



National Advisory Council on Women and Girls (NACWG) Satellite Wee Circle Event Report

Spotlight on Carers

Introduction

On 18 December 2019, the Health and Social Care Alliance Scotland (the ALLIANCE), Coalition of Carers in Scotland, Carers Scotland, Glasgow Council for Voluntary Services (GCVS), Carers Trust Scotland and MECOPP (Minority Ethnic Carers of People Project) jointly hosted a Satellite Wee Circle event in Glasgow to help inform and influence the work of the First Minister's National Advisory Council on Women and Girls (NACWG)¹. 18 people representing a diverse range of interests and organisations participated.

The event topic was in line with the NACWG's spotlight topic for November/December 2019: carers².

This report contains the feedback from small group and plenary discussions at the event, which were centred around the following key questions:

- In Scotland, what are the biggest equality issues for women and girls with carer responsibilities?
- In Scotland, what needs to change to improve gender equality for unpaid carers?
- What actions should the NACWG recommend to improve gender equality for carers in Scotland?

¹ <https://onescotland.org/equality-themes/advisory-council-women-girls/>

² <https://onescotland.org/tag/carers/>

In Scotland, what are the biggest equality issues for carers?

Our participants grouped their comments on key equality issues for carers under the following subheadings:

Race and Ethnicity

- Women and girls from ethnic minority communities are likely to be expected to undertake caring roles. BME people report that these expectations are as likely to come from social work professionals as members of the community.
- BME women/girls face triple disadvantages, with multiple caring responsibilities and less access to support and work; when local carer support services are being commissioned, BME community work is not always considered to be a core service, leaving BME women and girls more vulnerable to cuts.
- There is a lack of accessible information about social care services for people from BME communities, and lack of tailored services.
- There is a lack of accessible information about social security for people from BME communities.
- In some languages there is no word for 'carer' or 'disability'; terms do not always translate easily.
- In some communities people report a sense of shame in asking for help, as caring is considered a duty.
- Generally, there is a lack of referrals for services from ethnic minority communities.

Employment and Education

- Women and girls face a double disadvantage when they are carers; women are more likely to give up work to undertake unpaid caring roles, which has long-term effects on their health, education, and access to pensions.
- The gender pay gap contributes to women being more likely to care for others than men. In the long term, this pattern can contribute to inequality in education, attainment and earning potential.
- The eligibility rules for Carers Allowance prevent carers from combining full time study with their caring responsibility, therefore reducing employment opportunities. Many carers also report that the earnings rules are overly restrictive.
- Replacement care is not always available to enable carers to retain or return to employment. There has not been the same focus or level of investment in replacement care services to enable carers to remain economically active as there has in childcare to support parents in employment

Seldom Heard Groups

- Travelling community faces similar challenges and lack of assistance.

- Young women are often expected to undertake intimate caring and/or cooking and cleaning based on gender roles.
- Rural areas have more acute problems; frequently no services in same areas. There should be an obligation on local authorities to provide specialist options within reasonable distance.

In Scotland, what needs to change to improve equality for carers?

Tailored Solutions

- Blanket approaches to help seldom work – solutions need to be tailored to specific population groups (although there can be overlap, e.g. young carer needs in rural areas).
- Local Authorities (LAs) and Scottish Government need to commit to grassroots work and commission specialised support, such as BME carer support workers, for specific minority groups. This would enable support to be provided in a culturally appropriate manner – including involvement in religious spaces and communities.
- There should be an obligation on LAs to provide specialist options within reasonable distance, e.g. In theory carers have priority access to physio; in reality very difficult to get appropriate help themselves if services are not available locally.
- All LAs should invest in replacement care and short break facilities, suited for a variety of people's needs. People should have the right to choose from a range of services and facilities, to select the one most appropriate for their needs.
- There should be a duty for LAs to provide translation and interpretation for carers for whom English is an additional language (as well as Easy Read/other accessible formats). The current reliance on telephone interpreters is not fit for purpose in many situations and can mean incorrect information is given (both to medical staff and carers). Carers from some BME communities are less likely to speak about some health issues if they are speaking to/with a translator who is of the opposite sex (e.g. sexual health, mental health). There is a need for a variety of high-quality interpreters – and more flexibility in their provision. At present, in some areas if an interpreter is 10 minutes late, a GP can cancel the appointment entirely, which can leave people in crisis, and is discriminatory if it becomes an established pattern of behaviour – disadvantaging BME people's health.
- Stronger efforts should be made to raise awareness of carers (and available support services) in seldom heard from communities.
- More paid carers need to be recruited from ethnic minority communities.
- The Scottish Government should invest in research to increase the quality of available data on BME experiences of social care support, to better respond to the needs of people from BME communities.

- Carers for people with mental health problems are often missing out; they don't "count" as carers when the person for whom they care is in state hospital, possibly out of Local Authority – and there is currently no acknowledgement of the need for local support. More support is needed, as well as research into what their needs are, and suggested improvements (there is currently little data in this area).

Valuing Care

- Scotland's 680,000 carers need to be viewed as a priority. Typically, carers live in fear of cuts to service provision. Until Scottish Government and LAs tackle the status of social care and its public recognition, nothing will change; culture change is needed.
- There is a public perception that carers receive significant entitlements – needs challenging/correcting.

Employment and Education

- Workplaces need to commit to supportive practices for people with care responsibilities – with the public sector demonstrating best practice, as a significant employer in Scotland. Examples could include flexible working hours for carers, the right to request a move to part-time work (e.g. 4-day week), the ability to work from home if compatible with role, and the valuing of care work (paid and unpaid). Similarly, carers should have the right to take paid leave to care for people, followed by an extended period of unpaid leave without disciplinary consequences, if needed.
- Need for replacement care arrangements for carers in the workforce, alongside current childcare arrangements.
- The Scottish Government should build carer support into public procurement processes, with preference given to companies who commit to carer-friendly work practices.
- People should be better educated about care across the board – carers should be invited (and paid) to contribute to nurse and medical students' training at University, and to social work degrees.
- Local authorities should provide training/continuing professional development (CPD) for carers (paid and unpaid) on key tasks, e.g. CPR, handling, dementia support, mental health support – all at suitable times for carers.
- Need to raise awareness of unpaid care work in schools so young people can identify themselves as carers.
- Need to raise awareness in educational settings so teachers and staff can identify carers earlier.
- Need to ensure that all young people have access to carer services and opportunity to be relieved from caring duties.
- Remove the 'study' rule from carers allowance. Currently looked after children have stronger outcomes than young carers.
- Review the earnings rule for Carers Allowance.

Consultation, Participation, Representation

- Currently carers report that there is over-consultation without change, which leads to exhaustion and disengagement. Even within that environment there are voices left out. Scottish Government, LAs, and third sector groups need to think about who does not have access to conversations and who is left out. If consultations do not act, then they risk devaluing people's voices and time.

- Action following consultations, and meaningful engagement with minority communities on an ongoing basis – which, in turn, helps trust. Feedback is essential – if something isn't being done, don't just hide it, continue to inform people. Participation is key.
- There is a lack of carers involved in locality planning. Current representation on Integration Joint Boards (IJBs) is inadequate, information on how to contact said reps, carers reps' voting rights or lack thereof, and structural organisation. Even the basics of meetings times are often problematic (9am starts to meetings), and do not accommodate carer responsibilities. Travel costs are reimbursed (typically 30 days after the fact); why can a) these not be paid for in advance, and b) not include an honorarium for time committed? As it is many IJB carer representatives lose income to attend and contribute, unlike any other people attending (for whom it is part of their job).
- There needs to be carer input into social security planning – there is currently a dearth of meaningful engagement in this area (although the Experience panels demonstrate good practice in terms of carer representation).
- Equality impact assessments (EQIAs) need to be meaningfully embedded in professional practice at all levels. Currently there can be an expectation that women/girls with family members in need of care will provide it, irrespective of employment, with no consideration of EQIAs. Need to enshrine EQIAs in professional practice and challenge assumptions about appropriate levels of support for carers.

Integrated Health and Social Care

- Target culture in NHS compounds problems with care and needs to change to fully acknowledge the impact on integrated services. Complex needs can be hard to accommodate; some services are reported to opt to discharge patients without any further direction on where to seek help if they are too complicated – especially if they are under pressure with waiting list targets.
- Public service bureaucracy and connection of services can be hugely variable (and stressful), as can variance of GP support – with ensuing impact on outcomes for carers and the people for whom they care. There needs to be greater consistence of service provision.
- There needs to be better communication between public service bodies in Scotland and the rest of the UK, and accommodation of geographical division; e.g. particularly an issue for people in Dumfries and Galloway who may also receive treatment in Cumbria, or whose carers live over the border.
- Provide free glasses and dental treatment for carers (of all ages).

Finances and Processes

- Care charges should be removed across all local authorities, to prevent the current postcode lottery for disabled people and carers' household incomes.
- Five-year minimum funding models for third sector and procurement more generally would enable more continuity of services and reduce carer stress – especially with grassroots or minority population-specific groups.

- Introduce free bus passes for carers in their own right – especially impactful for women, who are more likely to use buses and have multi-stop journeys with complex care responsibilities.
- Reimburse primary care travel costs for carers (for visiting the GP to collect prescriptions, as well as attending hospital appointments). Primary care taxi fares are not reimbursed (and should be) even if fuel and bus passes are OK – which is a problem if carers do not drive and live in a rural area, or if the person for whom they care cannot use public transport for accessibility/health reasons.
- Scottish Government should commit to a fund to encourage grassroots innovation in support for both carers and disabled people/people living with long term conditions – particularly projects targeting key known problems (e.g. rural provision of social care).
- Carers centres are hugely useful – their work should be celebrated, and their funding needs to be secure and reflect the increasing demands they have faced since the inception of the Carers Act. Carers' centres should also be kept independent from LAs.
- Ensure that there is an effective and transparent complaint procedure, with consequences for breaching it, in place across Scotland. Reform the current complaints system.
- Implement the Carers Act across Scotland, with Carers Act funding being used for its intended purposes. Carers allowance: reconsider how many hours carers can work; where they can work (home); raise the earnings threshold; remove the 21-hour student rule; remove the age threshold for young carers allowance (15-18); make the application process easier for all.
- Trial paying carers basic income. Caring should not equal poverty.
- Currently there is a council tax discount for households where someone cares for a child or parent, but not if they care for their spouse. This is unfair and should be overturned, with the discount available for all households where someone receives care.

What actions should the NACWG recommend?

As well as several actions already identified above, event participants said:

- BME carers need better funded specialist services in every area.
- Young carers need earlier intervention (at primary school level), with more support given to educational institutions to identify young carers.
- The 'study' rule should be removed from Carers' Allowance to improve educational outcomes for all.
- Replacement care for carers should be given the same status as childcare.
- Carers Allowance should be fully implemented and be better funded.

Appendix 1: Event Agenda and Discussion Topics

Venue: The ALLIANCE, 349 Bath Street, Glasgow, G2 4AA

Date: 18th December 2019 (12:30 – 15:00)

Time	Action
12:30 – 13:00	Networking lunch
13:00 – 13:10	Welcome and introductions
13.10 – 13:20	About the NACWG
13.30 – 14.30	Small group discussions: <ol style="list-style-type: none">1. In Scotland, what are the biggest equality issues for women and girls with carer responsibilities?2. In Scotland, what needs to change to improve gender equality for unpaid carers?3. What actions should the NACWG recommend to improve gender equality for carers in Scotland?
14:30 – 14:55	Small group feedback followed by Q&A
14:55 – 15:00	Closing remarks and thanks

#GenerationEqual

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. The ALLIANCE has over 2,900 members including large, national support providers, small, local volunteer-led groups, and people who are disabled, living with long term conditions or providing unpaid care.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

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