

Scottish Universities Insight Institute project



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

Partner country profile: Wales

Context

Carer policy:

The Social Services and Well-being (Wales) Act 2014 strengthened the statutory rights of unpaid carers. For the first time unpaid carers had an equal right to an assessment and support as those they care for. Unpaid carers no longer need to demonstrate that they provide substantial care on a regular basis to be considered a carer. If unpaid carers have needs that are eligible for support, the local authority has a statutory duty to plan for and meet those needs which involves providing a 'Carer's Support Plan.' Since 2000, there have been a series of Welsh Government (WG) strategies for unpaid carers, the latest being The Strategy for Unpaid Carers (2021), outlining four priorities:

- Identifying and valuing unpaid carers
- Providing information, advice and assistance
- Supporting life alongside caring
- Supporting unpaid carers in education and the workplace

More recently, WG have identified another priority for unpaid carers to have increased opportunities to take care of their health and well-being. WG are providing additional funding for this, and for unpaid carers to be able to take a break from their caring role.

Implementation

In general, the aspirations of WG policy do not match the experiences of unpaid carers in Wales. There continues to be dissatisfaction around Carer Assessments and related outcomes. Severe resource constraints and challenges in recruitment and retention of paid carers have put pressure on unpaid carers to 'fill the gap'. Parents of disabled children are facing huge waiting lists for additional needs assessments of their children, without which essential support cannot be provided. On a more positive note, recent WG investment in funding short breaks for unpaid carers has been well received and there are many examples of creative short breaks, with positive outcomes for carers and the people they support.

What could help

Ten years ago Social Care Wales ran a pilot focused on training for unpaid carers and how paid carers could work more in partnership with them. This went well and could be revisited.

An all-Wales Outcomes Focused Homecare Community of Practice is well attended. It is exploring all aspects of moving towards more relational and responsive service delivery and this is being developed in a number of pioneering local authorities and provider organisations, e.g. Gwynedd County Council and Vale of Glamorgan Council. The learning may catalyse developments in policy and practice development.

Stories from Wales

Workshop one (October 2023) Researcher

We do a lot of work around storytelling and I wanted to share both a magic and tragic moment, one from a paid carer and one from an unpaid carer. The first is a magic moment from North Wales and it's a home care worker.

I was providing care to an older lady and I noticed that she had a lot of cross stitch samplers on her walls. One day I visited and noticed that my uniform was coming apart and I asked her if she wouldn't mind lending me a needle and thread to fix it. Her eyes lit up and she said she would be pleased to mend it for me. I handed her the uniform and in no time it was as good as new. She asked me if any of my colleagues had any mending jobs too. I now look out for anything she can mend, for me and others.

The other is a tragic moment from South Wales, from a family carer of an older person.

I've worked as a nurse for many years and was looking forward to working with paid carers to look after my husband who had Motor Neuron Disease. On the first day I welcomed them at the door and took them in to meet my husband. What can I do to help I asked. To which one of them replied, Sorry we are only allowed to work on our own, it's health and safety rules. I was then asked to leave the room to give them space to work and I felt awful.

The thing I wanted to point out to you was the first one was a hidden example of kindness. The care worker was a bit embarrassed to tell us about the mending that the lady was doing because she hadn't been following the care plan. She had shown initiative and that is what I want to focus on. Care workers can't work responsively and creatively because they are too worried about following the rules or the care plan written by a social worker months ago.

A psychologist from the US called Barry Schwartz and he says good care workers are like jazz musicians. Jazz musicians need some notes, they need some rules, but when you have too many rules, jazz musicians can't improvise and they stop playing.

Workshop two (December 2023) Unpaid carer

So this is a little one, just a very short one from Wales called Burden lifting. It was about a person who's caring for her mother who has only been in the care home for a week.

I was feeling really, really guilty. I felt I'd let her down, but just couldn't carry on in our stressful relationship around keeping her in her own home. One of the care workers picked

up on my mood. She took and held my arm and said. You're still your mum's number one carer. But now you can focus on the good stuff. It was such a simple statement. but it made me cry, and my burden of guilt began to lift.

So it's very short, but it's a powerful little story about this thing of guilt which can be such a killer, really, for unpaid carers.

Workshop three (February 2024) Home care organiser

I have a story that is a bit tragic, but then goes to magic. A few years ago we were testing out a change in the way that we work, moving from home care based on time and task to a more flexible way of working, which supports families better.

And our initial journey into this is with a lady. We enthusiastically asked her what she wanted. And she had 2 visits a day. She had had a morning call for some personal care than a lunchtime call. Her unpaid carer was her husband, who still went to work everyday. So she identified three things she'd like to change if she could.

So she wanted to go swimming because her consultant had told her she needed to retain as much flexibility and movement as she could, because that would help her and she hadn't been swimming for years and years she wasn't confident at all.

She wanted to use a little static bike in her house to help build her strength too, but she couldn't get that bike out on her own. Thirdly she wanted us to iron her husband's shirts, for when he went to work every day, because he was doing so much for her.

So off we happily went to have this conversation, but the Council disagreed. They said we can look at the swimming, because that's like a social thing but we can't get the bike out, because that doesn't fit into any of our boxes, you know. And they wouldn't accept the ironing either. So we said, okay, let's phrase it all a different way. So we sat down, and we wrote about the benefits including mental health benefits, and they said ok, we'll give it a go. So we got the bike out while we were doing the ironing, and then we arranged once a week going to the pool. But over a journey of the next two years she became more confident and more fit. The relationship with her husband moved back to some of the way it had been before her diagnosis. Eventually we reduced her care. She doesn't have care with us now, but we're still in touch. Her husband then retired, and they have a really nice life. So it went from a little bit tragic to very magic.

Workshop four (April 2024) Senior Manager

In Wales, under the Social Services and Wellbeing Act 2014, we're allowed as local authorities to set our own charging policies. We don't have to charge people for care. However, because of financial constraints, I think most if not all local authorities do charge. So we write our own policies that have guidance that tells us how to go about it. And I'm not particularly fond of the guidance, because it does talk about hours and trying to calculate the cost of care which we all know is virtually impossible. And it tends to force us to think about our commissioning practices and about commissioning hours

of care, as opposed to commissioning in terms of relationships and the things that we value. And but I'm just going to talk you through a scenario that's very common.

And in Gwyneth, social workers go out and have conversations, do assessments and decide whether or not somebody needs care that we either commission or we help somebody source through a direct payment. So we go through that process and decide. Then, somebody needs maybe care in their own home, and as part of that conversation, very often it's identified that somebody is offering support as an unpaid carer.

Now our charging policy. Guidance nationally tells us that we cannot charge an unpaid carer, for support given to somebody to release the unpaid carer, to go off and live their own lives, and have a bit of a rest. So what happens very often is that the social worker tries to build a relationship with the individual in their family context and say, what would help? Well, if this person had bits of support, then it would help them have a good life, but also help the unpaid care to live their life. And they get into this tangle around trying to decide whether that care is for the person who needs the care? Or is it to help the unpaid carer have some time to themselves. That leads then to an awful lot of discussion, emails, different documents being filled in, and if they want to justify the fact that this is for the carer they have to go off and fill another set of documentation.

So for me, that's a little bit of a tragic moment that occurs very, very regularly every day, every hour of every day, in every local authority in Wales. I don't think that the people writing the guidance ever intended that you know, but they haven't thought through that guidance from a practitioner's perspective on the ground.

So now a little bit of a magic moment, and not quite in force yet. Since the first of April there's a new National Office for Care in Wales. Through that there's a new framework for commissioning. It includes many shoulds and musts, as guidance tends to do. But we do have a commissioning framework which has relationships at heart, and I'll read the core objective of bringing together services and support networks that will achieve the outcomes important to me. Now we have a set of principles and I'm going to reflect on some of those that I hope will help us drive the agenda around, making sure that unpaid carers are considered, and that the person needing support is considered within the context of their life. So there's one key principle that we'll need to adhere to about relationships matter. And I can't believe those words are in black and white and linked to legislation. But they are. Relationships matter. Another one is value is what matters, so really pushing us away from looking at the concept of value in monetary terms. But looking at the value to the individual and helping people have a good life. And there's a third one which is collaboration, sharing risks and resources. And if we think of one asset as being an unpaid carer, for me this principle is about making sure that we're all in it together, and nobody's ignored. So these are just 3 principles that are 8 or 9 in total. Maybe I'm being a little bit too optimistic. But the way I interpret these is that ultimately, if we ignore unpaid careers when we're looking at an individual who might need care, as we commission, then we'll be going against the statutory guidance. And I believe that the people who set up the framework truly believe that. This is about to be formally approved so hopefully next time I see some of you, I'll be able to say yes, this had the rubber stamp, and this is now what we, as Commissioners have to abide by.