

Key issues from workshops

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.