members of the migrant community who may have been restricted from accessing healthcare previously and who may

⁸² UK Government (2020), The Provision of Health Services to Persons Not Ordinarily Resident (Amendment) Regulations (Northern Ireland) 2020, https://bit.ly/35JyOOi

⁸³ Get Vaccinated | COVID-19 (Coronavirus) Northern Ireland

⁸⁴ <u>Am I eligible to use the vaccine service?</u> | Guidance | COVID-19 (Coronavirus) Northern Ireland (hscni.net)

have a fear of coming forward due to hostile environment practices. A clear public statement from the Department of Health is needed to confirm that all persons can access the COVID-19 vaccination programme, regardless of status and that no data on people accessing vaccines will be shared with the Home Office.

Article 12 of the International Covenant on Economic, Social and Cultural Rights provides the right of everyone to the enjoyment of the highest attainable standard of physical and mental health and includes steps which should be taken by states to achieve this. The UN Committee on Economic, Social and Cultural Rights has clearly stated that this obligation also applies to migrants with or without status. The right to health and wellbeing is also found in Article 25 of the Universal Declaration of Human Rights. Therefore, removing barriers to access to healthcare is an approach grounded in human rights.

Recommendations:

- Going forward, as we recover from the pandemic, it is our belief that all NHS Charging and data-sharing with the Home Office should be suspended indefinitely and this must be accompanied by a public information campaign reassuring people that it will be safe for them to access healthcare, regardless of their immigration status.
- The Department of Health must issue clear public guidance on eligibility for vaccinations for members of the migrant community, including people living in Northern Ireland without settled status.

2.7 Trans Healthcare

The Brackenburn Clinic, which provides gender transition related health care to adult trans people in Northern Ireland, did not accept any new patients for around 3 years since early 2018, and many of those on the waiting list (now 485 long as of May 2021, with around 382 of those waiting longer than a year) have so far been waiting up to 4 years and 4 months for a first appointment. Recently, a clinician from Scotland has been

⁸⁵ <u>International Covenant on Economic, Social and Cultural Rights</u> (adopted December 1966)

⁸⁶ CESCR General Comment No. 14 (August 2013)

funded for a few days per month providing initial consultation to those on the waiting list, however this has resulted in many of those waiting - who may have accessed healthcare privately, self-medicated, etc - being pushed right back to the start of their treatment pathway, causing further unnecessary delays.

Gender-affirming healthcare is recognised as essential healthcare by the World Health Organisation and by regulatory bodies in Europe and the UK, and timely access is crucial. Trans communities suffer disproportionately from both mental health problems and from societal stigma and violence, both of which can be helped substantially by access to care. Currently, Northern Ireland - and the island of Ireland generally - has some of the worst waiting lists and worst future prospects for access to care of any part of the UK and Ireland. The COVID-19 pandemic has made the situation worse.

Waiting lists at the Brackenburn Clinic were and are predominantly due to the excessive psychiatric and psychosocial assessment processes used; the gender affirming care system will never be sustainable with this approach. These psychiatric assessments are not seen at such intensity anywhere else in healthcare, and demonstrate the disproportionate institutional barriers to reproductive care, bodily autonomy and basic human rights placed in the way of trans people of all genders.

Individuals who are denied care due to long waiting lists are highly likely to access care in the private sector, at high cost. As trans communities are more likely to experience poverty, this has disproportionate effects on housing security, health and quality of life. Those who are unable to afford private care often self-medicate with hormonal therapies acquired online through unregulated sources or via friends and family. This is particularly difficult for individuals requiring testosterone, which is a controlled substance. People who are unable to access these options, or those who are but are unable to access other essential care like fertility treatment or surgery, are highly likely to self-medicate with alcohol, smoking or drugs. All self-medication options are usually without any medical or endocrine oversight to ensure safety. Those who are unable to access gender-affirming care in a timely and appropriate manner are disproportionately likely to experience severe mental health problems, self-harm and suicide attempts.

The WPG supports the provision of community-based, sexual-health based models of gender-affirming care in line with global best practice, both to ensure access to care is provided, and to reduce the high costs inherent in the current care pathways. These services must be meaningfully co-produced and co-delivered with organisations working

within trans communities and the communities themselves in line with HSCNI policy and human rights treaty law.

We understand that there is currently a review of gender affirming healthcare services up to the point of surgery provision. While this is encouraging, this review will not address the persistent problem of trans individuals being forced to travel abroad for healthcare, ignoring the complete lack of publicly funded gender affirming surgeons on the island of Ireland. Further, many issues have come up over the past number of months. including under-18s and their families beina (unnecessarily) through traumatising court battles to access hormone blocking treatment, and the provision of bottom surgery for trans men ceasing temporarily across the UK. While COVID-19, the resulting lockdowns and impact on the health service has contributed to these issues, they are symptomatic of a wider reluctance to view gender affirming care as essential healthcare and worthy of investment and support.

Recommendations:

- Specialised gender identity services, following a human rights compliant and culturally competent service model, should be fully commissioned by the Department of Health and be available for trans and questioning people who wish to access them to explore their gender identity. This should not be a centralised service for all trans people and access to these services should not be a prerequisite to accessing gender-transition-related healthcare,
- The reinforcement of gender roles and stereotypes within Gender Identity Services causes detrimental harm to trans and gender nonconforming patients, in particular those who identify outside the gender binary, and should be removed in favour of a model which affirms the gender identity of the patient and supports diverse gender expression,
- New policies, service models or reforms within the health service which will have an impact on trans communities should be developed in consultation with civil society organisations and the trans community at large,
- Any new gender affirming services should be based in the community and on a sexual health model of care,
- The Department should conduct an exploratory review into the feasibility of all-Ireland commissioning of gender affirming surgeons with their counterparts in the Republic of Ireland,

- Trans men who have had their surgery processes interrupted by the current commissioning issues across the UK should be given priority for accessing surgeries when that commissioning process has completed,
- Following the recent High Court judgement ruling court orders unnecessary for many under 18s accessing puberty blockers, we urge the BHSCT & Department of Health to review their legal advice forcing young people through the courts for basic care, and communicate effectively with trans communities and organisations on this issue,
- A cross-border expert working group made up of trans-led organisations and trans expertise should be established to explore how best to ensure access to gender affirming services in border areas & on a cross-border basis,
- A review of access to mainstream healthcare services for trans patients, and adaptation of materials/advertising to recognise and include trans experiences, should be undertaken by the Department of Health.

2.8 Disabled Women

2.8.1 Disabled Women and COVID-19

Disabled women and girls can be subject to discrimination on two levels; marginalised on account of their disability and on their gender. The Government needs to recognise and implement the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) effectively within Northern Ireland to ensure that disabled women live in an equal society which is free from economic, social and cultural barriers.

Only 7% of disabled people are employed, but those who are face low-paid work and underemployment. In addition, disabled women earn 22.1% less than non-disabled men, 11.8% less than disabled men and 26% of households with a disabled person live in poverty compared to 22% of households overall. Disabled women are set to lose 13% of their annual net income by 2021 due to cumulative tax-benefit changes and austerity.

Furthermore, disabled single mothers will have lost 21% of their net income by 2021, and 32% if their child is also disabled.⁸⁷

The impact of the COVID-19 pandemic on disabled people has been drastic, as the Health Foundation highlighted following the release of ONS death figures for disabled people in England in February 202188:

"COVID-19 has had an unequal impact on disabled people who have been among the hardest hit in terms of deaths from the virus. Worryingly, today's data confirms this trend, showing that 6 out of 10 people who have died with COVID-19 are disabled.

Today's figures clearly show that current measures to protect disabled people are not enough and that there is an urgent need for more and better support. Disabled people are more likely to have one or more long-term health conditions, which means they are at greater risk of suffering severe symptoms if they get COVID-19.

However, as well as protecting disabled people from exposure to the virus, measures must account for the potential negative effects of lockdown and shielding. A significant number report that, due to lockdown, their health care needs are not being fully met or that they had treatment cancelled or delayed. Further action should include careful review of the support that is available to disabled people so they can access the care and essential services they need at home. It is also crucial that employment policy ensures that more disabled people get the support they need to work from home.

The high number of COVID-19 deaths among disabled people ultimately reflects wider failures in how the UK supports those who are vulnerable. Addressing this will require the government to address the major and long-standing inequalities that the pandemic has highlighted."

⁸⁷ Women's Budget Group (2018), 'Disabled Women and Austerity', (available online): https://bit.ly/3qouNsi

⁸⁸ Health Foundation (February 2021), '6 out of 10 people who have died from COVID-19 are disabled', https://bit.ly/35JnOAF

The initial Feminist Recovery Plan provided a comprehensive overview of Sisters of Frida Disabled Women's Collective recommendations on supporting disabled women throughout COVID-1989. This included emergency measures relating to access to food, health and medical services, including the voices of disabled mothers, access to support/paid and unpaid care and the right to independent living. One year on, widespread systemic discrimination against disabled women remains and we would like to again highlight some of the recommendations from Sisters of Frienda from 2020:

General Rights of Disabled Women and COVID-19:

- Ensure all disabled women's rights are upheld and protected throughout the entirety and recovery of COVID-19,
- Require all councils to release information on the specific supports they are delivering to disabled people during the easing of the lockdown.

Disabled Women and Domestic Violence/Abuse:

- Provide guidance and support to frontline violence against women organisations and refuges to the needs of disabled women in danger of domestic abuse; including the communication and access needs of disabled women and reasonable adjustments,
- Create greater flexibility in the provision of care packages, particularly for disabled women trapped in social isolation and in danger from Domestic Abuse,
- Support particular provisions of support for disabled women in both the Domestic Abuse Bill (for example, the Staysafe East amendments) and through specific support in any miscellaneous bill to follow the Domestic Abuse and Civil Proceedings Bill.

⁸⁹ Sisters of Frida, (April 2020), 'The Impact of COVID-19 on Disabled Women from Sisters of Frida: Voices of Disabled women in the pandemic', (available online): https://bit.ly/3vQxLqu

In addition, Sisters of Frida have since launched a 2021 research report on the impact of COVID-19 on disabled women and independent living⁹⁰. Some of the key findings include:

- The cost of living for Disabled women increased however income decreased. Many Disabled women were not eligible to access the government's £20 increase to Universal Credit. Discriminatory work practices and the government's failure to implement fair employment regulations led to unemployment, reduced work hours and reduced pay.
- Disabled women became more reliant on partners, family members and friends for financial support and care needs. Despite this, Disabled mothers were predominantly responsible for domestic duties, to the detriment of their impairments.
- The sourcing of food, basic household products, medication (including menstrual hygiene products) was made inaccessible by supermarkets, the medical system and local authority services.
- Disabled women's social care needs were not met, and many Disabled women found themselves without any personal assistance. Information on their social care needs was inaccessible, unreliable, often wrong and many struggled to get basic support such as PPE.
- Disabled women's mental health deteriorated sharply since the pandemic. Those with care responsibilities felt under-supported.
 Many Disabled queer people and shielders felt abandoned and experienced extreme loneliness and depression.
- Disabled women felt let down by the public's attitudes to social distancing and mask wearing. This impacted on their access to the community and green spaces.
- Disabled women's health got worse as their healthcare needs were drastically deprioritised by medical professionals. Many have also been deprioritised in the vaccine prioritisation process.
- Citizens Advice shows that in 2020, 1 in 4 Disabled people were facing redundancy⁹¹. Moreover, half of those who are clinically extremely vulnerable (shielders) were facing redundancy. Citizens Advice further reports that during the pandemic, there has been a

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⁹⁰ Sisters of Frida (May 2021), 'Disabled Women's Perspectives on Independent Living During the Pandemic', https://bit.ly/3vRwjE8

⁹¹ See Citizens Advice: https://bit.ly/3vRwIMg

- 370% increase in their services being accessed by people seeking advice on fair redundancy processes.
- The Trade Union Congress (TUC) have also raised concerns about Disabled workers' inability to get support when in work through the Access to Work scheme⁹².
- Women of colour are more likely to be in insecure work than white employees⁹³. Structural barriers such as lack of workplace adjustments and accessibility are an additional barrier for Disabled women of colour. Due to intersectional discrimination pertaining to race inequality, gender discrimination and disableism, Disabled women of colour are at a disadvantaged position at work.

Recommendations:

- Ensure that programmes and policies dealing with the elimination of exploitation, violence and abuse contain specific actions for disabled women.
- Urgently address the issue of disabled women being denied the same access to maternal health services, including sexual and reproductive health, as other women.
- Promote the employment of disabled women in all sectors, and support entrepreneurship development.
- Urgently review the Access to Work Scheme to improve disabled women's ability to overcome structural barriers to employment.
- Introduce staff education programmes, based on the social model of disability, to effect attitudinal change in all sectors; but particularly health and education sectors.
- Urgently address and reform the Personal Independence Payment (PIP) application process, Universal Credit and Welfare Reform, to prevent any further discrimination against disabled women in Northern Ireland.
- Increase mental health funding to be allocated for those facing intersectional discrimination such as disabled people, people of colour, members of the LGBTQI+ community and those on low incomes.
- Develop an inquiry into accessibility and independent living during the pandemic and implement accessibility measures to support all forms of independent living including BSL/ISL interpretation with

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⁹² See TUC: https://bit.ly/3wQMFy5

⁹³ TUC, (2020), 'BME Women and Work', https://bit.ly/3wQvop3

- all public provisions, accessible online bookings for essential services such as supermarkets and more.
- Ensure COVID-19 information is available in accessible formats such as Easy read, Large print, and in BSL/ISL and in various languages.
- Ensure all essential public broadcasts and NI Assembly updates are translated into BSL and ISL. Ensure people are aware of the alternative services, volunteer programmes, and how to access them including those not able to access the internet.
- There should be intersectional strategies for future emergencies on the groups that share protected characteristics so that disabled people impacted will not be deprived of food, similar to that of a crisis zone.
- Safeguarding of volunteers and carers should be reviewed to ensure that disabled people are not put at further risk.
- Ensure personal assistants and family carers are allowed to accompany disabled people with other physical or communication support needs at any time they are in hospital.
- Inquiry into the deaths of disabled people during the pandemic.

2.8.2. Personal Independence Payment (PIP)

Northern Ireland has traditionally had a much higher proportion of people claiming disability benefits than other areas of the UK. Prior to the introduction of PIP around one in nine people in Northern Ireland (208,760 people) were in receipt of Disability Living Allowance (DLA).⁹⁴ At that time Northern Ireland had proportionately twice as many people claiming DLA compared to the rest of the UK. The latest PIP statistics available show that there were 153,680 PIP claims in payment as at February 2021⁹⁵ and of these 81,220 (53%) were paid to women.⁹⁶ Northern Ireland has a higher incidence of mental health conditions per head of the population than

⁹⁴ Northern Ireland Benefits Statistics Summary, Department for Social Development, November 2015 https://bit.lv/3gov/1k

⁹⁵ Personal Independence Payment (PIP) Experimental Statistics, Department for Communities & NISRA, February 2021, https://bit.ly/2U1ydVO

⁹⁶ Personal Independence Payment Statistics - February 2021 | Department for Communities, https://bit.ly/3vLAAsJ

GB.⁹⁷ PIP claimant statistics show that psychiatric disorders are the main disabling condition accounting for 42% of awards.⁹⁸

While there are no significant gender differences in claimant numbers for PIP (53% of PIP claims in payment were paid to women) there are implications for women if the person they care for is turned down for PIP on migration from DLA. If the person they care for loses their PIP award then they will lose their Carer's Allowance payment (although this is currently mitigated for one year). This is likely to have greater implications for women than men as statistics show that women are more likely to be carers than men (64% of carers are women)⁹⁹ and women are more likely to be in receipt of Carer's Allowance than men (69% of Carer's Allowance recipients are women).¹⁰⁰

The introduction of PIP has been controversial in Northern Ireland with many claimants reporting they have lost the benefit after inaccurate assessments carried out by private firms. The PIP assessment process has been widely criticised and labelled "demeaning and degrading" by many claimants, voluntary and community organisations as well as local politicians. Problems with the process and assessments have led to an increasing number of PIP appeals.

A written answer to an Assembly Question asked by Rachel Woods MLA in September 2020 on the number of successful PIP appeals as a percentage of all PIP appeals received highlights the rise in the numbers of successful appeals over the last number of years. The percentage of PIP appeals that were successful has risen from 0.2% in 2016/17 (PIP was introduced in June 2016), to 20% in 2017/18, 35.3% in 2018/19 and to 76.4% in 2019/20.¹⁰² This clearly points to the fact that there is something wrong with the assessment process for PIP.

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⁹⁷ Mental Health in Northern Ireland, Northern Ireland Assembly Research and Information Service, NIAR 412-16, January 2017 https://bit.ly/2Snb7sb

⁹⁸ Personal Independence Payment (PIP) Experimental Statistics, Department for Communities & NISRA, February 2021 https://bit.lv/2U1ydVO

⁹⁹ See Carers UK Facts and Figures: https://bit.ly/3gObtkM

¹⁰⁰ Benefits Statistics Summary Publication (National Statistics) - February 2021, https://bit.ly/3vOjf2j

¹⁰¹ BBC News, (2018), 'PIP: New Benefits System Demeaning and Degrading' https://bbc.in/3wQz3mx

¹⁰² AQW 6277/17-22: https://bit.ly/3qPH9GH

The Covid-19 pandemic has had an impact on the PIP process particularly in relation to the appeals process which is having the effect of delaying this important financial support to people with long term illnesses and disabilities. There has been a significant reduction in appeal hearings with thousands of people in Northern Ireland waiting for their appeal to be heard due to a backlog caused by the crisis. Between March and July 2020 all PIP appeals were suspended and since then Covid-19 restrictions mean that accommodation to hear appeals has been severely restricted. The delay in appeals has also meant that first time applicants appealing refusal of PIP are being excluded from Covid support payments such as the Covid-19 heating payment worth £200.

The full evidence and recommendations from the WPG COVID-19 Feminist Recovery Plan Relaunch: One Year On can be accessed here.

Thank you for taking the time to respond to the consultation.

Please submit your completed response by 17 September 2021 using the details below:

E-mail:

OrgChgDir@health-ni.gov.uk

Hard copy to:

Department of Health Future Planning Model Annex 3 Castle Buildings Stormont Belfast BT4 3SQ

 $^{^{103}}$ BBC News (November 2020), 'Coronavirus: More than 4,000 people waiting for PIP appeals in NI', $\underline{\text{https://bbc.in/35JKqRq}}$