



## **NCO response to Scottish Parliament Health and Sport Committee call for written evidence to the Social Care Inquiry**

### **The National Carer Organisations**

The national carer organisations welcome the opportunity to provide a response to this inquiry. There are seven National Carer Organisations (NCOs) in Scotland. Together we have a shared vision that all Scotland's unpaid carers will feel valued, included and supported as equal partners in the provision of care. The NCOs aim to achieve this through the representation of carers and giving them a voice at a national level. The NCOs are Carers Scotland, the Coalition of Carers in Scotland, Minority Ethnic Carers of Older People Project (MECOPP), Carers Trust Scotland, the Scottish Young Carers Services Alliance, Crossroads Caring Scotland, and Shared Care Scotland.

We believe we can deliver more for carers by working together to share our knowledge and experience, and by focusing our collective efforts on achieving improvements in areas of policy and practice that are of greatest concern to carers.

### **Introduction**

Carers' support is valued at £10.8 billion a year, but this comes with high personal costs. Many carers are suffering from loneliness and social isolation, have to give up work to care, and are facing their own health problems as a result of their caring role.

This is in addition to the significant financial cost of caring; with 37% of respondents in State of Caring in Scotland in 2019<sup>1</sup> saying that they are struggling to make ends meet, and almost two thirds reporting that they regularly use their own income or savings to pay for care or support services, equipment or products for the person they care for. A higher state pension age means that people are working for longer and are more likely to be working alongside caring. With workplace support still very varied across the country, nearly 600 people every day have had to give up work to care.

In the recent Carers Parliament, carers said that social care does not have the value placed upon it that it should and much more investment is needed. They recognised that good policies are in place, such as self directed support and health and social care integration, but that they are not working consistently and there are still barriers in place.

---

<sup>1</sup> State of Caring in Scotland 2019, Carers Scotland

## Q1 How should the public be involved in the planning of their own and their community's social care services?

*Don't 'do it to people, do it with them'<sup>2</sup>*

Unpaid carers and those they care for must be actively involved in the decisions that affect them and be supported to co-produce solutions. People are often not told the problem; instead they are told the preferred solution from the service or authority and asked their views on it. At the recent Carers Parliament in October 2019<sup>3</sup>, carers said that *"real partnership and trust are needed"*: from carers having a real voice and being valued on IJBs to trusting people to know and choose what they need using their SDS budget, giving real choice and control.

The experiences of carers and those they care for show that co-production needs to be at the heart of planning both individual and community social care services.

### Community level

Co-production needs practical support to make it happen. Engagement and consultation often involve public meetings at times and places unsuitable for carers, particularly in rural areas where public transport is poor or non-existent. For many carers they simply are unable to leave their caring responsibilities without replacement care and other support such as expenses that enable them to attend. Carers must be fully involved from the beginning. In addition, it can often be more effective to go to people where they meet already, for example, mental health carer groups, carer forums and workplace carer groups.

There also must be consideration and work to address the additional barriers to involvement for some carers. There are many organisations with significant experience of supporting people to be involved e.g. MECOP, Inclusion Scotland, Coalition of Carers in Scotland, Carers Scotland, Glasgow Disability Alliance to name a few and Boards should draw upon this experience to support involvement.

Carer involvement must be resourced and supported by Integration Authorities. This must include every area having an expenses policy and reimbursing all out of pocket expenses for carer representatives, as well as replacement care costs to enable those with a significant caring role to become involved in planning.

IJB Board meetings and strategic planning meetings need to be accessible, with carers treated as equal partners and able to contribute to discussion and decision making. Induction training and ongoing support should be provided.

Many of these practical considerations are outlined in the proposals from the Scottish Government's review of Integration and the Coalition of Carers report 'Equal Expert and Valued'<sup>4</sup>

---

<sup>2</sup> Quotes throughout (unless otherwise noted) are from carers from the Carers Parliament 2019 and from feedback from carers to the consultation from the Coalition of Carers in Scotland: Rural and Remote Sub Group and Carer Awareness of the Carers Act survey.

<sup>3</sup> Carers Parliament held on 30 October 2019. Reports and films from the event at: <https://www.carersuk.org/scotland/policy/carers-parliament#sec0>

<sup>4</sup> Equal, Expert and Valued (3<sup>rd</sup> edition), Coalition of Carers in Scotland, May 2019 <https://carersnet.org/wp-content/uploads/2019/05/It-can-be-downloaded-here.pdf>

Integration Joint Boards must build in time, space and resources for co-production. But this co-production must go beyond the services within the remit of the Boards. The NHS and Councils and other statutory organisations (with voluntary and independent sector partners) must co-produce solutions with their communities so that decisions are joined up.

A lack of joined up involvement can mean that services that contribute to improving outcomes and prevention, in both the statutory and voluntary sector, are lost as a result of decisions made elsewhere. There are many examples of vital supports lost or decisions made that increase inequality to carers and those they care for. This could (and has) included for example, decisions that reduce access to advice, advocacy or transport, investments that do not provide sufficient levels of accessible or adaptable housing built, closure of community buildings without alternative spaces available, new buildings erected without Changing Places toilets and more.

#### At an individual level

The Carers (Scotland) Act 2016 gives carers rights to be involved in the decisions that affect them, including the assessment of the person they care for (with their consent). Yet often, although policy recognises that carers are “equal partners in care”, for many carers their experiences do not reflect this.

*“The experts (need) to listen to me when I’m talking about my Dad.  
There’s no point in having a “what matters to me” if nobody reads it.”*

*“One of my biggest challenges was “experts” not listening”*

In a recent survey of carers<sup>5</sup> by the Coalition of Carers in Scotland, which over 1,000 carers contributed to 47% of carers did not know they had a right to be involved in the planning of carer services and 42% did not know they had a right to be involved in discharge planning if the person they cared for was being discharged from hospital.

*“When my mum was discharged from hospital recently, following a stroke the only part of the discharge process that I was involved in was collecting her and taking her home!  
There was no conversation re what to expect, her new medication, rehab, nothing.”*

Carers make a huge contribution to the lives of those they care for and to our wider society. Despite this, too many are going without the support they need and all too often they are going without any support at all. Research<sup>6</sup> found that one in five carers (20%) neither buy nor receive support for their caring role, only a quarter (28%) receiving practical support for care with care workers coming in. Less than 1 in 5 (18%) receive a break from caring, vital to maintaining their health and wellbeing and sustaining their caring role.

This suggests there is still a large level of unmet need, with many carers struggling without any support at all, with the resulting often significant impacts on their health, wellbeing and aspirations.

---

<sup>5</sup> Carer Awareness of the Carers Act, Coalition of Carers in Scotland, Feb 2020 (1,189 responses)

<sup>6</sup> State of Caring in Scotland 2019, Carers Scotland <https://www.carersuk.org/scotland/policy/policy-library/state-of-caring-in-scotland-2019>

*“I went bankrupt as a result of taking on a full time caring role and not being able to work properly any more.”*

Despite legislation waiving charges for services that support carers, to manage their caring role, many carers are spending their own income on support. Over a third of carers (68%) regularly use their own income or savings to pay for care and support, equipment and products. For some carers the proportion of those who use their own funds is even higher including older carers (70%), those caring 50 hours or more each week (73%) and shockingly those struggling to make ends meet financially (79%).

Almost a third (31%) have experienced a change in the services they and the person they care for. For 29% this was because the amount of care or support arranged by social services was reduced, whilst for 11% of respondents the care or support service was closed with no replacement offered.

Very few, only 9%, are confident that the support they currently receive will continue in the future. Almost a third of carers (29%) worry that the support might be reduced and almost half (44%) expect their quality of life to get worse.

This paints a picture of carers not being equal partners in care, going unsupported and not being involved in co-producing solutions. This needs to change.

The Social Care (Self Directed Support) (Scotland) Act 2013 put at the heart the right of individuals, including carers to have choice and control over the services and support they receive. Yet for many this is far from their reality. In recent research<sup>7</sup>, carers were asked if they or the person they care for get SDS from their local authority or health and social care partnership to pay for care and support services directly e.g. a direct payment or personal budget that they can direct. Seven in ten (70%) carers do not receive this for either themselves or the person they care for.

At the Carers Parliament in 2019, and identified by carers in previous years' Parliaments (and in other events with carers), there were a range of issues that carers believed directly impacted on their ability and the ability of the person they care for to have real choice and control. These included:

- Training of staff - staff are not explaining SDS properly and often are not trained (or do not appear to be trained) in SDS and its principles. *“Staff member hadn't been trained when [they] came out to visit son about SDS”*
- Budgets and support offered: support and budgets are not realistic to meet needs and deliver outcomes. There is a lack of trust and respect, with carers and individuals being challenged and restricted on spending and difficulties in getting the right support/services or PAs.
- Lack of consistency: carers speak of a *“postcode lottery”*, the lack of portability of packages, difficulties in identifying and accessing services, particularly in rural areas and different approaches and availability of options in different authorities (and indeed even from area to area within an authority).

---

<sup>7</sup> State of Caring in Scotland 2019, Carers Scotland

These examples reflect the findings of Audit Scotland in reflecting the experience of many carers; that “authorities have not yet made the transformation required to fully implement the SDS strategy” and whilst “there are many examples of people being supported in new and effective ways through SDS.... not everyone is getting the choice and control envisaged in the SDS strategy”

Whilst many carers and those they care for do not have the choice and control envisaged by the legislation and Strategy, for some it is a great support. However, more work needs to be done to ensure that SDS is the norm for all individuals who need support.

*“My SDS package is working great – took a long time to get there but working out fantastic”*

*“Was able to get funding to put support in place. Not everyone knows where to go.”*

## **Q2 How should Integration Joint Boards commission and procure social care to ensure that it is person centred?**

The commissioning and procurement of social care services must be person centred, flexible and responsive to the changing needs of carers and those they care for. Yet too often it fails to meet this aspiration.

IJBs should consider the value of procurement and commissioning in its current form. The costs and benefits need to be considered more closely, including the resource involved for organisations who are tendering. Competitive tendering exercises for carers’ services have resulted in loss of experienced staff and trusted services, which have strong links with the community and a track record of delivery. Time and task based commissioning must be replaced by a person centred, outcome focused system that supports services that are person centred, flexible and responsive to changing needs.

The national carer organisations also question whether the current approach to procurement reflects the intention of equal partnership within Boards and partnerships. The third and independent sectors do not necessarily have an equal playing field with statutory services. This is not about questioning the quality of in-house services but rather that the third and independent sector may be being held to a different standard of best value and paid different rates compared to those services provided by statutory partners in the IJB.

In addition, commissioning can create a power imbalance with the third sector, who are both partners in integration, but are also continually required to apply for funding and to justify the funding they receive in a way which statutory partners are not required to.

*“Whilst we are included in both strategic and operational planning, I don’t know if we can say that we are “equal partners”. It is difficult to be an “equal partner” with agencies who hold the power (financial) in the partnership.”<sup>8</sup>*

---

<sup>8</sup> Carers Centre Survey of 29 responses from 31 areas in Scotland, Coalition of Carers in Scotland, February 2020

Commissioning is too often driven by finance and not the needs of individuals and their carers and the outcomes they wish to achieve. People who use services and their carers should be involved in decisions and a full understanding is needed of the risks and impact of withdrawing funding from often valued service providers.

The national carer organisations support the view of Community Care Providers Scotland that *“competitive tendering as routinely conducted by councils... is largely antithetical to a person-centred approach, and seriously hampers the third sector’s capacity to provide good quality, personalised care.”* They note that these processes are *“overly complex”*; *“driven by risk avoidance”*, *“highly prescriptive”* and *“incapable of adequately assessing quality”* ... and that the competitive tender process *“runs counter to SDS principles”*.

In supporting this view, the national carer organisations believe that commissioning must be outcome focused and measure the things that matter to carers and people who use services. Building on our earlier comments about self-directed support, this needs to be built upon delivering outcomes and enabling people to have control and more choice and flexibility over the supports for their lives.

Real partnership is needed with more funding intended to make a difference for carers reaching the voluntary sector. A carers centre survey and freedom of information request<sup>9</sup> found that funding is not reaching such services providing support to carers. There is a need to shift resources to where the need is.

As an example, according to the carers centre survey, only 42% of carers centres have seen an increase in their funding from health and social care partnerships this year and much of this additional funding was used to cover the staffing costs to prepare Young Carer Statements and Adult Carer Support Plans.

Referrals in the same period have risen by an average of 36%

### **Q3 Looking ahead, what are essential elements in an ideal model of social care e.g. workforce, technology, housing etc.**

In Scotland, the Carers (Scotland) Act 2016 gives all adults and young people caring for someone the right to an adult carer support plan or young carers statement from their local authority. These support plans should look at the impact of carers’ caring role on all aspects of their life and what support they and their families need as a result. Only 21% of carers in Scotland reported that they had an assessment, Carers who are providing palliative care and those looking after someone with dementia were slightly more likely to have had an assessment with 31% of each group respectively saying this happened in the last year whereas only 19% of parent carers had an assessment or review in the last 12 months.

Most carers (71%) waited less than six months for this assessment (which is still a considerable time) but 29% waited longer than six months.

---

<sup>9</sup> Analysis of Funding in 2018/19 for the Carers Act, Coalition of Carers in Scotland, Shared Care Scotland and Coalition of Care Providers in Scotland, January 2019.

<http://carersnet.org/wp-content/uploads/2019/03/Report-on-the-First-Years-Funding-for-the-Carers-Act.pdf>

*“All areas were thoroughly considered and I get excellent support from Quarriers, but I am not able to seek sufficient support for my cared for or myself to actually make the right difference to juggling, breaks etc. My cared for is ineligible for social care as he is not in crisis. I am on the waiting list for social care as a carer.”*

Age Scotland reported that 43% of older people assessed as needing substantial or critical care in 2018 waited more than six weeks to get social care packages. The average waiting time for an assessment was three weeks, with the average waiting time to receive care being 2 ½ weeks.

There is a clear need for much quicker access to assessment for both the person receiving care and to Adult Carers Support Plan or Young Carers Statement for carers and young carers. Identifying needs early helps prevent some of the negative impacts of caring and reduces the likelihood of carers having to give up work to care, with the resulting increase in inequality and poverty.

There is a need to build prevention and anticipation into all assessments and services. Guidance on the Carers (Scotland) Act 2019 highlights that prevention is critical.

*“Prevention is pivotal in how carers and the people that they care for are supported. Much of carer support is focused on intervening as early as possible in a carer’s journey, including by providing information and support to promote quality of life, independence and engagement with their communities in order to prevent deterioration in their situation.”<sup>10</sup>*

Carers have to be identified early and supported effectively to provide care and have a life alongside caring. This includes regular breaks from caring and support for the carer when caring ends. This support also needs to recognise the significant financial impact of caring, particularly where carers have had to reduce working hours or give up work entirely.

The experience of carers reflects that this is not yet the case. Only a third of carers (35%) said their ability and willingness to provide care is considered and around a quarter (28%) that their need for support to look after their own physical and mental health alongside caring had been thoroughly considered; only 19% said that their need to juggle work and care or return to work was properly considered, a similar proportion to those who wished to stay in or return to further education and learning.

This experience that carers have shared suggests that implementation of the Carers (Scotland) Act is varied across Scotland and they are not yet realising the benefits that were intended by the legislation. Even for those carers who had a positive experience of the assessment itself, often there is no support available locally following on from it to relieve any of the issues they have raised.

And, in a challenging environment of squeezed public finances and tightening eligibility criteria, good intentions on prevention and supporting carers is often not translated into action when commissioning services.

---

<sup>10</sup> Carers (Scotland) Act 2016: Statutory Guidance

Small interventions can make a difference and the experience of the Time to Live funding reflects this. Through Shared Care Scotland, carers centres can apply for funding to be able to provide a fund to offer small grants for breaks to carers in their locality.

*“It’s lovely to get out and be part of a community for a wee while and feel normal.”<sup>11</sup>*

In commissioning services, partnerships should recognise the value of providing carers centres and other such groups with flexible preventative budgets to provide carers with early, small interventions to maintain their health and wellbeing and avoid lengthy waiting times for support

Anticipatory planning should underpin social care. It is entirely predictable in some conditions and end of life care that increasing service provision will be required. Carers and families need to have confidence that additional support will be delivered quickly without additional waits for reviews or reassessments.

Furthermore, much more also needs to be done to plan for transitions from children to adult services.

*“Children with disabilities grow into adults with disabilities and this is known before they leave school. Why all the difficulties with transitions? Sad to hear parents are still going through the same as we did 10 years ago.”*

In “Facing the Future Together”<sup>12</sup> more than three quarters (76%) of parents carers with a young person still at school did not have ‘an agreed, written down plan to support their transition’. 76% said they had no plan, with 14% not knowing if they did or not. This meant that 90% were effectively unaware of any formal plan for their child’s transition. Even for those who have had some discussion, carers often felt unsupported and ill prepared. One parent said: *“I have had an initial meeting with school who explained what the process would be and the key areas to focus. I have had no support outside school. A recent meeting with social work told me that we would not qualify for support from the council as we are seen as “coping”.*

Some parents whose child had left school talked about their experiences and discussed the “battle” they had experienced in accessing the support their child needed.

*“My daughter left school- she gets a budget which took a 9-month fight; my son gets no budget. I care for my mum she gets no help at all.”*

#### **Q4: What needs to happen to ensure that there is equitable provision of social care across Scotland?**

Self-Directed Support must be rolled out to all people. There is a need to move from large contracts which tie up funds in traditional in-house services and task and time block contracts rather than providing people with the choice they need.

---

<sup>11</sup> Shared Care Scotland: Time to Live carer quote

<sup>12</sup> Facing the Future Together, Scottish Transitions Forum

Much more work is needed to address the issues faced by carers and people receiving care in remote, rural and island communities. Often, despite being assessed as requiring support (and in some cases having an SDS package) there are little or no services available to buy in. Budgets based around hours of support often do not consider distances that need to be travelled to provide a service making support provided shorter and more limited. The Scottish Government needs to give consideration to further measures to encourage recruitment and retention of care workers and to help organisations providing care services to thrive. Such measures have been implemented in, for example, recruiting GPs but the wider health and care workforce is of equal value and necessity.

*“I care for my son 24/7 and we lost our PA. Been waiting 6 months on the social worker getting back to us. They are quite happy to run me into the ground. No trust or faith in them anymore.”*

In addition, valuing care work is a priority. This is not simply a matter of warm words but of investing in the care work force, their terms and conditions and career opportunities across all sectors. Recruiting and retaining a skilled workforce is the foundation of good support and governments at UK, Scottish and local level need to work together to invest to realise this ambition. Carers have also expressed anxiety over care workers from both EU and non-EU countries and the impact of policies after Brexit. Many recognised, particularly in rural areas, the key role that they play and the potential impact if recruitment becomes harder. The immigration system is a matter for the UK Government but we hope that both governments will work together to ensure that sustaining both the care and health workforce is seen as a major priority.

Information sharing, recording and communication needs to be improved. Carers we have engaged with across the years frequently spoke of having to tell their story again and again, including to people within the same organisation. A “tell me once” approach should be developed.

Funding which has been allocated to social care and supporting carers needs to be ring-fenced to ensure good policy initiatives are delivered. Legislation must be fully implemented and the Parliament should be involved in scrutinising the effectiveness of legislation and policy at key stages.

Specifically for carers, the Carers Act needs to be fully and consistently implemented across Scotland. A carers survey by the Coalition of Carers in Scotland showed that even where carers were aware of their rights, they are not always able to access them.

*“I know that might rights are, but finding it hard to action these rights as our local authority put barriers and constraints in place to provide as little help as they can.”*

There is a wider need, nationally and locally to recognise that social care is not simply about providing personal care and preventing admission to hospital. A greater focus is needed on the rights of individuals to live independently, improve health and wellbeing and, for carers, to have a life outside of caring that enables them to meet their aspirations. Action must be put in place to change policy and practice that does not reflect this focus. Narratives which dehumanise people who need care and support and their carers (e.g. the use of the term “bed blockers”) need to be consistently challenged to focus on the individual at the heart and delivering positive outcomes.

*“I need professionals to see there is so much more to my daughter than her litany of medical ailments. She is a person with hopes, dreams, passions, rights, hobbies, friends. She is a fierce light; she deserves a seat at every table.”*

Many carers centres have been commissioned to deliver ACSP and YCS, with only those with substantial or critical needs then being referred to social work departments. There is a need to ensure that services and support to carers are provided as quickly as possible. As noted previous, carers centres could be provided with funding to hold flexible budgets to resource carer support in a personalized and preventative way.

*The assessment covered a lot of details but nothing happened afterwards and I feel I might as well not have had it*

Finally, breaks from caring are vital and there is a need to ensure that all carers who require a regular break are able to do so. Shared Care Scotland and the Family Fund have both been funded to support carers to have a break from caring, with some funding devolved to Carers Centres to deliver small grants to carers to fund breaks through the Time to Live Fund. Other services such as Crossroads Caring Scotland deliver flexible regular breaks to carers, often contracted by Health and Social Care Partnerships. Some carers centre e.g. Dundee Carers Centre have developed their own short breaks services. The value of breaks cannot be underestimated and more investment centrally and locally is needed.

*“I need time off every day, the opportunity to come down a peg from being in a constant state of high alert. Time to recharge so I can deliver the best care possible to my child.”*

And finally, we would like to end our response on a further quote from one carer at Carers Parliament 2019:

*“I know that there is no magic cure but all I want is to be listened to, not judged, felt cared for and make me feel as if I am actually a human being and not a robot providing care for others 24/7. Is this too much to ask for?”*

**Fiona Collie**  
**Carers Scotland**  
**on behalf of the National Carer Organisations**  
**20<sup>th</sup> February 2020**

### **Contacts**

Fiona Collie, Carers Scotland, [fiona.collie@carerscotland.org](mailto:fiona.collie@carerscotland.org)

Paul Traynor, Carers Trust Scotland, [p Traynor@carers.org](mailto:p Traynor@carers.org)

Claire Cairns, Coalition of Carers in Scotland, [coalition@carersnet.org](mailto:coalition@carersnet.org)

Suzanne Munday, MECOP, [suzanne@mecopp.org.uk](mailto:suzanne@mecopp.org.uk)

Kate Hogarth, Shared Care Scotland, [kate.hogarth@sharedcarescotland.com](mailto:kate.hogarth@sharedcarescotland.com)