

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 by Christina McKelvie, Minister for Older People and Equalities

It's an absolute pleasure to be here today to open the 7th Carer's Parliament.

I can't go any further without thanking Judith for her introduction and to acknowledge that big events like these are a challenge to organise so thanks to everyone involved for making it happen.

It's a delight to be in the Central Hall, here in Tollcross.

Tollcross is a historic, ancient part of Edinburgh and once you cross the threshold of this unassuming building you enter an airy, welcoming space, designed to bring people together.

Central Hall was designed and built by a pair of Scottish architects called Dunn & Findlay in 1901.

They also built the iconic Scotsman Buildings on Edinburgh's High Street, which I'm sure you'll have all seen when looking up at the Castle and the Royal Mile from Princes Street!

Dunn & Findlay left a legacy in Edinburgh and in the process, are now a part of Edinburgh's history.

Sitting here today, in a beautiful building which is now 118 years old, we are surrounded by history.

But history is not just about major events.

It's much more than famous buildings, soldiers and battles, and kings and queens.

It's also about stories.

Stories about real people.

Real people like us here today, real people like Abbie and Becca who produced that fabulous film we've just seen.

Abbie and Becca's film tells stories – your stories. The stories that are your daily lives as carers.

Your stories tell us about the hugely important role you play by caring for others, and even when that can often be of detriment to yourself.

I would like to congratulate Abbie and Becca for their excellent film!

I know that media training was an element of this year's Carers Festival and you have clearly learnt a lot and gained many new skills.

So as with the Festival, today is a day that you can take a break from your caring responsibilities, and do so without worry.

Today is a day to voice your experiences, your concerns about things that matter to you and of course, tell your stories.

A critical part of my 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.

Who are Carers?

I was invited here today in my capacity as Minister for Older People and Equalities, to talk about diversity.

But first, there are a few things I would like to touch on around who carers are.

We know that numbers fluctuate year on year, but latest figures estimate around 680,000 carers in Scotland.

Carers are spread across all age groups.

Carers are at school, in higher education, working or retired.

Carers are more likely to be women and girls.

Carers come from all nationalities, speak many different languages and have many different beliefs.

Carers might be Gypsy/Travellers, living on sites or roadside which makes their caring even more challenging, or maybe forced into housing to make it easier to care for their loved ones.

But carers share a lot of commonality too.

Carers – you - put other people first.

And being a carer can have a huge impact on your education, your career, your social life and even your own health.

You are always on call.

You often don't have time to enjoy a hobby or spend time with other friends and family.

Or you might be juggling caring with other responsibilities like childcare and running a household.

And you may not access the help that is available to you (we know from MECOPP's work that this is certainly true of many carers in the Gypsy/Traveller community.)

So let me just say this.

I'm enormously proud of all of you here today for making so many sacrifices for the benefit of someone else.

It is a huge and genuine pleasure to be able to

acknowledge your role and say thank you for what you do.

Supporting Young Carers

Just last month I had the pleasure of taking four young carers on a tour of the Scottish Parliament.

During the tour we talked 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.

Getting into school every day is vitally important. And young carers need to be supported.

That's why we are funding an education worker with Carers Trust Scotland to develop resources and improve awareness, identification and support for young carers in schools.

This work and resources will be in partnership with Education Scotland and the General Teaching Council and linked to new rights to support for young carers under the Carers Act.

Now I have to pause here because I have been explicitly asked to remind the young carers in the audience about the Young Scot Card!

The four young people I met were taking advantage of their Young Scot Card when they came to visit the Parliament – so I want to encourage those of you who are still to sign up to please do so!

You can get lots of discounts!

And Young Scot are here today and have all the information you need.

Getting older

For all of us, life changes direction and we all get older.

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.

And we know that with Scotland's quickly ageing population, these numbers are only likely to grow.

So we 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.

Social Isolation and Loneliness

We also know that Social isolation and loneliness is a major issue. It can affect any individual, at any age and stage of their life.

But carers can be more at risk.

If you have had to give up work or have to go straight home after school or college to care for someone, you automatically lose the satisfaction and interactions that those environments can bring.

And it can also be harder to keep in touch with friends and family.

We 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.

It reflected the findings that loneliness was not just an issue that older people faced, but something that had the potential to impact everyone in our society.

Since the publication of the Strategy, I have chaired 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.

This is a cross government issue.

I've also established A National Implementation Group, which will develop a delivery plan, look at funding, and strengthening communications around this agenda.

We will report on progress every 2 years between now and 2026 and create more opportunities for learning and development in this area.

Fair Work

Alongside the risks of social isolation from giving up work or reducing working hours, there are obvious financial challenges and uncertainty for carers and their families.

In most cases this will create an immediate strain on a family's finances, but may also have a longer term impact on future career opportunities and earnings.

But caring can also impact on organisations.

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.

It is estimated that unpaid carers leaving employment cost the UK public purse £2.9 billion a year in welfare payments and lost tax revenue.

In fact, over a quarter of women in this age bracket are carers so this is particular issue for women in the workforce.

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.

We are working for a fairer Scotland for woman through a range of actions in our Gender Pay Gap Action Plan published in March.

We know that flexible working and thinking about job design are crucially important to those who have caring responsibilities.

The 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.

We 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.

We understand the Government has an important role in tackling these issues, and we have been working hard to create the conditions for change.

We believe 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.

This will not only bring vital benefits to carers but also employers and the economy.

A range of Scottish Government policies aim to recognise and promote these benefits. Some of these are specific to carers. Many are part of the wider Fair Work agenda but will have particular importance for carers.

Through our Fair Work agenda we are 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.

Carer Positive Scheme

Our Fair Work Action Plan recognises the challenges many carers face in sustaining a job.

It commits to promoting awareness of carers in the workplace and flexibility for them through Carer Positive.

The Carer Positive accreditation scheme has been developed on behalf of the Scottish Government and administered by Carers Scotland since 2014.

We and Carers Scotland are working hard to both increase awareness of the scheme and increase the number of employers signed up.

In fact I'm proud to say that both Joe Fitzpatrick and myself are accredited Carer Positive employers.

This demonstrates that employers of all shapes and sizes can have practice and policy that supports working carers.

Conclusion

So it's time for me to finish up!

You will soon be hearing a lot more from Joe Fitzpatrick, the Minister for Public Health, Sport and Wellbeing who is also speaking today.

But after the debate concludes I hope you get a chance to enjoy the various exhibits and workshops.

It's your day so please make the most of it!

Framing the Debate

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

Good morning everyone. Thanks to Carers Scotland for inviting me to be here today, and to you all for having me. Also a very warm welcome to our international visitors from Eurocarers who have travelled to Scotland especially for this event. At this time of change and uncertainty, it is vital that we maintain close

connections and friendships with our European neighbours so we can both continue to benefit from shared learning and development.

This is my second Carers Parliament as Minister with portfolio responsibility for carers and I'm very glad to be able to open this debate.

We've already heard from some inspiring young carers about their time at the Young Carers Festival this summer. I can confirm that lots of fun was had and the sun was shining down.

Thanks also to my colleague, Christina McKelvie for her opening words. It's crucial that we work across Ministerial portfolios when it comes to developing support for carers, as we know that the issues carers face are much broader than health and social care. Just as I work closely with Christina, I know the connections with education, social security, employment and transport are equally important to creating a Scotland which supports the diverse range of caring situations.

Introduce the motion and theme of diversity

And on that note of diversity, I was 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

And it's important that the system in place for supporting carers recognises and is responsive to this range of circumstances. The Carers Act, which has now been in effect for a year and a half, takes the approach of personalisation and prevention. We know that being supported 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.

And personalisation is key to addressing this diverse caring landscape. This means carers being listened to and actively involved in designing their own support, with a focus on acknowledging individual strengths and personal outcomes, not just on problems. That's why carers' rights to support under the Act incorporate tailoring to their individual needs and circumstances.

Reform of adult social care

Carers also have rights to choice and control over how statutory support is provided. To get the social care that we as a nation need and want, self-directed approaches must be at the heart of current practice and future thinking. We know that our system needs to change if it is to stay fit for purpose. That is why, in June the Cabinet Secretary for Health and Sport and the COSLA Spokesperson for Health and Social Care launched

a national programme to support local reform of adult social care. Its aim is to ensure a high quality and sustainable social care sector both now and in the future.

Last year's Carers Parliament debate specifically focused on social care reform while we were developing that programme. To get this right we are also working with those who have lived experience of social care, carers and a range of other partners to drive the change needed.

I am very happy therefore that Alison Avison from COSLA 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

I want to talk about another national programme of reform that will be of importance to many people in this room. That is the work underway to deliver our devolved social security benefits – including to improve support for carers. We recognise that social security is a human right and are creating a system based on dignity, fairness and respect.

We are making every effort to ensure Scottish social security is accessible to all. Our 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, we have introduced and paid out seven new benefits, including Carer's Allowance Supplement. The Supplement puts an extra £452.40 this year into carers' pockets, an investment of over £37 million this financial year alone. Furthermore, we are working with carers and stakeholders to consider longer term changes to Carer's Allowance.

And there are more improvements afoot. We have considered evidence on the impact of caring for more than one disabled child. In recognition of these impacts we will introduce additional financial support for these carers by spring 2021.

And finally, on social security, we were thrilled to open applications last week for the brand new Young Carer Grant. We want young carers to be able to access opportunities that are the norm for many other young people. At this important time of transition in a young person's life, it's vital that we give them that extra bit of support to allow this to happen.

If you'd like more detailed information about any of this, Social Security Scotland has a stall you can visit this afternoon.

Close

I will be staying for the duration of the debate and just as I would do in the chamber of the Scottish Parliament, will try my best to respond to the issues raised. Alison Evison from COSLA will be doing the same. You may notice my supporting officials passing me notes, as would be the case during real Parliamentary debates like this – this is so my response to you can be as helpful and informed as possible. Thank you and it's now over to you. I'm really interested to hear what everyone has to say.

Carers contributions to the debate

Stecy 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.