



SOCIAL CARE

LISTENING FORUM



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Introduction

Since my election, I have received a constant flow of requests from constituents looking for support with issues relating to social care. The most common concerns include:

- **Budget Cuts:** Significant reductions in both social care provision and carer's respite budgets have left families struggling. Some carers have had to place loved ones in full-time care due to insufficient respite support.
- **Delays:** Hospital discharges and SDS assessments are frequently delayed, often taking months, which disrupts care and increases stress for carers.
- **Service Reductions:** Community services like day centres and transport are being cut or restructured, limiting access for vulnerable individuals.
- **Communication Failures:** Poor, inconsistent communication from social work departments is a recurring issue. Carers often feel uninformed, unsupported, and undervalued.
- **Low Trust:** Carers report feeling like they must constantly justify care needs, leading to frustration and a breakdown in trust with social services.

I wanted to hear more from people who were using social care services, so I held a Social Care Listening Forum in the Spring where I invited people from across the constituency to come and talk about their experiences of social care – what worked, what the challenges were, and what were their hopes going forward. Over 60 people attended the event, with a mix of people who use social care services and people who were caring for a family member. Pam Duncan-Glancy MSP and Cllr Margaret Cowie attended and I also invited various third sector groups who were able to offer advice and support to people who came along. My team followed the event up with visits to two community groups to hear from more service users.

It is clear that there are many people working across the public, third, and independent sectors who are committed to providing the best care that they can. However, it is also clear that the system is creaking and there are many people who feel that they and their loved ones are falling through the cracks. It is vital that the experiences of those who use care services are at the centre of all policy development and services planning. This report offers a snapshot of some of those experiences.



Summary

Five key themes came out of the discussions.

Processes

Many people found the assessment and review process difficult, particularly when accessing for the first time. They found the process lengthy and finance rather than needs led. The system focused on critical needs and did not look at broader well-being. People wanted a more person-centred, rights-based approach grounded in dignity, inclusion, and respect.

Resources

People valued existing services, particularly community-based supports, but highlighted a lack of scale and variety to fully meet the need. Hospital discharge was a particular problem, with people either staying in hospital longer than necessary or being discharged without support in place. People highlighted the risk that a lack of community-based resources will lead to more people needing full-time care.

Staff

Most people valued their social workers and carers, but some had negative experiences. Concerns were raised about staff shortages, frequent changes in social workers, and the pressure workers face, which can reduce their ability to provide empathetic care. Low pay and high stress were seen as contributing to staff turnover, leading to a loss of valuable skills and continuity in care.

Carers

People who were caring for a loved one described their role as meaningful but also relentless and undervalued. They described working around the clock with limited respite and support. They expressed frustration with limited and reducing carer budgets and inconsistency in how to use this budget.

Communication

Cutting across all themes was the issue of communication. Whether people were discussing assessments, care planning or budget decisions, poor communication consistently emerged as a barrier. People often felt uninformed, unsupported and left out of key decisions, with unclear guidance, inconsistent messaging and delays in responses from social work teams. Improving communication by making information clearer, more consistent, and more timely was seen as essential to improving outcomes across all aspects of social care.



Processes

Many people said they found the assessment and review processes challenging and difficult to navigate. This was a particular issue for people coming to the process for the first time. Information about the assessment can be hard to find, and the information available can be hard to understand for people who are not familiar with the system, or who are stressed when accessing it: *“at the beginning it’s very daunting”*. One person said, *“if I didn’t know other parents, I wouldn’t know what my child was entitled to.”*

Some people spoke about the length of time they have had to wait for assessments to be started, and then to be completed. People spoke about various frustrations with the system, including having to submit paperwork repeatedly.

The transition between children’s and adult services was identified as a challenge by several people. At this point, young adults are often moving on from structured and predictable support. If services are not put in place this can leave them unsupported: *“my son left school two years ago and I was promised college and a day centre but I’ve still not got the day centre.”*

Several people said they felt that the process is financially led and not focused on needs. They said they felt they were being asked to justify the financial spend on their child, rather than their child having a right to support: *“the attitude ‘this is council money’ – but he’s entitled to it.”* One person spoke about the Resource Allocation Group (RAG) which feels distant from service users, making significant decisions about people without anyone in the room advocating for the person about whom the decision is made. Self Directed Support was generally seen positively, although a few people suggested it was not being implemented as it should be. One person noted: *“we’re not criticising social work, we’re criticising the procedures and systems.”*

The banding system of assessing care needs as critical, substantial and occasional, was described by some people as a problem. They felt that there is a focus on meeting critical needs, but these cannot be seen in isolation as this does not take a holistic view of a person’s life.

The focus on critical needs does not take account of how important the other needs are for a person’s fulfilment. Two people spoke of different situations where their adult child lost a college place because the additional support that they would have needed to access the placement was not seen as critical. Where needs that are not assessed as critical are left unmet, this can put pressure on a person’s situation and over time can lead to a situation becoming unsustainable.

One person said they felt the system focused on deficits rather than potential. They found it frustrating to have so much focus on what they can’t do rather than what they can do, and to have to describe their worst day in order to get support: *“you have to describe your worst day, but all we want to do is be proud of our kids”*. Some people described a lack of concern for the potential of their children:



“I was told his education was a privilege”

“He’s been offered the chance to do a music course and my social worker said “what does he want to do that for?”

For carers, they see the person they love – someone with potential who is entitled to the support they need to achieve that potential and to live a good and fulfilling life, within their capacity: *“They didn’t ask to be like this, they should be treated with the dignity and respect that they deserve.”*

One person suggested that the process of assessment should be balanced by a focus on a person centred and rights-based approach, and founded on the values of inclusion, equality, respect, honesty, and transparency. These three together – process, approach, and values – would then make a triangle that ensure a holistic approach to assessment and care provision that put the person, not the process, at the heart of assessment.

Resources

People spoke well of many of the resources across the public, third and independent sectors, but they also highlighted the lack of the variety or scale of resources to fully meet need in the community. This means that people are not getting all the support they need to flourish and to achieve their potential. In particular, third sector services provided by charities and community groups such as churches were seen as vital in providing support for both service users and carers.

People told us that groups run by LEAP and Camglen Buddies, provided lifelines to them and their families and they wouldn’t know what to do without them. Some people noted these were not valued or funded as well as they should be. It was noted that there is very little choice in relation to care companies. Some people said they waited a long time to get adaptations to their homes. One person said they ended up paying privately for adaptations due to the length of the wait.

The lack of resources is a particular issue for people in hospital and waiting to be discharged. A lack of community-based support can lead to either people having to stay longer in hospital which puts financial pressure on the health and care system, or people leaving hospital without the care they need in place which can put pressure on relatives or risk a quick readmission to hospital:

“Delays with my care package meant I was in hospital for three months before my package was ready.”

“The only way I got out of hospital was to move in with my son.”



Some people identified specific gaps in service provision. These included a lack of facilities for young adults who are high functioning with severe disabilities, and for those who have challenging behaviour. A few people also mentioned the challenge in accessing GP services, which can add to the challenge in getting support. One person described the challenge of different health board boundaries. She was caring for someone who was in hospital in Glasgow and so had to travel to rehabilitation services in Gartnavel rather than in Hairmyres which would have been much easier to access.

Many people spoke about respite care. They identified this as an essential service to maintain people in the community and avoid the need for full time care. However, people also spoke about the significant lack of available respite. This included both breaks of a few hours, and overnight breaks. Some people said that their respite care budget had been cut without any consultation. Others were frustrated that the respite budget was capped. One person noted that their neighbour, who lives in a different local authority, has a significantly higher carers' budget.

Many people spoke about the implications of not adequately meeting the needs of people living in the community who are substantially cared for by unpaid carers. People acknowledged the financial constraints that the council faced but highlighted the longer-term consequences of not adequately resourcing community-based care: *"it seems to be a saving of money to spend more in the future"*. If you compare the cost of care in the community with putting someone in a care home, one person commented, *"it's a no brainer"*. Someone else commented: *"if we took all our kids to Almada Street and said we couldn't cope, it would cost six figures to look after them, we're just asking for thousands"*.

Staff

Many people spoke highly of the staff they had worked with, both the social workers carrying out assessments and the carers providing care. They used words such as "kind" and "caring" and spoke about how they took time to listen and understand, and to get to know both the person they were caring for, and their family. However, some people described less positive experiences. Some people said that at times it felt like workers were just going through a checklist. One person said: *"When I say I need help I feel I'm under suspicion."*

People identified several constraints they perceived that workers were operating under. They felt there were not enough social workers, and it was frustrating when they were allocated a new social worker due to staff absence or sickness. One person said, *"people go into social work because they are empathic, but in this role they are just budget managers."* Some people pointed out that levels of pay for carers are often low and so carers might be tempted to go and work in the supermarket, in a less stressful job for the same money. It was noted that whenever staff leave due to stress or pressure of work, whether carers or social workers, valuable skills and knowledge are lost.



Carers

Many of the people who took part in the listening forum were carers, either for their children (many now adults) who have significant disabilities, or for partners who have become frail or disabled in older age. They wanted to do this for the sake of their loved one: *“my life is giving him life”*. However, many people spoke about how constant and at times relentless their role was:

“We work 24/7, no holiday, for £1.20 an hour”

“As a carer you can’t call in sick”

“They tell you to find “me time” like you can just knit it”

“If you wrote the job description, no-one would take it on”

People spoke about the significant impact that the caring role can have on them and the whole family. It can be hard for the family to engage in ordinary social activities with wider family and friends. One person spoke about how hard it is to hear what their friends and family are up to: *“they tell me about their holidays – ‘I’ve been here and I’ve been there’ – I’m just lucky if I’ve been to Morrisons.”* Holidays can be a particular challenge, as the person cared for can struggle with the lack of their usual routine: *“we need a holiday after a holiday.”* and so it is often easier not to take holidays: *“the last holiday I had was before my son was born and he’s now 19”*. Someone spoke about the long-term impact of not being able to join in with social activities because of the struggle to find sitters: *“you don’t bother ... then the invitations just stop”*. Some people spoke about how the social isolation impacts siblings. It is harder for parents to include them in activities with their friends as it can be difficult to get them to activities, and sometimes they don’t get invited in the first place in case they bring their disabled sibling along. They identified that there should be more support for siblings.

Another concern that some carers highlighted was what would happen to the person they care for when they can’t care for them anymore, and who will be responsible for their care. One person said: *“his brother must think ‘I’m always going to have to look after him’”*. This is also a concern for people who are caring for partners with poor health or dementia – they are concerned about what will happen when they can’t manage or are not around anymore.

Many people spoke about issues with the carers budget. One issue was the level of the carers’ budgets. These were generally static or being reduced, sometimes by a significant amount, despite there being no assessed change in need. This leads to carers feeling undervalued:

“I have received an offer from SL health and social care partnership headed ‘Funded support for carers’ which says I as a carer am appreciated and valued. However, our carers budget has not increased since 2021 - instead of feeling appreciated/valued, we feel devalued each year, especially in a period of inflation.”



Another issue was the lack of guidance on how the budget can be spent. Decisions on what the budget can be used for are inconsistent. Several people said they wanted flexibility to use this budget in a way that is suited to their situation, but often felt they were not being trusted to decide what to spend the budget on. People said they would value clear and transparent guidance on this. It can also take a long time to get a carers' budget allocated, with one person saying they waited a year and a half.

Several people spoke of their frustration that if they receive carer's allowance they can't work more than 16 hours, and that if their pay goes over a certain limit they lose the whole allowance. Some people asked why Carer's Allowance is not paid to people on the state pension.

Appendix

Summary of casework issues relating to social care

18

cases related to **budget cuts** – specifically cuts to users' care budgets

13

cases related to **carer's budget cuts** – mostly around reduced or hard-to-access respite

9

cases involving **delayed hospital discharge** – where care packages weren't available

8

cases involving **assessment delays** – assessments taking 3–6 months to complete

6

cases about **closure or reduction of services** – e.g., the Wednesday Club nearly shutting

14

cases falling into a mix of **miscellaneous issues**



Budget cuts – service users – 18 cases

This relates to budget cuts in service users' budgets. In several instances, service users experienced budget reductions exceeding 50%, significantly affecting the capacity of carers to provide adequate support. Some families tried to make up the shortfall themselves, but not everyone could afford to. The team has pushed social work to review these cases, but positive outcomes have been rare.

Budget cuts – respite/carer budgets – 13 cases

This mainly affects those on SDS. Respite cuts have been even more severe than care provision cuts. The reduction in carer's budgets has been particularly severe, with a new cap of £3,500 replacing previous allocations of up to £15,000–£18,000. This has resulted in a substantial decrease in available respite – from approximately 25 nights per year to just 10 in some cases. A few families have had to move their loved ones into full-time care because they simply couldn't cope anymore – which ends up costing the council more. The team has managed to get a couple of budgets increased above the cap, but only twice.

Delayed Hospital Discharge – 9 cases

There have been cases where people were ready for discharge for over 8 weeks but remained in hospital for over eight weeks due to the unavailability of care packages. Following enquiries from the office, social work departments have generally responded positively and arranged the necessary support. However, it generally takes 6–8 weeks to hear back.

Delays in assessment process – 8 cases

Annual reassessments for those on SDS are taking 3–6 months to complete. This leaves carers in a constant state of stress, unsure of what services or budgets they can access. Whilst these discussions are ongoing, if they take longer than expected, in some cases people have been unable to access carers budgets etc or any new services, because the assessment process hasn't been completed. In some cases, assessments were wrapped up quickly after the team got involved, which was a relief.

Closure or reduction of Services – 6 cases

Examples include the potential closure or introduction of fees for the Wednesday Club, and the reduction of transportation services to and from clubs. Some day centres have begun requiring personal assistants (PAs) for certain attendees which is challenging if individuals lack the remaining budget or already allocate Independent Living Fund (ILF) resources elsewhere, leaving them with difficult choices.

Miscellaneous Cases – 14 cases

These include a variety of issues such as Power of Attorney (POA) enquiries, child welfare concerns, and problems with care homes. Some of these matters have been resolved successfully, while others remain unresolved.



Communication

Challenges

Communication is an underlying issue across all case types. Carers report not receiving regular communication from their social worker, despite trying to get in touch, and when they do it's not clear. They report not understanding what the various budgets are and not understanding which of those budgets they may be able to apply for/access. The processes in general are not communicated well to service users and carers, they often do not have any idea on how to get from say, beginning to end of an assessment for a budget and what happens when.

An example of this is the carer's budget, no one really knows what they can and cannot spend their carer's budget on. Some people were told they can spend it on anything for them, such as getting a massage or anything that would bring them some form of respite without formal respite facilities. However, it appears as though others have been told they can only spend it on formal respite arrangements. It feels like there is a lack of consistency.

How Carers and Service Users Are Feeling

Carers have noted that improvements in communication would improve their relationship and how they felt about social work in general. At the moment, carers feel like they are just a number and so are the people they care for, they have to fight tooth and nail to justify why the person they care for deserves care. One carer told me about how she wants to be able to sing the praises of her son, who she cares for, but instead she feels like she's always talking about things he can't do, in order to justify to social work why he needs help and support. Carers recognise that social work are under a significant amount of pressure, but they also feel that they shouldn't be penalised for that. Overall, carers do not feel appreciated for what they do, they feel let down and like they don't matter to social work. The relationship as it stands is not great and trust in the system is low.

Communication with my office

It's worth noting that communication between the social work department and my office is not good. Responses generally take around 7-8 weeks to be sent and often follow a generic format along the lines of: 'Thanks for raising these concerns on behalf of your constituents... we are working with the family to help resolve these issues and support them...thanks again for raising this...'. The responses are almost never helpful and always require multiple follow ups.
