

Scottish Universities Insight Institute project



From competition to collaboration: the interface between informal and formal carers

Partner country profile: Scotland

Context

Carer policy

The Carers (Scotland) Act 2016 gives carers rights to an adult carer support plan or young carer statement to identify each carer's personal outcomes and needs for support. It gives carers a right to services to support them, where they meet local eligibility criteria and includes a focus on breaks from caring. Carers have a right to be listened to in decisions about the care and support of the person they are caring for, including a responsibility on health boards in relation to carer involvement in discharge planning. There is further emphasis on early intervention and prevention which also underpins the duty on local authorities to provide information and advice to carers.

The latest National Carers Strategy was published in December 2022. The Ministerial Foreword acknowledges the key role and additional pressures on carers during the pandemic. It also identifies the current cost crisis in Scotland as a 'humanitarian emergency' which is disproportionately affecting carers and makes a commitment to supporting carers to achieve fulfilling lives alongside caring. Key aspects of the strategy are as follows:

- Supporting carers with recovery from covid
- Valuing, recognising and supporting carers including involvement in decision-making and uphold rights to information and breaks from caring
- Provide health and social care support to carers, including improved access to breaks from caring
- Social and financial inclusion through financial support, continued employment and education and participation in their community
- Support to young carers to avoid negative impacts on their education, social lives and future opportunities

Implementation

Across Scotland as a whole, a lot of implementation work has taken place on the Carers Act since 2018, supported by carer centres in each local authority area. There is more carer awareness and some carers have benefited from preventative support and services. There are examples of effective joined up support between statutory and third sector services for carers. However, implementation of the Act has been patchy.

There are currently serious concerns about the financial situation affecting all services in Scotland (and the UK) with moves already evident away from prevention and early intervention. This has serious implications for relationships between paid and unpaid carers

as there are fewer staff and a tendency to focus on crises with many families struggling to get the support they need. There is a sense, represented in the Carers Strategy, that alongside intended improvements, current efforts are focusing on avoiding reversals of previous gains for carers in face of the ‘humanitarian crisis.’ Implementation of the strategy is being monitored by a steering group, based on outcomes for carers.

What could help

We don’t need more policies. We do need to avoid increasing tension between paid and unpaid carers. We need to change the language so that both paid and unpaid caring are properly valued. Work is currently underway to add a care outcome to the Scotland’s national outcomes and this could be a step in the right direction. We need to prioritise relationships and partnership working in practice as well as within and between organisations to make policy work better and pull all our resources together in face of the current crisis. This includes creating safe spaces for dialogue and shared learning. There is also a need for recognition of the importance of relationships to both paid and unpaid carers, and that the time to do this effectively must be protected to avoid staff leaving their jobs and to promote carer wellbeing and national outcomes need to promote this.

Stories from Scotland

Workshop one (October 2023) Researcher

So I’m going to start with a story from a professional perspective. This is Lesley who is an occupational therapist who works in a local authority nearby and she says –

*I’m an OT and a while ago I was interviewing carers for my Masters dissertation about carer outcomes. I recorded my first interview as a student and thought it was good at the time, until I played it back to myself. I realised I wasn’t listening to the carer, I was focused on the processes of the system and was defending colleagues if the carer said anything negative about the service. I had thought I was person-centred but you don’t realise how much you have been conditioned by the system. With all the bureaucracy you are only partially listening as you have all the forms to fill in and boxes to tick. I realised **I was going to have to wear a different hat to learn to stop processing people and really listen to their stories.***

Thinking about the story we just shared, the idea of having to ‘wear a different hat’ is an important one in thinking about better collaboration between paid and unpaid carers and one we will come back to during this project. One other thing I wanted to mention is the implementation gap with carer policy. Recent research on social care in the UK for last 25 years, by Needham and Hall (2023) – asks why can’t we get it right across the 4 nations. The implementation gap is partly about the funding model – social care has been a Cinderella service for too long. But it is also about how we do what we do, and this came through in our discussion this morning. Needham and Hall emphasise that policies often contain inherent tension between standardisation which includes processes, measurement and tools, and on the other side differentiation and personalisation which includes an emphasis on relationships. And I think it’s fair to say that in Scotland we have had lots of progressive legislation with good intentions but very often within those policies there is tension between the values they incorporate and then the mechanisms which can act against the

principles. This bit about conversation, which we heard about this morning, and relationships; we have to make space for them.

Workshop two (December 2023) Unpaid carer

I'm Jaynie and I work for a carer organisation in Scotland. But I'm also an unpaid carer, for our son who is 26. He has moved into his own home with his own team back in March of this year. So it's still very new, but one of the things is that it's been incredibly important to us now and throughout the years with Ross's support is that we build relationships, relationships, relationships. And I need to have a relationship with the people that provide support to Ross. Ross doesn't really speak to communicate, so we rely on those around us and around him picking up on what he's saying without words to know that he's doing okay. So we have a family Whatsapp chat and we get an update every night about how Ross has been.

And I just wanted to give you a snapshot of three of Ross's support workers and what they feed back to us. Trust takes time. And Ross had been at an event in Glasgow Botanic Gardens. So Gillian had sent me a message, saying, just a wee update from myself and David to say we had a fabulous day with Ross. Ross really enjoyed it, and he was very chilled throughout with lots of photographs to follow. Both David and I feel very privileged to work with Ross and to be able to share these experiences with him. We are feeling very lucky and humbled. So that's the stuff that's incredibly important to me as a mum, and to hear that they are connecting with Ross.

So I suppose for me, those are my magic moments, and they're not always magic updates that we get for Ross, but they are becoming more and more as he becomes more settled and confident in his own home.

Workshop three (February 2024) Social worker

My name is Vicky, and I've been a social worker for 23 years. The situation for carers in our area is tragic. At present a cap has been set at 4 hours a week for support, and even requests at that level can be refused. I was struggling to think about a magic moment to share to day. But my situation has changed in the last week, and my story involves changing hat from paid to unpaid carer. My teenage daughter Charlie has just gone through an autism diagnosis. Without going into detail she has had an extremely difficult time the past 2 weeks, and I have had to take time off work.

I didn't fully grasp the reality of providing 24-hour support even for someone you love deeply. Until now the only outside support Charlie has is a support worker, Francis, who is wonderful and who tries to get her out for a run in the car once a week. Sometimes it works, and sometimes it doesn't. Francis is an amazing sounding board for me. I wouldn't cope without her.

The experience means that I've been thinking about my professional role supporting carers alongside my personal caring experience. I've noticed before that when I attend carers' events as a social worker it can help to build trust when I share a little of my own caring

situation. But I worry about what my role is when I know how little support is there for carers now. Giving people glimmers of hope can't be followed up by people being left alone and unsupported.