

Carers Parliament 2018

Evaluation

141 carers attended the event, 41 of whom were young carers or young adult carers. 68 delegates took part in the evaluation survey of Carers Parliament 2019, 65% of whom were adult carers and 2% of which were young carers or young adult carers. The remaining responses came from observers, facilitators and stallholders.

Morning Session

The morning session was a debate. This was chaired by Paul Gray, Chief Executive of NHS Scotland/Director General of Health and Social Care (Scottish Government).

The debate was opened by the Minister for Public Health and Sport, Joe Fitzpatrick MSP followed by contributions by carers. John Woods from COSLA and the Minister then had the opportunity to sum up and respond to the issues raised by carers in the debate.

We asked delegates to rate the morning session. **83% said that this was excellent or good.** On the debate itself, **82% said the time set aside was about right**, although 11% said it was too short.

Some respondents also made comments, below are a selection of these.

“Having a timer was a great idea as it stopped people from dominating the debate. It provided a great platform to hear the different experiences of carers across the country.”

“I felt that the statements made were all very concise and constructive, The chair did an excellent job of keeping things moving at a good pace, but also reviewing and making people feel heard.”

“The debate was very interesting and I really enjoyed it. The chair was brilliant and fabulous at keeping people to time and being involved.”

“A lot of good, healthy and important discussions emerged from the debate. Hopefully a lot of these will be actioned.”

“Great to hear so many carers reflecting the complexity of carers' situations.”

“The young carers were really impressive.”

“I appreciated the age differences in the room, different life stories/experiences. A good choice when it comes to the room as the arrangement. I liked that the event included different professions.”

“Well planned, well chaired, and carers' voices loud and clear. Also good integration of young carers voices in the whole debate.”

“It was really valuable hearing the experiences of carer and young carers. I think the Carer Parliament is a great initiative for reaching out to groups who often aren't heard/listened to in the health and social care system. Also, Paul Gray was a great chair and the fact that the NHS Chief Exec facilitates this debate, shows a good level of commitment to supporting carers to live better.”

“Joe Fitzpatrick was very engaging. The debate went really well, the timer was a good idea and provided opportunity for focussed discussion.”

Suggestions for the future included:

- More structure for debate e.g. 3 different questions
- Inclusion of education
- Time for COSLA and Minister to prepare responses e.g. a short coffee break.

Lunch time

Delegates had the opportunity to watch films about caring and organisations to support carers over lunch time, visit information stalls from a range of organisations and record messages about the future. **37% viewed the films, 88% visited the stalls and 15% recorded a message.** Some carers added comments, below are a selection:

“It seemed like a good idea to have interactive options., and it is always good to have a chance of talking with people.”

“The lunch break was way too short. There was not enough time to be able to catch up with everything above. However, I really appreciated the initiatives.”

“I visited the gardens which was most enjoyable and the fresh air was welcome after the morning spent in a lecture theatre. It also gave me the opportunity to network”

“The film was great from young carers and I recorded a message”

Suggestions for the future included:

- More stalls
- More seating over lunch time
- Stalls or representation from each local authority/partnership to showcase what they are doing.

Afternoon Session

The afternoon session included a presentation from young carers, two carers interviewing one another, followed by workshops and a presentation by the Cabinet Secretary for Social Security, Shirley Anne Somerville MSP. We asked delegates to rate each element.

Young Carer Festival feedback and film

Young carers fed back about the young carer festival, showing films and talking about the experience of the young carers festival. **98% rated this as excellent or good.** Comments included:

“It was an extremely courageous session for those who took part. Those who spoke to camera were equally courageous. The camp is a fantastic idea. It is such a shame that we cannot provide this for all young carers who would like to attend such an event. The immediate impact of the session was

obvious, can we capture this and be transformational in respect of assistance to young carers in the future?"

"Although scripted, the young carers were confident and unfazed to speak in front of such an audience. It was great to see the work being done with these young carers in that part of Scotland. It would be good to have more young carers over Scotland involved."

"Amazing as an adult carer finding out the problems young and young adult carers have. A wonderful presentation."

Carers Interview

A young adult carer and adult carer interviewed each other about their experiences of caring. **95% rated this as excellent or good.** Comments included:

"Both had clear and strong emotional attachment to their experiences. There was an appropriate level of humour that offset nicely what could have resulted in a level of despondency. Both were engaging and spoke well."

I love this part. Both carers were honest and funny. The adult carer brought about information that will be of use and it was emotional to listen to the young carer.

"This was a great section and insight into the similarities of their experiences. I found it touching and was tearful"

"This was a fantastic session and definitely one to repeat in the future"

"One of the highlights for me They were both wonderful and have to be admired for their efforts to help carers"

"This was amazing and cannot thank both ladies enough for this emotive and inspiring part of the day."

Suggestions for the future included:

- A carer interviewing an MSP or Chief Executive about policies and practices

Workshops

A range of workshops were held. **70% rated this as excellent or good.** Below are the details of the workshops and proportion of respondents to the evaluation who attended each.

- Dignity and Respect: how can social security deliver better outcomes for carers and those they care for (31.03%)
- Healthy Communities: how can integration and primary care deliver better health and wellbeing for carers (24.14%)
- Improving futures: support for young carers and the Young Scot card (12.07%)
- Equal Recognition: a fairer deal for older carers (6.90%)
- Making it Work: employment and employability for carers and young adult carers (12.07%)
- And the Rest: innovating and offering better breaks for carers (6.90%)
- Consultation on the Young Carer Grant (3.45%)
- Tour of the Gardens (3.45%)

65% said that the time set aside for the workshops was about right but 29% said that the time available was too short.

Social Security

The Cabinet Secretary for Social Security made a keynote speech to the Carers Parliament followed by a short question and answer session. **71% rated this as excellent or good.** Comments included:

“It was good to hear Ms Somerville speak about the changes she has made and hopes to achieve. I hope that she will be able to take on board the comments and debates that happened throughout the day and that we will be updated on this.”

“I was really impressed that she had done her research prior to the meeting as this is not always the case. I thought her presentation was very clear and concise.”

“She gave a very eloquent speech on the achievements and plans of the government. This was reflected in that there were so few questions asked, and of those asked, she could give an appropriate answer.”

Suggestion for the future included:

- The Cabinet Secretary being able to speak to carers and young carers informally, if possible to spend more of the day at the Carers Parliament.
- Carers being able to send in questions in advance.

Afternoon session overall

We asked delegates to rate the afternoon session overall. **87% said it was excellent or good.**

Chairing

As noted earlier, the Carers Parliament was chaired by Paul Gray, Chief Executive of NHS Scotland and Director General of Health and Social Care at the Scottish Government. **97% rated his chairing and contribution to the day as excellent or good.** Comments included:

“Paul was a great chair and obviously “got it” in terms of the issues that carers experience.”

“Set a gentle and encouraging tone without letting a few people in the audience dominate the debate. I thought he was pretty responsive and sympathetic to some of the thornier issues that came up. Kept mostly to time.”

“I thought Paul Gray set the tone perfectly and also got the balance just right”

“Noted genuine empathy to my challenging point in debate”

“He seemed formal/professional and informal/human! Structured and funny.”

“He came over as a very caring gentleman who cared about the carers and the NHS. He appeared to value the contribution.”

One suggestion for the future came from these comments which reflected the value of Paul’s contribution and role in the NHS.

“If I'm honest I really would have liked him to speak more about what the NHS is currently doing and be a bit more in depth about facts, figures.... More in line with the style of Shirley-Anne's presentations.”

Venue

We asked delegates about their views on the venue. **68% said it was excellent or good.** Some parts of the venue were viewed positively but accessibility and seating for lunch were raised as issues. Comments included:

“The dining area was too small.”

“Not easy to get to apart from by taxi.”

“Finding it to start with was hard but inside was great.”

“Needed more space for lunch and opportunities to sit down and talk.”

“The auditorium was great but not enough room for delegates at lunch.”

“The venue was amazing however there was not much space for lunch time, for people to sit down to have their lunch.”

“I liked the room where we had the debate and where the speeches were held.”

“Difficult to get to. Would be better to have a more central venue nearer to main train stations in Edinburgh or Glasgow.”

Catering

We asked delegates about their views on the catering. **62% said it was excellent or good.** However, comments reflected issues including the fact that food had arrived late and caterers had not, as requested, adequately labelled food or special diets.

Final Comments

Finally we asked delegates for comments and suggestion for the future:

“Would love to attend again. I got a lot out of the day. I would say there needed to be more local events and possibly a better suited space for all to get to. Transportation to and from events could be an option to allow others to attend. Updates about the day would be helpful and newsletters or emails about carers and the carer Parliament would be great.”

“The venue was good and I would definitely like to be able to attend again. Because I had to make special arrangements for care for my wife I couldn't travel the day before consequently leaving home at 06.15am on the day of the parliament to ensure I arrived in time. My caring concern is mainly to do with Multiple Sclerosis and it might be worthwhile if it could be arranged for stands from the various charities, not just for MS but possibly from the areas of Cancer, Heart Disease etc.”

“Ministers for children to come along. Parent carers felt under-represented in the panel discussions. We have different issues that need to be explored too.”

“I just want to congratulate you for organizing this great event and also thank you very much for giving delegates from other countries the opportunity of taking part in it. We have already organized one Carers Parliament in Finland that was very much inspired by your model. Warmest thanks from Finland to Scotland!”

“My first Carers Parliament and thought it was an excellent event and would definitely be interested in attending future events. It was great to see the level of engagement from the Scottish Government and great to have input from Ministers at the event. Definitely more of this please. One thing that

would be good to see would be a piece from a Carers Centre and an employer (maybe one that has reached the Exemplary Level of Carer Positive) to highlight "What good looks like".

"A welcome area for individual carers, who may arrive knowing no-one else there, would make it easier for them to meet up with other carers, which is a nice aspect of the day."

"Would only be interested in attending future events if there is to be clear output. There needs to be genuine opportunity to make a difference and not just an opportunity to 'relieve blood pressure/get things off your chest'. The high level of Scottish Govt officials and politicians involved in the day suggests clear desire to improve and develop the support given to carers and to hear the voice and opinions of carers."

"Have education there for parents. 26 percent of children in Scotland have additional support needs and parents are struggling. Please help."

"Would really like to hear from different areas what they're doing and comparing notes"

"I found the day to be very emotional and great to be with people who are going through the same issues as me. Has given me a new focus to try and influence my employer to support carers already working and think of ways to support others trying to get employment. It does seem a missed opportunity to hear from our European carers about best practice from throughout Europe. Given the debate about supporting new carers perhaps this is a specific topic that needs covered."

"Would like to see it in West for a change, or it would be helpful if 2 from an area could travel together. Would certainly like to see it being given more PUBLICITY, i have not seen anything about this years anywhere How about inviting Press."

"Would be interested in attending again, would be good to have an initial briefing as to what happened as a result of previous year or has all the talk been merely a tick box exercise"

Further information

Films and workshop notes, and a profile of delegates attending are available at www.carerscotland.org

Carers Parliament 2018

Profile of Carers

Carers, young carers and young adult carers from across Scotland attended the event. Alongside these, observers from a range of voluntary organisations and Scottish Government departments attended to listen to carers experiences and take these messages back to their respective organisations.

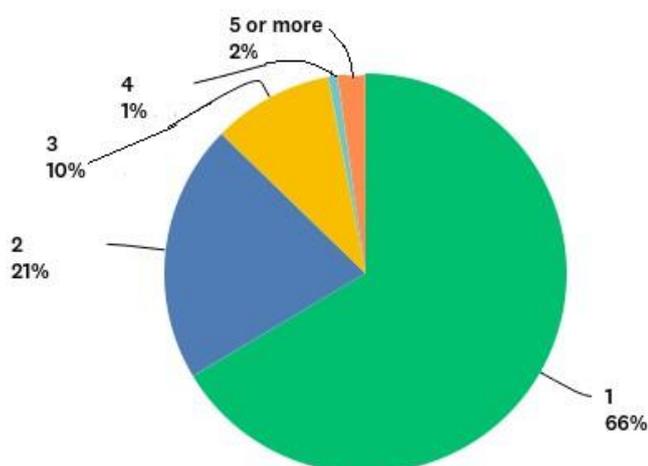
Carers attending included carer representatives from integrated joint boards/health and social care partnerships. We also asked carers what local groups they were represented on to have a picture as to how carers were involved locally and could take information back to their respective areas (and feed in to the Carers Parliament from these groups). Two thirds were involved in local bodies – from carers centres to carers strategy groups.

- A health and social care partnerships/integrated joint board - 18.88%
- On a local carers strategy group - 11.19%
- On a local NHS public partnership group - 2.80%
- A local carers forum 29.37%
- On a carers centre board or management committee - 7.69%
- On a voluntary organisation's board or management committee - 13.99%
- On another group - 14.69%

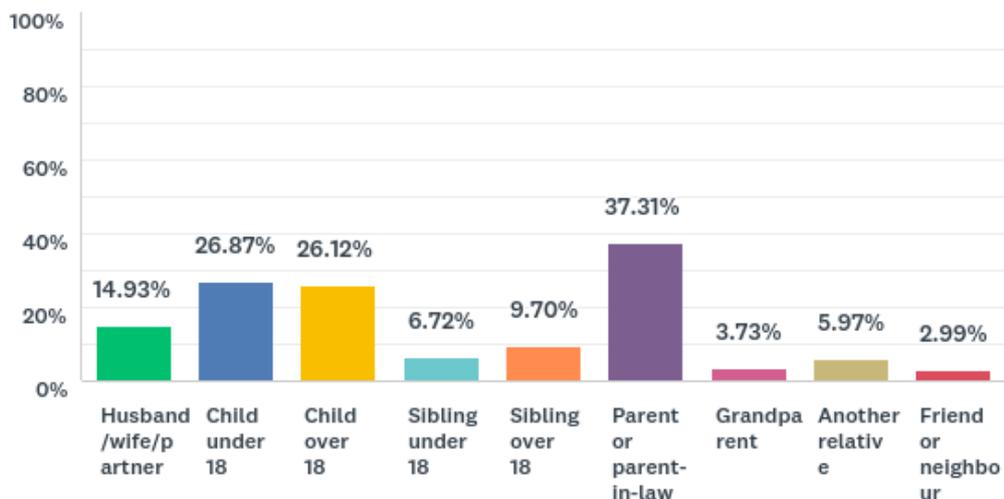
About delegates' caring role

Those attending had a wide range of caring roles and the following is a summary of the profile of those who attended.

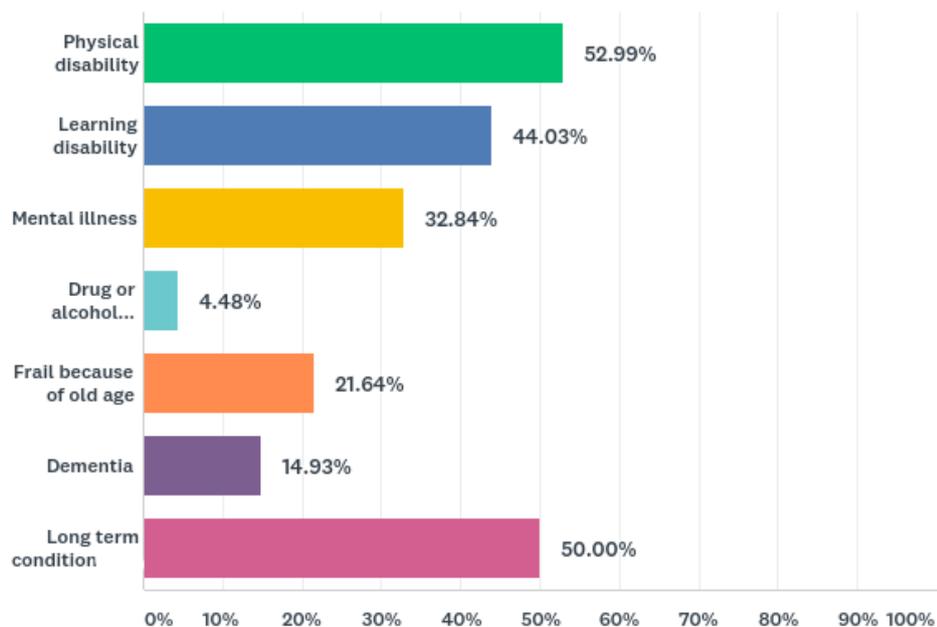
We asked carers attending how many people they provide (or provided for former carers) unpaid care for.



We then asked who carers are providing care for. The largest proportion were caring for a child, be that under 18 or over 18, followed by parents and parents in law and then spouse/partners.



Carers provided care for people with a wide range of conditions. We asked carers to provide information of this (they could choose more than one option). Some people who are cared for have more than one or multiple conditions, reflecting the complexity of carers lives.



Most carers attending had been caring for many years.

- 23% had been caring for 20 years or more

- 12% between 15 and 19 years
- 23% between 10 and 14 years
- 25% between 5 and 9 years
- 7% between 1 and 2 years

No one attending had been caring for less than a year.

Demographic profile

We asked carers to tell us a bit about themselves, including age, gender, ethnicity and whether or not they themselves also had a disability or long term condition. Not all young carers filled in this section so the percentage of young carers attending was higher than stated below. (A total of 41 young carers and young adult carers attended.)

Age

- | | |
|-----------------|-----|
| • 17 or younger | 10% |
| • 18-20 | 5% |
| • 21-29 | 6% |
| • 30-39 | 11% |
| • 40-49 | 16% |
| • 50-59 | 28% |
| • 60-69 | 17% |
| • 70-79 | 7% |
| • 80 or over | 1% |

Gender

There were significantly more females (82%) than males (17%) attending, with 1% of carers attending stating that they were transgender.

Sexuality

77% of those attending stated that they were heterosexual, 2% lesbian and 3% bisexual. 17% preferred not to say.

Ethnicity

The majority (93.5%) of those who attended were white, with 85% of those white Scottish, 5% white English, 7% white British and 2% white Irish.

5% of those who attended were Scottish or British Pakistani and 1.5% were of mixed ethnicity.

Disability or Long Term Condition

36% of carers attending have a disability or long term condition.



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