

Carers Parliament Summary Report

Introduction by Judith Robertson, Chair of the Scottish Human Rights Commission

Judith introduced the day and highlighted some key issues which included the issue of gender. More carers are women and women have more expectation that they will give up their paid employment to care. Asked carers to think of one thing that would make their caring role easier.

Young Carers Festival and Film

Presentation by Abbie Christie and Becca Howe

Two young carers showed a film and presentation outlining the following key issues. NB: This film and presentation will be available for carers to view in due course (via Media Education).

- ¾ of young carers have mental health issues
- NHS need to allocate more funding to children/young people's mental health services
- Schools need to be more understanding of young carers issues/challenges
- Need systems to deal with constant change in support needs
- More funding is needed for respite breaks
- The young carers finished by posing the question: what is the one thing you can do to help young carers?

Opening contribution

Christina McKelvie, Minister for Older People and Equalities

- Began by welcoming and congratulating Abbie and Becca for their contribution and film.
- Noted that the Carers Parliament is a day for carers to “voice your experiences, your concerns about things that matter to you and of course, tell your stories.”
- Noted that a critical part of her role as a Government Minister is to listen.
 - Listening allows us to learn.
 - Listening allows us to do things better.
 - Listening allows us to think differently.
 - But in order to listen, someone has to speak.
 - So use your voice today to make your points, tell your stories and influence others. Make people listen.
- Recognised the diversity of carers and caring but also that carers share a lot of commonality too: putting other people first, always being on call, not having time for leisure and social activities, juggling care with other responsibilities and that being a carer can have a huge impact on education, career, social life and even own health.

- Noted a group of young carers visiting her at Parliament and talking about some really important issues including access to support through local young carer groups, access to sport and leisure facilities and the consistency of awareness and support on offer in schools. Noted Scottish Government are funding an education worker with Carers Trust Scotland to develop resources and improve awareness, identification and support for young carers in schools. Noted the Young Scot card and signing up to get the benefits from that.
- Discussed social isolation and loneliness and how it impacts on carers. Recognise that social isolation and loneliness is an issue for many people in Scotland so last December we published our first national strategy, “A Connected Scotland”, which aims to tackle these issues and promote social connections. There is a Ministerial Steering Group, which includes the Ministers for Children and Young People; Local Government, Housing and Planning; Business, Fair Work and Skills; and Mental Health. Noted that this is a cross government issue. Also established A National Implementation Group, which will develop a delivery plan, look at funding, and strengthening communications around this agenda.
- Carers have to, at some point, juggle work. There are approximately 270,000 carers in Scotland who combine employment and unpaid care. This represents around 1 in 8 of the workforce. Estimated that carers leaving employment cost the UK public purse £2.9 billion a year in welfare payments and lost tax revenue. Losing valuable employees with specific skills and experience is damaging to an organisation. Losing carers from an already shrinking workforce is a concern for the wider economy.
- Knows that with Scotland’s quickly ageing population, these numbers are only likely to grow. Need to acknowledge the reality that most people will be carers at some stage in their working lives. It is now vitally important that our workplaces are inclusive environments so that carers can take up or maintain meaningful employment alongside their caring responsibilities.
- Caring disproportionately effects working age women in their late 40’s and early 50’s. Women giving up work to care, or not taking up promotion because of the existing pressures of caring, contributes towards Scotland’s gender pay gap. Working for a fairer Scotland for woman through a range of actions in our Gender Pay Gap Action Plan published in March. Knows that flexible working and thinking about job design are crucially important to those who have caring responsibilities. Action plan includes the commitment to encourage employers to normalise flexibility for all employees and to recognise that these types of adjustments are reasonable and a necessary part of creating a fairer Scotland.
- Continue to fund Family Friendly Working Partnership to support and promote the development of flexible workplaces to employers, and this year we are funding a feasibility study for a ‘Centre for Flexible Work’ for Scotland. This Centre, a UK first, would design, test, embed and scale new approaches to increase the availability of quality, flexible work in Scotland. Believes that part of ensuring carers remain connected and have good wellbeing, is to support them to balance work and caring if that is what they want. Through our Fair Work agenda working to embed fair work within and across Scottish workplaces to achieve the aim for Scotland to be a world-leading Fair Work nation by 2025.
- Recognises the Carer Positive accreditation scheme developed on behalf of the Scottish Government and administered by Carers Scotland since 2014. With Carers Scotland are working hard to both increase awareness of the scheme and increase the number of employers signed up.

Framing the Debate

Joe Fitzpatrick MSP, Minister for Public Health, Sport and Wellbeing

- Introduced the debate and thanked previous speakers. On note of diversity, pleased to read the motion for today, which acknowledges and celebrates the uniqueness of each caring situation. There are estimated to be around 680,000 carers in Scotland. In a country where we value multi-culturalism and strive for social justice, it would be a big mistake to assume all carers have the same challenges, opinions, identities and experiences. However, there are also many things that unite us and having an opportunity like today to share and learn from people's diverse experiences is of huge value.
- **Carers Act:** important that the system in place for supporting carers recognises and is responsive to this range of circumstances. The Carers Act, now been in effect for a year and a half, takes the approach of personalisation and prevention. Support at an earlier stage results in better outcomes for all. This includes through involvement in decisions, access to information and advice, and participation in effective conversations.
- **Reform of adult social care:** noted that carers also have rights to choice and control over how statutory support is provided. Self-directed approaches must be at the heart of current practice and future thinking. Knows that our system needs to change if it is to stay fit for purpose. That is why a national programme to support local reform of adult social care was launched. Its aim is to ensure a high quality and sustainable social care sector both now and in the future. Noted that this requires partnership and welcomed presence of Alison Evison President of COSLA who is here to contribute to today's debate. Given that the duties under the Carers Act sit at local level and our reform programme is one that requires partnership, it is essential that we work together. Hearing from you today will play a role in shaping our evolving national priorities.
- **Social Security:** Recognises that social security is a human right and are creating a system based on dignity, fairness and respect. Wants to ensure Scottish social security is accessible to all. Charter is available in eight languages as well as Braille, audio and large print. It sets out what people should expect from the system. This includes our commitment to treating everyone equally and fairly, without discrimination, and offering services in a way which works for them, in places that are convenient and accessible. This includes home visits if appropriate. Social Security Scotland recently celebrated its first birthday and since September last year, seven benefits have been introduced and paid out, including Carer's Allowance Supplement. Working with carers and stakeholders to consider longer term changes to Carer's Allowance. More improvements afoot. Government has considered evidence on the impact of caring for more than one disabled child and will introduce additional financial support for these carers by spring 2021. Pleased to open applications for brand new Young Carer Grant. We want young carers to be able to access opportunities that are the norm for many other young people.

Carers contributions to the debate

Steyc Yghemonos – Euro Carers

- Euro carers will relay what is said today to wider audience
- Policy environment in Scotland is the best in Europe
- Carers Parliament is example of good practice – want to learn and replicate model through Europe

Carer – PASDA

- Carers Act being discussed – all carers to be recognised and have same outcomes
- Austerity has hit carers hard
- Local authorities can only respond when they have funds
- Where needs are not being met – should be recorded. This should be made compulsory.
- COSLA would not operate this – minister said he would not include requirement in Bill but would be included in papers behind Act

Carer - HSCP North Ayrshire

- Needs to be requirement to spend the money of Carers Act as it was intended
- Plugging respite funding

Carer - Glasgow

- Battle for services
- Parent for a disabled child
- 3 and a half year battle to access SDS for daughter
- Concerned over possible Brexit impact on medication access
- Made homeless
- Emotional turmoil
- Constant fight

Carer - Ayrshire

- Funds to local authorities and health boards need to be ring-fenced
- Exhausted after caring for 20 years
- How many carers now have long term conditions as result of caring role?

Carer – East Kilbride

- Parent Carer
- Out of work teacher as gave up work to be a carer
- Fighting for services and support
- SDS fight
- Lost Carers Allowance for taking up part-time role although caring same amount of hours
- Mental health improved through work

Carer – Borders

- Multiple caring roles
- No benefits and support
- Told behavioural issues
- Son has Asperger's
- Bullied, threatened and lied to
- Had to go private with health service to get diagnosis
- Fighting the systems with everything
- Nobody listens

Carer - Tiree

- Parent carer for autistic daughter
- Package of support when moved to Tiree, didn't follow with them
- Forced to place autistic daughter in a facility
- Fight for everything
- Got SDS eventually, but live on an island and there are no services
- When daughter comes home, the lady has to give up work and receives no benefit
- System is failing

Carer - North Ayrshire

- Ring-fence Carers Act money in local authorities
- Mental health problems due to caring role?

Carer – Midlothian

- People with severe learning difficulties cannot earn money, but having huge amounts taken off them by local authorities e.g. contributions towards taxis, child costs carer by breaking things. Benefits are being used on care charges. This is not acceptable
- Local authorities need to provide for people in this position – NOT take funding away from vulnerable
- They deserve a life of their own (daughter with learning difficulties)

Carer – Royal Bank of Scotland

- Support to keep working carers in work
- Helping carers back into work without negative financial impacts – better off in work
- Work can be good for mental health and isolation
- Employment support for carers: how to get carers back into work and not suffer financially.

Scottish Young Carers Festival Media ambassador - Auchterarder

- At age 16 young adult carer
- Only one support worker in my carers service, they have left and now there is no one
- Support, respite lessened after became 16. Difficulties dealing with family situations and worsening mental health – no support
- What could you do to change this?

Carer - Perth & Kinross

- 36 yrs. old autistic son in residential home as couldn't be cared for in community. Suffered abuse at residential home in Dundee. Police intervened but decided son wasn't reliable witness. Plans for a special unit but now plans pulled. She moved house to Invergowrie to support him but now doesn't know where son will be placed. Not being listened to – human rights being breached

Young adult carer

- Cares for mum and sister
- Young people not entitled to Young Carer Grant because mum has been refused PIP

Parent carer

- Daughter in mainstream education
- Gave up role as senior position in NHS and own business
- Made to close business and make people unemployed
- Shouldn't come to crisis to be heard
- People forced into residential care

Carer - Stirling Council area

- Parent carer
- Good experience with work and how they were treated
- Needed 2 people to look after my daughter
- Intensive care and at home
- Had to give up work as wasn't getting the support and additional care they required
- Wants to go back to work
- Social work told that it's not their role to provide childcare!

Carer – Renfrewshire

- Parent carer
- Renfrewshire carers been an excellent support
- No budget for son and had to battle for SDS package
- Lifelong payment of those and caring for 2 adult children

Carer – Edinburgh

- Parent carer of primary school child with an invisible disability
- Have no choice
- Also carer for dad
- My kids don't have a childhood
- Should never have to get to a point of crisis for support
- Get to a point of resenting caring role
- Need cultural appropriate support

Young Carer – Aberdeen City

- Young carer – ASL listing in school and should be getting picked up
- Young carers are not being identified
- Young carers are not being recorded
- Sibling carers are not being recognised

Carer - Hub Project Glasgow

- Parent carers: community to help each other
- Urging Scottish Government to recognise carers for someone who are not receiving a disability benefit
- Childcare etc
- Information of how to access support
- Black minority, ethnic groups face additional charges

Carer – Aberdeen

- Recognising carers are still carers even when the cared for person goes into a facility/care home
- You don't stop being a carer
- Former carer term should be abolished
- Where is the care for former carers?
- Carers own health suffers

Carer – Edinburgh

- Parent carer for son
- CPG carers focus on transitions
- Community carer is decimated
- Young people need to be valued
- SG ask for a safety net
- If changing or reviewing support, you lose your existing benefit
- Pension provision for carers
- Proper financial support

Carer – Falkirk

- Parent carer
- Mad fight CAHMS, Education, Barnardo's etc
- Promised the world and nothing came from it
- I had to get a video camera to record my son having a seizure to prove he had epilepsy
- Funding ceased for transport support to let daughter go to young carer services

Carer – North Ayrshire

- How come it takes so long to get a CSP written and get the support needed?
- I got approved SDS but still waiting on the finance coming through

Carer - Clackmannanshire

- Not getting the support needed
- Carers assessment given but what was offered was not what was needed
- Need help at home and was only offered respite – cared for person banned from all the respite services
- How can someone with no qualification overturn a medical professional?

Carer – East Lothian

- £123 per week earnings threshold needs to be changed – cannot work

Carer

- Cared for 22 years for daughter – fight, violation, is there any privacy? – daughter needs 2 to 1 but happy to leave her with 1 person in charge
- Legal battle – in education provision, she was restrained, beaten. As carer there are additional costs
- Works full time for Scottish Ambulance but will fight to have justice for abuse

Responding to the debate: COSLA and the Scottish Government

Alison Evison, COSLA President: response to debate

- Represents 32 local authorities
- Here to listen
- Personal experience – mother and carer for father
- Can't give lots of answers today but will take them forward
- Commit to work with participants to cooperate, not fight
- Local Government is suffering austerity
- Care experience is unique but equally important right to supportive conversations
- Personalised support: everyone has a right to a conversation to support their care – a personalised plan
- Local area carer strategies important and there is a duty to involve carer reps in strategic planning. Local authorities have key role, carers strategies set out support
- Autism strategy with input from families: needs to be more supportive/effective.
- Must be a sustainable system
- Need more local decision making – creative solutions for funding efficiency
- Need to work with public and third sector partners
- Carry on working together with Scottish government and NCO's
- Challenges in rural areas
- Need to share proactive where things are working well
- Easier access to service – single point of contact. Reduce bureaucracy
- Social care charging
- Reform of social care programme: New models of care
- Young carers – they have challenged us today
- Teachers/school staff working to increase awareness of young carers needs
- Focus on the mental health of young carers – young carers past age of 16
- Lots more to do – essential services
- Committed to ensuring that carers are aware of rights – support available
- COSLA committed to proving support that is needed

Joe Fitzpatrick MSP, Scottish Government response to the debate

- Difficult to hear some of the stories today
- Shouldn't have to battle for services.

- Importance of mental health discussions and issues brought up
- Unmet need recording – should be in strategy.
- Extreme pressure – Carers Act – right for all carers.
- Updated implementation plan
- ACSP timescales – reasonable prioritised timescales – most urgent cases
- Ring fencing the funding – balance between national direction and local decision making – asking for more transparency
- Charges for non-residential social care will be scrapped. Charging social care – carers can't be charged for carer support
- Those who are battling – engage your local MSP
- Accessing support for cared for person including access to advocacy for individuals and carers.
- Carers Act provides a right for all carers – urge everyone to access that.
- Loss of Carers Allowance due to part time jobs – looking to change that once it comes over fully to Social Security Scotland admin. Currently carers allowance managed by DWP – look at doing better in Scotland. Noted criteria for young carer grant and noted that PIP is not yet administered by Social Security Scotland.
- Employment recognises skills, experiences carers can offer
- Importance of respite to prevent burn out
- Encouraged to visit the engagement zone today
Everybody's situation is different. Person centred – tailored to need. Treat with respect and humanity. Be mindful of invisible disabilities.
- Young Carers – more talk about mental health – important to talk about it. Dedicated minister
- Carer Positive – Employer understanding of challenges carers have
- Commended Young Scot for their programme
- Voices all been heard today

Key issues from workshops and engagement zone

Adult social care reform

It came through strongly from participants that:

- social care does not have the value placed upon it that it should and more investment is needed
- the Scottish Government could do more. Good policies are in place, such as self-directed support and integration but they are not working consistently and there are still blocks in place.
- ring fencing should be considered to ensure that legislation is implemented both consistently and as intended and recognition is needed of the gaps that currently exist e.g. for support in rural carers and the anxieties about staffing when Brexit happens
- real partnership and trust is needed – from carers having a real voice and being valued on integrated joint boards, to trusting people to know and choose what **they** need using their SDS budgets; giving real choice and control.

Women and Caring

It came through strongly from participants that:

- the expectation that women will be the main caregivers is still entrenched and needs to be challenged at all levels.
- support for carers to remain in employment is critical and more is needed to embed this into current policy and practice, including the fair work agenda.

- there needs to be more support to enable carers to enter further education and the social security system should support this and not be the current barrier. This is also a part of enabling carers to return to employment following/alongside their caring role.
- More work is needed to address the health and wellbeing of carers, including social isolation. This could be done in a more consistent way, for example, offering health checks to carers.

Human Rights and Carers

It came through strongly from participants that the following rights were really important for carers:

- the right to information – to support their caring role and information on both their rights as carers and their human rights.
- the right to family life and services that support this
- the right of assembly: to have access to carers groups/carers parliament etc and support to attend these
- the right of social security: a decent income
- the rights to work
- the right to participate in cultural rights and arts
- the right to rest and leisure

There is a need for transparent and simple ways to complain if these rights are not being realised. There is also a need for accountability to ensure carers rights and human rights are being delivered and consequences if they are not.

“Caring and You”: for families with disabled children and young people

It came through strongly from participants that:

- There is a real diversity of experience in information provision. Most participants said that when it came to being aware of their rights as carers there was consensus that most information is gleaned from other parents/carers. Lack of information remains a significant barrier.
- With regards to Adult Carer Support Plans, there is some confusion regarding where these sit with regards to the previously existing Carers Assessments. Furthermore, there is some fear that if approaching a local authority for a re-assessment of needs as a carer, a support plan which was previously agreed might actually be reduced.
- Carers involvement in discharge planning is inconsistent. Experiences included staff having no idea when a discharge will happen and then family members being discharged with nothing in place and a lack of consultation on palliative care package. Some insisted on care package being in place before their child was discharged.
- Access to breaks is not easy. Some participants did not know how to get a break and others spoke of inappropriate breaks in care homes for children. Some carers have had no break for years and only are able to have any sort of break without the support of family. There is a need for much better access to activities like summer playschemes etc to support families.
- Comments in the discussion highlighted the lack of co-production and working with carers/parents as equal partners, the need for more staff training and the lack of accountability for decisions at all levels.

Short Breaks

It came through strongly from participants that:

- Carers have a budget there but no one to provide the provisions
- A lot of respite centres provide mental health, not physical health. There is a lack of choice available

- Carers know what they want/need but when asking for it – told no
- Social workers are not clear on what a short break is

Through discussion it is clear individuals need very different provisions – some want/can't go away with the ones they care for. Others cannot, but getting away causes stress at thought of individual going into e.g. care home

- Point was raised whether carers could cut out social services and go direct to charity or trusted person to access funding on a local level
- Point raised as to whether social workers have the capacity to horizon scan and understand changing policy

Food and the person you care for

It came through strongly from the discussion with participants that:

- There needs to be more recognition of the issues of malnutrition, its causes and impacts and support for carers in food and the person they care for.
- Examples such as Food Train are supportive and the value of this should not be underestimated but it is not available in all areas.
- The wider impact of food schemes needs to be valued and supported including the befriending aspect in reducing social isolation and loneliness.
- The costs of malnutrition are very significant – nearly £20b. Investing in ways to reduce malnutrition and ensuring that people have access to healthy nutritious meals could save the NHS significant sums and improve outcomes for people.

Housing, care and carers

Participants heard from Housing Options Scotland and discussed housing in Scotland for people with additional needs and considered what might help improve availability:

- There are different models of housing that might support people better but are not necessarily being considered locally or nationally.
- Developments across all tenures needed
- Housing also needs to consider issues such as extra rooms for a carer or family member to stay over, additional space for equipment etc. but is the right housing being built to respond to this?
- More options for conversation need to be identified
- There are different approaches by different local authorities so no consistent picture.
- Lack of support from local authorities in terms of planning around housing
- Housing is just part of the picture of an ideal home. When planning should consider: social networks, gardens, accessibility to community.

Carers voices

This workshop discussed getting carers' voices heard, coproduction and engagement. Issues raised by participants include:

- That experts listen to carers when they are talking about the person they care for. when No point in having a 'what matters to me' if nobody reads it
- Fairness – let what is in practice be as good as is promised in policy and legislation

- That the reality is the same as the published information
- Action as a result of discussions - follow up on things and turn conversations into action
- Be more pro-active in listening and acting to help and support carers. Need to say and show that they care.
- Being listened to and supported in school or college. Need to have an understanding of carers' circumstances, listen and make the changes that are needed to support young carers.

Engagement Zone

The engagement zone provided a space for carers to highlight key elements of what a good service was and wasn't and to identify good practice and what needs to change.

Carers highlighted what is needed to make services and support more positive and their lives easier:

- not having to expend precious time and energy in fighting for support.
- getting the right support at the right time
- that professionals/services listen, are honest, understanding, do not judge and make carers feel cared for.
- ask about the carer themselves: how are they feeling and what can be done to lighten the load and support their health and wellbeing e.g. practical support, mental health support, time off
- get transitions right and start early
- that there is accountability
- for professionals to understand that the person cared for is not just the sum of their illnesses and conditions.

Further information

There are fuller notes from each workshop, a more detailed transcript of the debate and a range of films from the day available on the Carers Scotland website at www.carerscotland.org