

Carers Parliament 2018

Workshops

This report provides information on the workshops that were held at the Carers Parliament, bringing together key issues raised by carers and young carers.

Dignity and respect:
how can social security delivery better outcomes for carers and those they care for?

This workshop was facilitated by Nikola Plunkett, Head of Disability and Carers Policy at the Scottish Government and Fiona Collie from Carers Scotland. The workshop focused on future developments in social security as it is devolved and carers' priorities

Transitions and Employability

- The issue of employment and employability for young disabled people and people with mental health issues was raised, particularly the lack of meaningful opportunities.
- Mental Health/Autism: What is being done to assist back into the workplace and help keep in workplace (assisting employers to understand these conditions?)
- Transition from child benefits to adult benefits and how this transition can leave families with a shortfall of money (e.g. 13 weeks). There is no support explaining benefits and the different process – shortfall for 3 months leaving families in difficult financial situation.

Personal Independence Payment (PIP) forms and processes

- Carers with long term illness/disability are being denied PIP because they are caring. There appears to be a perspective that if they are fit enough to provide care then they do not require PIP.
- Forms need to be more concise (cut down on repetition)
- Specific PIP forms for people with a mental illness – and the appeal process need to be clearer
- Reviews for (long term conditions) - is this needed?
- Need to be able to assess both mental health and (physical) disabled health on same assessment
- Carers to be involved in mental health assessment of cared for person
- Weight to be given to both medical reports and carers report (voice/experience)
- Motability (payment) scheme – will this change in line with benefit test? How can we assess and better assess mobility needs?

Carers Allowance

- Look at when allowances are stopped suddenly (eg child in hospital and parents still caring in hospital but disability allowance and families left with financial problems – Carers Allowance stopped) eg Carers Allowance stopped after bereavement – how can this be phased in some way?

Representation, advice and advocacy

- Welfare rights support – how is this going to be funded and provided? Advocacy services are receiving more requests for this and this is separate from welfare rights support.

Other issues raised

- Training of young carers (i.e. moving and handling) providing time to do it/services to provide training
- Respect/Dignity – letters sent from local authority don't show respect (e.g. letter changes to benefits etc.) (wording of letters). Bodies should be working the same way and sharing good practice
- Young Carer Statement/Adult Carers Assessment – why is there a different process and how is this fair?

Healthy communities:

how can integration and primary care can deliver better health and wellbeing for carers?

This workshop was facilitated by William Griffiths from the Health and Social Care Alliance and explored integration and primary care transformation and how this can improve outcomes for both carers health and wellbeing and improve services and support for adults and children with disabilities.

Transitions

- 18 yrs. old daughter in transitions – it isn't working – no one can make decisions – That's social work – I can't authorise that – Needs one coordinator
- Experience in a transition to adult support through having specialist 'transition' social work (7 years ago)
- Long way to go but has potential
- Pathways – service planning eg for transitions in Edinburgh only starts 6 weeks before
- Transitions/some children's services not included in partnerships – has big influence on the experience
- Potential to support carers – transitions from experience in same area
- 'Good transition strategy'
 - What is the point in strategies if none of the 'targets' are being met?
 - No consistency in transitions: taxis stop, friendships stop
 - Set up group and now social work want to refer people in
 - Things happen because carers set things up – bridge the gap

Carers as experts

- Could overcome: Could be carer as carers is expert – SILO'D thinking, taking sides, not recognising expertise of 3rd sector – Professional jealousy
- Training is needed
 - Has recognised authority
 - Understanding the roles
 - Be independent
 - Listening
 - Person centred

Challenges

- Time consuming everyone at meetings – 156 hours of meetings
- If it is the law who is holding IJBs to account? And making sure that it is person centred
- An experience in adult care (older adult) in Glasgow – carer asked what was needed – involved in discussion but paperwork is appalling (volume of)
- Why is there a separation between primary care & health and social care?
- Carers are service providers not service users – who talks the loudest – service improves

Good practice

- Good examples of specialist condition – specific training also being delivered to carers – ‘sold’ positively as having good impact on healthcare professionals

3 Key Messages

There is a need for a Coordinator Role

- Digital passports
- Hold your own data – decide what to share
- From birth?

Children’s Services should be included in integration

- Would make huge difference in transitions
- Include education, third sector
- All services
- Link workers

And the rest: innovating and offering better breaks for carers

This workshop was facilitated by Don Williamson from Shared Care Scotland and focused on short breaks, innovation and developing the right breaks for carers and the people they care for.

Ideal Break

- Being able to relax
- Being confident in those who take care of someone while we’re away
- Good food
- Disneyland
- Travel, new places, city breaks
- Summer programme (young carers)
- Meet new people – games and activities, playing piano. Feel better at home because I know my mum’s safe
- A holiday as a family with support or carer (paid care worker)

Actual experience – good or bad

- Funding from family fund was good but no extra support from anyone
- Who has responsibility for inclusivity? – family? society?
- Access to Summer activities is difficult as parents often have to stay with child ‘a day off’
- Being away is not really ‘respite or short break’
- Lack of groups for disabilities

- Bring people into the house, it's a familiar place – appropriate accommodation

What would you change?

- More support for my parents to let my dad have a break from his caring role
- More support in evening and weekend to care for person to support working carers
- More facilities in Scotland for all abilities and disabilities
- Awareness of caring
- Better training, more staff to provide appropriate services
- Transparency, not clear how the system works

Consultation: Young Carer Grant

This workshop was facilitated by Paul Traynor and Thomas Grant from the Carers Benefits Policy team at the Scottish Government and focused on the young carer grant consultation. Copies of the paper were tabled on the proposed Young Carer Grant for discussion and to give the group the opportunity to take part in the consultation survey.

The package of support for young carers consisted of:

- A £300 payment for young adults with significant caring responsibilities beginning Autumn 2019
- Piloting free bus travel to recipients of the grant from 2020/21.
- A bespoke carers element to the Young Scot Card providing non-cash benefits for young carers 11 to 18 to be rolled out from April 2019.

In opening the discussion, the group were asked to think about setting goals and to focus their thoughts on how they would spend this grant. Some initial thoughts/questions were:

- To buy a laptop for school/university
- To enable a young person to be a young person, and maybe enjoy going out
- To help treat younger siblings
- How do you get the money?

It was explained methods of applying were, by on-line application, by telephone and through local hubs throughout Scotland where staff would assist with completing the application.

Q. A group member asked how long would the application take?

A. Turn around was planned for 2 weeks from the date of application.

Q. Would you have to evidence base this?

A. No

The eligibility criteria are ages are 16, 17 or 18 still at school.

Q. What about those at college?

A. The consultation survey gave 18 in all circumstances.

To receive the grant you must be caring for someone for 16 hours per week in receipt of a disability benefit. This is a self-declaration.

Q. What would you have to submit?

- A. School records and permission from the cared-for person that they are in receipt of one of the disability benefits.

You can only receive the grant once in a 12 month period and can reapply each year for the grant.

Q. Will there be any kind of reminder?

- A. The date of renewal will be on the application.

The group were encouraged to take part in the Young Carer Panel and survey focus groups to help shape the grant.

A parent carer referred to the SEEMIS tracking system through primary education which was passed onto secondary education and was concerned if young carers were being picked up at this stage.

Q. If there are more than 2 young carers in the family, will they both be able to apply?

- A. There is a question in the survey that asked that. This would be based on the number of caring hours. Views on this should be put into the survey.

The consultation survey was tabled and young carers were given time and encouraged to complete this.

Outcomes from the Workshop

- The grant should include people in higher education
- Consider age range
- Use as a mechanism to identify young carers

Equal recognition: a fairer deal for older carers

This workshop was facilitated by Claire Cairns from the Coalition of Carers in Scotland and Suzanne Munday from MECOPP. It focused on what support could be available to older carers who do not qualify for Carers Allowance as a consequence of the overlapping benefits rule. It also included a discussion about Attendance Allowance.

Participants were asked what could help them and give recognition of them as carers. This could include a range of options including grants, services etc.

- Carers Allowance does not compensate for loss of wages
- Accurate of information
- Depends on how it is implemented. What would the eligibility criteria be?
- Help to join up services – education, health, care
- Something that connects with existing benefits – DLA
- GPs should be identifying carers and signposting them to support
- Emergency funding for older carers
- Respite breaks
- Discounted heating in winter
- Council tax reduction/exemption
- Car insurance and road tax

- Better planning for hospital discharge
- Attendance Allowance
- An older carers support allowance

They were then asked what a better process/good journey would look like for attendance allowance.

Attendance Allowance – What a good journey looks like

Q. Finding out about attendance allowance (how?)

- A. Should be flagged up automatically by social work services, community nurses and GP's
- A. GP's and health workers should alert you
- A. Key role to be played by doctors and hospital/health staff when an individual presents for an appointment. Also carer support groups should raise awareness.
- A. Currently viewed as a 'hit or miss' process and that an individual has to go out of their way to find out about it.
- A. Should be told about it automatically by social work services or GP
- A. Social workers, GP surgeries and CAB's should let people know

Q. Getting help to make an application (how and who?)

- A. Essential that help is available promptly and without long waiting times
- A. Healthcare professionals, welfare rights services (third sector or Council) and family
- A. Carer groups and CAB's have key role. Should also consider specialist hospital/health centre based welfare rights staff who are benefits specialists
- A. Local carer centres and disability groups
- A. Social workers and CAB's

Q. The application process – filling in forms

- A. Forms should be simple, only requiring relevant and essential information and help should be available to complete them
- A. Forms should be easy to read and understand, concise and to the point and should include 'tick boxes' for speed or completion
- A. Perception that questions are left deliberately vague to 'trip you up' and reduce your chances of a positive outcome
- A. 'Checking' service should be available to ensure you have as much chance as possible of succeeding
- A. Separation of concessionary travel element from attendance allowance as some people may not need the financial element but do need subsidised transport

Q. What evidence should be used to make a decision and how should it be gathered?

- A. Primary sources GP and community nurses supported by evidence from relevant services individuals are in touch with
- A. Health professionals and social workers, evidence should focus on need for extra care considered in relation to 'average' requirements
- A. Satisfied with process (undertaken in 2011)
- A. The amount and type of care/support need and the number of hours of caring delivered
- A. Far too much evidence is required when there is a medical diagnosis to support claim
- A. A diagnosis from the doctor or hospital

Q. How should the decision be made?

- A. if the condition is permanent or progressive, then why do we need to keep repeating tests for eligibility – if condition is lifelong then benefit should be awarded on an ongoing basis
- A. Decisions are inconsistent and unfair taken behind a desk in front of a computer
- A. Decisions should be made in consultation with the carer based on the amount of care needed
- A. Decision should be based on need
- A. Depends upon the condition, it should be for life (if the condition is permanent) with reviews only for temporary conditions

Q. How the appeals process should work

- A. It should be simple with access to peer or advocacy support and no bullying
- A. Simple to understand
- A. Appeals should be made to a panel completely independent of the original deciding officer or department and any benefit should remain in place until the appeal decision is finalised
- A. A lot of people won't even consider an appeal, it appears to be the 'default' result for some

Making it work: employment and employability for carers and young adult carers

This workshop was facilitated by Sue McLintock from Carers Scotland who leaves on the Carer Positive Award scheme for employers who support their carer employees. The discussion focused around employment and employability and the following points were raised by participants.

Carers Leave

- Carers Leave – Other forms of leave such as parental leave available
- How to get carers leave? All annual leave used up for caring responsibilities – 43 types of leave, not carers leave.
- Affects pension – have to cut hours.
- In Belgium – 5 days paid leave, parliament in favour, needs to go to legislation

Policies and Flexibility

- Working practices – flexible hours
- Employer policy would help but still need line manager who understands and trusts that time is essential
- More jobs are flexible working – tends to be larger companies as they can offer cover – small orgs find it harder. Private sector – give and take to get right person – fewer 9-5 jobs
- Workplace – shift so we don't expect everyone to be available M – F, 9-5 and protect home life time. If employers respect 'home time' don't need to disclose caring role

Employer Support/Awareness

- HMRC Carers passport – goes into HR record so don't have to keep explaining to new line managers
- Balance of work/caring difficult – having to pretend 'normal' at work
- Carer groups – could give a stigma. Have to take annual leave to attend carer network. Run by volunteers, more positive – not enforced – more informal
- Carer Positive – updated Carer Positive, peer support, flexibility, paid leave
- Awareness – more employers will realise carers in workforce will all need to raise awareness

Support in education and transitions

- Carer at college – multiple carer roles – unsure how to balance role and bringing in support at college
- Change at school needed – before employers. Variable support by teachers
- Transitions are difficult enough anyway.
- Skills Dev Scotland – make sure carers are able to learn about skills they need – recognition of skills as carer

Employability

- Work experience – focus on disability, could also be carers
- Employability skills while caring

Improving futures: support for young carers and the Young Scot card

Two facilitators, Edward Fitzpatrick and Kandice Wood from Young Scot, led the participants through what Young Scot is and what they do for young people in Scotland.

The Young Scot card was explained as not all in the group new about it: a card that gives entitlements and rewards to young people aged 11-25 across Scotland. There are rewards that can be gained by gathering points, and certain entitlements are inherent to the card – for example 10% discount in Topshop, discounted entry to the Inn Bru Carnival.

Young Scot outlined their co-design process with young people and stakeholders in their projects, with relation to the Young Carers Panel. All involved are included from beginning to end, ensuring that the final output and conclusions are the most valuable possible. They are looking at what they can provide for young carers as a specific group.

The Young Carer Panel is working on what Young Scot can provide young carers.

The group then took part in participative exercised. They discussed the challenges faced by young carers in relation to community; education; social; and work. This was conducted as a post-it exercise, and was then placed on a flipchart.

Community: the groups discussed that access to leisure activities and travel can be restricted because of access to money. Lack of awareness of young carers and the challenges they face is an issue in its own right, as well as leading to social isolation. There can be a lack of transport links in areas that restrict young carers from getting around.

Education: awareness and understanding from staff is a huge part of whether young carers can participate fully in education or not. Young carers responsibilities can result in incomplete homework, and being late to class which impact relationships with teachers as well as keeping up with work. Juggling different pressures can make it difficult to concentrate on school work.

Work: Access to training and opportunities can be limited for young carers. Managers don't always understand the situation young carers are in, and work places don't always offer flexible working hours. Young carers sometimes do not have the time to work because of the care they need to provide, and sometimes are late or miss work due to caring.

Social: Making friends and fitting in is difficult when there is a caring role, as young carers have to return home to caring duties. A lack of awareness of carers and the stigma faced can be difficult for young carers trying to socialise. Trying something new can be daunting for young people who struggle to integrate because of their caring role. Social isolation as a result of these factors is faced by many young carers.

The group then moved on to what rewards they would like to see made available to young carers through the Young Scot card. It was discussed that these could be earned by e.g. attending young carers group for six weeks, earning points for a reward that could be logged privately online. It was discussed that there could be a way of being entitled to rewards for looking after wellbeing. The discussion focused on what could Young Scot do to combat the challenges discussed before.

Examples of ‘what do you want?’ answers that were noted are:

- better travel discounts specific to young carers
- gym membership discounts
- local attraction discounts
- days away
- hotel stays/discounts
- art/school supplies
- sporting events tickets
- free music tuition
- accreditation/training.

Everyone was asked to personally reflect on what they think would be the priorities for Young Scot to deliver.

Then, the group discussed the **‘Best ways Young Scot could promote our Discounts, Rewards and Entitlements so that you and young carers are aware of what we have to offer?’** This was discussed as a group

- through social media platforms like Facebook and Instagram
- school assemblies
- have GP’s/Mental health services aware of Young Scot
- awareness posters in youth clubs, libraries, schools etc.
- communication via text, letter, email
- youth groups such as Scouts, brownies, cubs, rainbows could discuss it with members
- Local Authority partnership to allow local authorities to disseminate information.

This information will form part of Young Scot’s ongoing consultation work with young carers, which has worked with young people on what discounts, rewards and entitlements young carers would find most relevant.