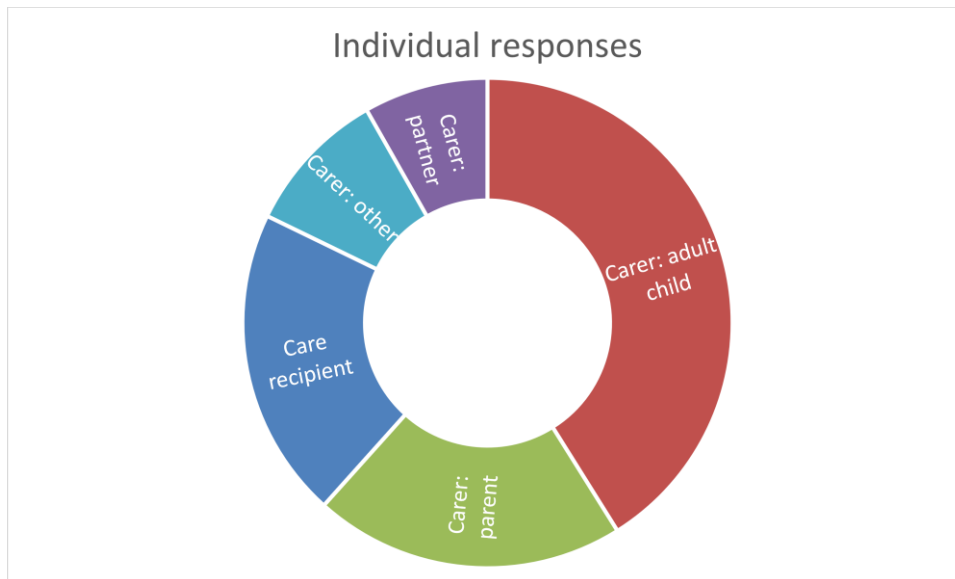


SOCIAL CARE INQUIRY: RESPONSES FROM MEMBERS OF PUBLIC

The call for views on Citizen Space received 73 responses from individuals who either receive care themselves or are a carer for someone else.



Individuals were asked two questions:

- *Tell us your story about your experience of social care in Scotland*
- *What would you change about your experience of social care?*

Some people also chose to answer the survey questions that organisational respondents were asked.

SUMMARY OF THEMES

Assessment of needs

Agreeing and delivering care packages can take a long time, be complex and have too many steps and too many people involved. A named person should be identified who would lead on planning and coordinating care for an individual.

“A shared assessment process and a single point of contact for primary Carer. At present I need to liaise with four separate agencies if there is a change to my Mum's routine.” (Carer for parent with dementia)

“My GP was no help and it was only through a friend that I found out about Direct Payments and being assessed for a care package... I have always experienced it as having to fight for anything I needed and who I engaged with often made the difference positively or negatively.” (Adult with degenerative condition)

“it took 2 years and 6 different social workers to finally get a budget for my daughter.” (Carer of disabled daughter)

Services can be a postcode lottery in terms of what is available and what charges are made. There should be national standards for care which are transportable between local authorities.

"Disabled people are apprehensive about moving home from one local authority area to another because they know that they will have to go through yet another assessment process. Most of them will have battled with social services for years to get the support that they have currently and are not keen to have to repeat the trauma..." (Adult with stroke)

"Same assessment models, same resources, equal budgets per head. Thus a Scotland wide social care policy, and not left to individual local authorities to interpret or misinterpret the policy." (Carer of daughter with complex care needs)

Needs assessment should be proactive and preventative, not crisis driven.

"Social care doesn't exist in isolation from other public services so it would be better for all local plans, NHS plans, third sector plans as well as individual care plans to consider this question. It is very hard to plan effectively in a crisis which is what social care is often used to manage." (Parent of daughter with learning disability)

Replies highlighted inconsistency in the way needs are assessed - between younger adults compared to older people, between children's services and those for over-18s and between people with different medical conditions.

"The distinction between medical needs and social care is often contrived, meaningless in real life etc. No one chooses to have dementia, MND, Parkinson's etc. so why should they be treated differently from say a cancer patient?" (Carer of parent with dementia)

"Care packages often seem oddly skewed e.g. a young autistic person with their own team in a dedicated unit with a car and holidays paid for vs a paraplegic with dementia with a care budget of £50 a week. These are hard choices, everyone is deserving of the best care but often the allocation of care provision looks quite random." (Carer of parent with dementia)

"The difference between children's and adults is vast but just because my son is older it doesn't mean he will require any less support in fact he needs more support." (Carer of son with disability)

Person-centred care/SDS

Emphasis on the need for creativity, flexibility and variety of services— one size doesn't fit all. Individuals should be able to commission the support they need, not a

pre-determined package. Services are time limited without taking account of individuals' needs and the needs of their carers.

"The social care system is not flexible, it's not responsive to change and it is very much NOT person centred. I cannot get low level flexible support to meet my needs as the system with agencies is set up for same time every week" (Adult with ME)

"Let people be creative with there SDS budget. Not everybody wants to go to Blackpool, or go to a centre each day and look at the same people...Trust the families of a person with an SDS budget to commission services themselves." (Carer)

"I would like local councils forbidden to prescribe e.g. 15 minutes for a shower, 15 mins for food preparation/eating/clearing up etc. I would like not to have to justify every minute of my time and needs. When severely physically disabled simple tasks take so much longer than 'normal' persons might imagine. 'Clients' should be trusted." (Care recipient)

"the 15-20 minute care visit is woefully short of what is actually required by anyone, but particularly for older people. it feels disrespectful, no matter how well intentioned the worker might be." (Carer for parent)

Only a small number of responses had positive stories to tell.

"I am always supported in a person-centred way and am fully involved in all decisions about my support. I have a team of 5 personal assistants who I choose. I am fully involved in the recruitment process from writing the job advert to taking part in interviews. (Adult with cerebral palsy)

"He has a great package of care and now has his own house with 24hr support. He is living as independent as possible in his local community. Support is provided by the third sector. This is an expensive package but this package keeps him stable and avoids hospital admissions and he is treated as an individual." (Parent of son with autism)

Carers and care recipients need to be more fully involved and listened to in decision making.

"No decisions should be taken without the direct involvement of the recipient / prospective recipient." (Adult with stroke)

"The SDS legislation is quite clear...the problem is the lack of resources to actually implement the principles of the legislation: involvement, collaboration, informed choice, participation & dignity." (Advocate for person seeking care package)

"I would like to know who is there to support me? Who makes sure I am able to carry out all the tasks I'm expected to carry out...I go along to care

meetings for my son, and I'm just expected to do the next 'thing' in his treatment plan without even being asked if I feel ok about this." (Carer)

Each organisation involved has its own rules, approach and culture e.g. in relation to procurement, administration of medicines. This can make it difficult to get consistent approaches across all the care providers.

Costs/finance

Decisions are felt to be driven by cost and the availability of budgets rather than needs assessments. Assessments should be more independent, with straightforward and independent complaints and appeal processes and more advocacy support available.

"I would like it to feel more personal and approachable rather than feeling like cuts are being made without thinking about my physical and mental needs"
(Adult care recipient)

"Assessments are not done based on the need of the person but on the cost of the care that will meet those needs" (Advocate for person seeking care)

"Roll out SDS properly with realistic budgets - after all if you can keep someone at home for £600 a week, it's a lot cheaper than residential care."
(Carer for parent with dementia)

"The subtext is always that people will try to con the system and claim to much/more than they are really entitled to. There is evidence from Australia that where people are really able to control their own care they actually spend less than when funding is controlled centrally." (Carer of son with LD)

"If all elements are approached with common sense and empathy, then it would all fall into place. Different departments are always concerned with their own budgets above all, and there is no incentive to save each other money or resources. Change that and provision will be better and cheaper overall."
(Carer of daughter with ME)

Alternatives to independent living

There are not enough options between staying in your own home and moving into a care home. Examples given of services that are difficult to find included:

- Community living developments with 24-hour care
- Affordable, accessible sheltered housing
- Suitable accommodation for specific conditions e.g. alcohol-related conditions
- Availability of different levels of independent living e.g. a choice of meals provided or cooking for self, individual supported flats
- Age-appropriate respite care for younger adults
- Respite care that doesn't separate couples

Staff

Caring staff should be better trained and paid higher wages – the work is generally seen as low status and low value. This leads to high turnover and lack of consistent care from known carers.

“the rate of pay does not properly reflect the effort, skills required or commitment that it takes to care for or support specific conditions or disabilities.” (Adult with stroke)

“Carers is a high turn over job as it is stressful and underpaid and often undervalued.” (Carer for partner)

Staff are required to work to tight timetables which are not consistent with providing high quality care.

“In my experience, the more caring the carer, the more likely they are to be disciplined by the manager who is more concerned about keeping to 15 minute time slots than delivering the kind of care that makes people feel valued.” (Carer of parent with dementia)

“Too many times we saw care workers having to rush from one place to another because of rotas being inadequately prepared, or working with 'total mobile' system which left no room for flexibility or initiative...It [total mobile system] sees people as tasks, not as people who need care and time, conversation and contact.” (Carer of parent with dementia)

Technology

Technology is useful but cannot replace real people. This is a particular issue in relation to night staff cover being replaced with remote monitoring.

“Having a box in the corner shout at you to ask if you’ve taken your tablets might be great for some people and humiliating and dehumanising for others” (Adult with ME)

“Since 2010 it has been a battle to keep his night support...The aim of his support organisation is to replace this with telecare technology. Lock my brother in and replace a support worker with sensory beams and cameras.” (Carer)

“Stop the move to using technology instead of people. Both have their place but technology is no substitute to having a conversation with someone, or having someone there to help someone feel safe and supported.” (Carer of parent with dementia)

Public involvement/consultation

The public should be consulted in a range of different ways to create understanding and public buy-in for the standards of care to be provided and how these will be financed. People with experience of receiving care should be involved in planning and commissioning services.

“Genuine community engagement via existing community groups and fora is most useful for the sharing of ideas, views and experience. The creation of new and specific fora to evidence engagement is tokenistic and results in consultation fatigue. (Carer)

“Consultation has to be honest. You won't be able to deliver on everything people want, but you have to show them how they can be involved in change. That if they've experienced the care system, that they're the experts and are the best people to ask what works and what needs to change”. Carer of parent with dementia)