COLLABORATION FOR CARE

Led by the Universities of Strathclyde and Dundee with Eurocarers

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OVERVIEW

"Collaboration for Care" was a knowledge exchange project which ran for seven months until April 2024. A range of partners working to improve support to informal carers in Scotland, Wales and the EU (under the umbrella of Eurocarers) wanted to work together and with others to promote collaboration in practice and policy (appendix 1). Recognising escalating international challenges from climate change, increasing poverty and inequality, to shortages of staff in key jobs, the project provided a timely opportunity to consider the question:

How do we promote collaboration between informal (unpaid) and formal (paid) carers despite enduring structural limitations?

The aim of the project was to inform more effective strategies to improve outcomes for informal carers and care receivers by exchanging knowledge about changing relationships between formal and informal care.

This project was led by the Universities of Strathclyde and Dundee, with diverse European partners. The first workshop in Glasgow was treated as an in-country study visit by Eurocarers, who funded ten EU delegates to attend. This project was warmly welcomed by UK delegates, given reduced European connections due to Brexit.

The project involved four workshops, each prioritising one set of voices. Workshop participants included informal and formal carers, commissioners, regulators, policy makers, researchers and others. While there was not a workshop dedicated specifically to care receiver perspectives, the emphasis on people receiving care is crucial and was stressed in all four workshops:

- Glasgow: October 2023, research perspectives
- Online: December 2023, unpaid/informal carer perspectives
- Online: February 2024, paid/formal carer perspectives
- Glasgow: April 2024, policy perspectives

We used methods from Developing Evidence Enriched Practice (DEEP), prioritising story and dialogue. Participating countries contributed a magic and/or tragic moment (story) to each workshop. We then used dialogic methods to exchange ideas, and reach new understandings.

This report blends existing resources from partners, magic/tragic moment stories from workshops and dialogue extracts (from audio recordings).
We have made sure to include stories and voices from all European partners. Some contributors provided stories in their home language. Extracts included here are all in English, translated from the original language where necessary.

While the project originally focused on the interface between informal and formal carers, we recognised the need for a tiered approach to support better working relationships, as reflected in the following three themes:

- ·Valuing care and making it visible
- ·Relationship based practice (including support planning) and
- ·Relationship based policy making and implementation.

At the request of our partners, the report has a strong focus on practice and further dialogue. Each theme therefore contains a guiding principle, key findings, relevant practices, plus points for discussion and related questions.

VALUING CARE AND MAKING IT VISIBLE

Principle

Caring is a distinctly human activity that can be complemented but not replaced by machines. Caring (informal & formal) forms the glue that holds societies together. Yet, caring is undervalued and needs to be made more visible.

Identifying a guiding framework for the project

One of the starting points for our project was the recognition that care and caring are not valued as they should be, and often remain invisible. From our first workshop, there was a consensus that societal attitudes and actions must shift to recognise caring as an essential human activity, with **care ethics** emerging as a guiding framework.

Care ethicists believe that responsibilities derive from relationships between particular people, rather than from abstract rules and principles; that decision-making should be empathy-based; and that personal relationships have a particular value often overlooked by other theories.

Through this lens, care is seen as both a practice and a way of being involving interrelated thought and action, usually directed towards an agreed end. Providing an integrated, holistic approach to meet concrete needs is the ideal of care.

On the most general level, Tronto and Fisher (1993: p103) suggest "that caring be viewed as a species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible." Care ethics speaks to the international challenges that give context to our project.

As a guiding framework for the project discussions, we found it pertinent on many levels, speaking not only to valuing care and the need for recognition, as emphasised in the EU care strategy (2022), but also to our considerations of relationship based practice and policy in the sections that follow.

Equalities and inclusion in caring

Inequalities and exclusion are arguably the most significant consequences of the societal failure to recognise and value care and were recurrent concerns throughout the workshops, impacting informal and formal carers.

The EU care strategy (2022) highlights the importance of providing support and services to informal carers whilst enabling them to balance caring responsibilities with work or education. The strategy also emphasises the importance of financial and social protection to prevent informal carers of all ages from being excluded, with implications for health, wellbeing and participation in life.

The most common observation during the first workshop was surprise that there was more commonality across European countries than differences. One prevalent theme, albeit to varying extents, was that caring is still predominantly carried out by women. This is also relevant to care ethics, which holds that caring is undervalued because it has traditionally been a female role. This was particularly emphasised in Tenerife, where it was identified that gender norms continue to shape the status of care and inadequate remuneration for informal caregiving, resulting in financial and social exclusion:

Currently, it [caring] is an obligation and the care system is depending on involuntary, unpaid, invisible work of family carers, mostly women, conditioned by tradition… and of course gender stereotypes. And stories like Raquel's are not an exception but a reality. I would like to finish with our caregivers demands: we don't seek any more applause; we need and ask for resources. This begins with a law that recognises, regulates and protects caregivers. (ACUFADE representative Tenerife, workshop one)

In Finland, it was noted that there was a stronger focus on financial support (in some cases) for informal carers, partly influenced by recognition that keeping people at home longer reduces the costs of residential care. However, speaking to care ethicists' concerns about the commodification of care, the emphasis on financial support had contributed to insufficient attention to good services and support for carers, with still some way to go to wider financial security for carers:

With our carer allowances, we focus too much on how much money they get – what is the level, should it be tax-free, what is the pension. We forgot the rest of the care aspects which are at least as important. (Researcher, Finland, workshop one)

Our first workshop involved discussion about the extent to which the skills of formal carers should or could be transferred to informal carers. There was a strong case made that this skills transfer is essential to sustaining care. However, on the other hand, the need to define limits on how far this could go was also identified, with concerns relating to professionalism and responsibilities, most firmly in relation to young carers:

We discussed the term 'young carer'. In some countries, there's a push not to see young people as carers....There was a danger of recognising a young carer that then actually places too much responsibility on them. (Discussion group, workshop 1)
And with young people... they are particularly vulnerable, and we need to make a particular effort with young people to make sure you know their future life isn't so compromised. (Discussion group, workshop 3)

Concerns about equality and inclusion for particular marginalised groups extended to formal carers. Project participants reminded us that although migrant care workers increasingly fill the gaps in services across countries, they face discrimination and poor pay and conditions. Alongside instances of positive interactions with migrant care workers, examples were shared where tensions with families receiving support could arise due to different cultural expectations, showing the need for investment in relationship building to avoid this.

Tronto (2005) argues for care as citizenship. This requires caring about the flourishing of people beyond those closest to us, including workers from the majority world who are increasingly deployed to do care work in European countries at lower financial cost without gaining status as citizens in the most fundamental sense.

More broadly, our discussions touched on the failure to value formal care as contributing to the continuing staffing crises. Further, as later expanded upon in our policy considerations, formal carers themselves expressed concerns during workshops about voice, particularly the lack of opportunities afforded them to contribute to strategy within their organisations or at any policy level.

Balancing social and economic value

In the workshop led by informal carers, we included the results of an informal carer diary exercise, led by an economist colleague, Emma Congreve, from Strathclyde. This exercise involved logging caring hours and calculating alternative costs of care. This was balanced with narrative data gathered in the diaries and qualitative analysis of more relational aspects of care. This included often very complex psychological and emotional dimensions, and the importance of just '*being there.*'

balancing
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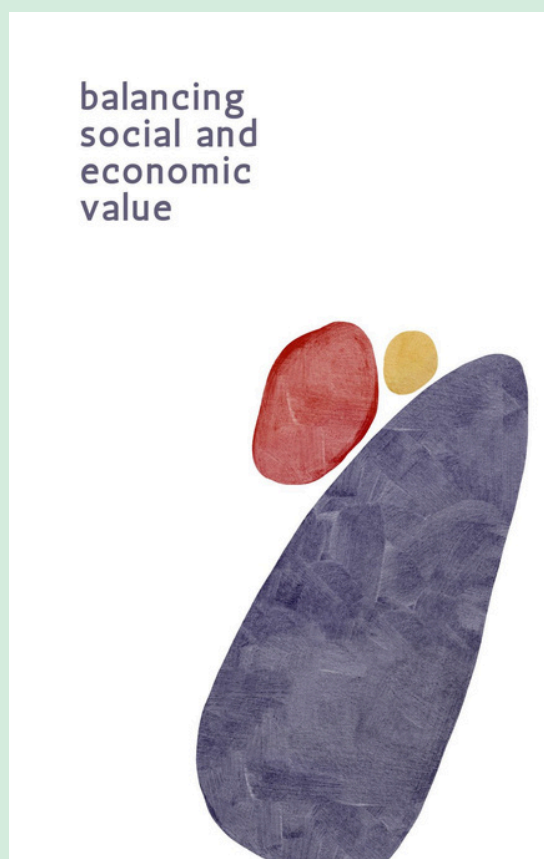
Throughout the project, there was debate about calculating the economic value of informal care in this way. The argument for doing so was to strengthen advocacy for care funding at the policy level; to simplify complex issues to avoid them being ignored. This necessarily involves crude assumptions about care to produce the figures.

While different views about this persisted, there was agreement that balancing the statistics with qualitative evidence at individual level brings authenticity and can increase impact. Most importantly, the relational aspects of care cannot be captured by time-use figures alone. Understanding the full value of caring – economic, relational and social - involves including stories.

Examples of less quantifiable and often hidden aspects of informal caring included:

- When care is needed – and how pervasive this is – sometimes throughout the day and night – versus concerted blocks of time
- Highlighting collaboration when formal carers are in attendance (helping, calming etc.)
- The nature of care (with psychological /emotional care sometimes not considered alongside personal care)
- Preparation for the next day / never switching off
- The mix of skills required – and how little they align with minimum wage assumptions

Learning from our project also highlights that within the spectrum of formal caring professions or roles, there can be a tendency across countries to place higher value on roles that are more technical and less care-focused. Jobs with the title 'carer' or 'support worker' are often underpaid, with people in those roles less likely to have a voice in the system compared with those in more professionalised roles.

At the same time, campaigns for remunerating informal carers are evident across countries. There are existing policies to pay carer allowances in some countries, but, even in the most generous case of Finland, many carers are still excluded. There is a campaign in Ireland for a participation income. Financial and social inclusion is essential to maintain wellbeing and sustain a workforce.

Practices

Here we identify several practices and approaches found to promote the caring role, increase the visibility of caring and address attendant concerns regarding equality and financial and social inclusion.

The (appropriate) use of stories and dialogue in promoting good practice and policy is essential, reinforced by project feedback stating that what people remember are the stories. Stories used as a stimulus for dialogue invite others to share their stories, thus building a broader picture from different perspectives.

Stories also emerge as an essential component of attempts to quantify informal care in financial terms, bringing often hidden aspects of caring and different types of value to light.

Our EU carer policy story points to different methodologies available that focus on the contribution of informal carers to society rather than the cost of such care.
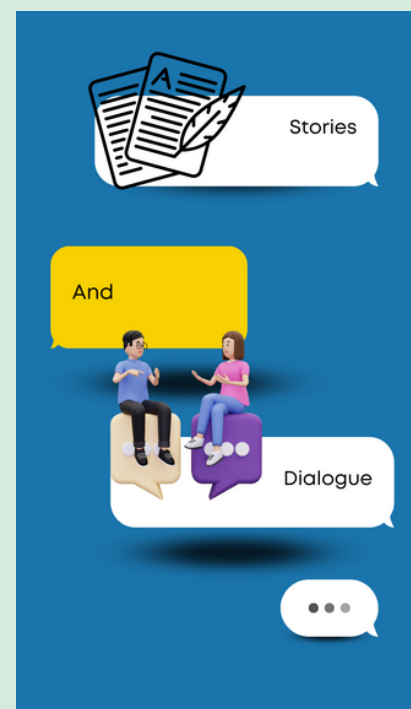
Blending stories and statistics can be effective in engaging media attention, painting a broader picture of care and raising awareness of caring to a wider audience. Stories are needed to bring the care phenomenon to the everyday level/individual level. Many of the research and informal carer organisations participating in our project are well placed in blending different types of evidence. Importantly, this includes skills in analysing qualitative data; that is to say carefully analysing multiple stories to tell a bigger story (Miiler and Barrie, 2016).

European Carers Day and National Carer days/weeks also contribute to growing awareness of informal caring. Many of our partner organisations have amassed understanding of and expertise in the hard work needed to make these events successful.

The inclusion of the voices of informal carers at all levels is seen as essential. There are examples of strategic representation of supported people and informal carers and materials to support this.

The Young Carers Covenant is a UK-wide commitment setting out ten key outcomes that young carers from across the UK have said are key to improving their lives. Any organisation or individual in a position to take action to help achieve these outcomes is urged to sign up to the Covenant. The Covenant was launched on Young Carers Action Day 2024. The Carers Trust in Scotland promotes recognition and support of young carers in school.

Finally, although this project purposefully included formal carers, there is less focus in general on their inclusion in policy making, with more attention beginning to be paid to informal carer involvement. it is essential to extend formal carer participation in developing and embedding strategy at organisation and policy level if we are to begin to address the implementation gap, and the continuing staffing crises.

Discussion Point

Tronto talks about caring as a species activity. It shouldn't be something that happens out there. It is about all of us. (Last words, workshop 1)

Questions

How do we bring our own experiences and encourage people we work with to think about their personal experiences rather than seeing the roles as separate?

Do we need a blend of stories and statistics to make the case for care, and what blended examples already exist?

How might we use our international learning e.g. Contrast between Tenerife and Finland to reinforce the need for both financial and social support for informal carers?

European carers day and national carer days/weeks already contribute to awareness raising - could there be a day for both informal and formal carers – in addition to or perhaps as part of a national carer week?

RELATIONSHIP BASED PRACTICE

Principle

The importance of relationships to both formal and informal carers, as well as people being cared for, is clear. These relationships can become strained in the face of financial and structural pressures. A focus on developing shared purpose and collaboration can help, whether at the individual or collective level. Policy has a role in creating the conditions for relationship-based care rather than being prescriptive or adding more tick boxes

Relationships, emotion and reflexivity

As discussed in the previous section on valuing care, care ethics was an important framework for our project. Care ethics entail shifting the focus away from rules and rights towards responsibilities and relationships. Relationships inherently involve mutuality – and the nature of these relationships will vary in each situation, reflecting personality, preferences and the nature of any existing personal or professional relationship. When viewed through a care ethics lens, the nature of caring relationships becomes less binary and roles less fixed. Fluidity does not lend itself well to tick boxes, but it is necessary for relationship based care which in turn is essential for human flourishing.

Many examples underscoring the importance of relationships between different actors in caring situations were shared in workshops. One parent carer shared her family's positive experience of a new paid carer from the Congo and the value of the distinctive type of relationship he developed with her son:

But what I noticed with Daniel this time was that he's so connected with Bhuto…Normally Daniel would have a meltdown after school but, with Bhuto there, he laughs, he smiles, he engages. Daniel vocalises and Bhuto vocalises every sound back to Daniel, making Daniel feel respected. It is important to have that friendship with Bhuto, separate from me (Informal carer, Ireland)

Alongside relationships, another human factor underplayed in most systems is emotions. Stories shared by participants emphasised the importance of recognising, attending to and being unafraid of emotions in caring work. An occupational therapist from Tenerife highlighted how impactful this can be by sharing an example of work to improve the quality of life of older adults with dementia and their family caregivers through sensory experiences:

My patient, due to Alzheimers was experiencing moments of disorientation at home, causing episodes of agitation and high level of stress. She couldn't stop crying. Her family caregiver did not know how to relax her mother, causing her frustration in her daily life. After seeing the situation, I proposed that the patient and her family caregiver attend a sensory stimulation session together to evoke positive and relaxing emotions after the session. The patient told me: "You have changed my daughter and my life. Thank you". (Formal carer, workshop 3)

Emotional intelligence is an extremely valuable attribute but is often undervalued compared to technical competencies. The importance of honest conversation in building trust and beneficial relationships between informal and formal carers was clear:

And I think quite often we were talking about how a bit of defensiveness can creep in whenever the system is difficult. That it's not surprising now that many care workers are feeling under stress and quite burnt out and overworked. And similarly, carers are feeling the same. So they're starting from a very difficult position, and that can lead to difficulties in terms of the relationship. But that's not to say that even in very difficult contexts, with care and support, you can't develop a good relationship. So, we talked about how being honest and instead of, you know, sitting, filling in forms and thinking, I must ask this question because it's got to go on a database… to actually have a conversation and be honest with each other. Even the conversation, and despite what it may or may not lead to can be really affirmative in itself. So that's really important. (Group discussion, workshop 3)

There was a strong sense that even formal care practitioners who begin with high levels of emotional intelligence can become ground down by uncaring systems, with bureaucracy and box ticking identified as barriers. This raised questions of whether training is the right route for supporting relational practice, with a view that, instead of or in addition to current practice, systems need to support relational practice continuously:

We spoke about training…It wasn't about working in relational ways. And a lot of that is almost best learnt on the job through reflective, everyday practice and supervision, rather than going into a classroom setting. It's…creating those reflective practitioners, isn't it, really, who are responsive and creative (Discussion group, workshop 3)

Research on relationship based practice emphasises the importance of reflexivity as the 'key determinant' in making it work (Ruch 2005, p115). Reflexivity requires time to think and space to reflect on work. Other research emerging during our project emphasised the importance of the context in which formal carers work: For relationship-centred practice to become widely embedded, we all need the knowledge and skills to build relationships, and we need to be supported by processes, protocols and norms which liberate relational work. (Lloyd Rose et al 2024).

Boundaries and setting expectations

Boundary setting was another important sub-theme. Exploring and understanding the expectations of both the informal and formal carer (and the person being supported) at an early stage can avoid misalignment, disappointment and frustration. Again, these conversations take time but save a great deal of time later, improving outcomes for people. Informal carers from different countries identified the importance of trust, in handing over the care of the person they care for to others. This included being able to define preferred ways of communicating at an early stage, as well as connection:

I believe that if all these people are going to be in my son's life, if they are going to make a difference, we have to have a connection. They have to be able to connect not only with him but with me. (Informal carer, Finland)

I need to have a relationship with the people that provide support to Ross. Ross doesn't 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 (Informal carer, Scotland)

Equally, there were references to the expectations and communication needs of formal carers. From the paid carers' perspective, the importance of making communication manageable on both sides included avoiding situations where diverse carers within a family express divergent views:

We talked about some of the difficulties that paid carers may have, identifying unpaid carers within the family. And who's all contributing to that care and finding one voice in the family. It can also be too complicated within some of those relationships, and then managing expectations with multiple voices involved. (Discussion group, workshop 3)

A practitioner identified additional struggles when family carers only communicate instructions without dialogue or negotiation, which in turn can impact outcomes for the person being supported:

For me, the biggest problem is communication. Some family carers only communicate with me through instruction sheets. Sometimes I would like more support from them. If they also encouraged their relatives to go for walks outside, for example, it would be easier for me to persuade people to be more active (Discussion group, workshop 4)

For formal carers, being able to support informal carers effectively over time could require boundary setting to maintain wellbeing:

We touched on professional boundaries again, and the emotional labour. When you really care about people, how that comes at a price, really? And how do we support people through that… And how do we get the balance between getting over involved and under involved? (Discussion group, workshop 3)

Again effective supervision and reflection on practice was deemed important for formal carers, although often unavailable.

Access to resources

A concern across all countries was the limitations in resources available to support informal carers. This was viewed in part as a reflection on the value attached to caring alongside the economic challenges facing countries. The potential impact on the caring interface was significant. One social worker in Scotland described the situation for informal carers in her local authority as moving to *'tragic'* as resources had become so restricted. She worried about the risk of people being *'left alone and unsupported'* and about the impact on her role.

It is important to acknowledge that many meaningful moments centred on small, often relational, actions that had made a difference to people. One example was a social worker in Ireland who had gone *'old school'* to establish contact with an older carer who had not responded to emails or phone calls. She decided to reach out by sending a letter, which the carer responded to, and which she reported *"gave me hope that somebody really cared."*

While small actions can be significant, formal carers also need access to resources to maintain hope and feel equipped to support families and informal carers.

A further challenge is that the time, identified above as promoting relationships, is further reduced when resources are constrained.

Yet time to talk may be the ingredient that holds things together for people and gives meaning to care staff, helping them avoid leaving their job.

Building trust and navigating complex family dynamics are core in caregiving contexts. Our project underscores the importance of time, flexibility and responsiveness in fostering meaningful relationships between all carers and care recipients.

Stories from across countries emphasise the need for connections and shared experiences, whether through joint training sessions, family WhatsApp chats, or simple acts of kindness like sharing coffee or food. The importance of consistent support is not a new theme for building trust and relationships. Organisations must keep striving for this, and approaches to commissioning services play a key role, which we will discuss further in the policy section.

Support planning

Principle

Support planning is viewed as a key component of relationship based practice. This should value all perspectives, include a whole family focus and enable flexibility and responsiveness rather than being driven by rigid guidelines

Several countries referenced the value of family-based approaches to support planning. While it is important to engage with individuals to ensure their perspectives are included, and they can speak freely, partners have identified that focusing exclusively on one person in the family can undermine important aspects of family life, strengths and connectivity.

The Eurocarers research group report from Ancona (2023) identifies features of services viewed positively by delegates which are of relevance to support planning, including single points of access to avoid people having to repeat their story and multi-disciplinary approaches that support holism.

Our discussions indicate that the support plan has come to be viewed as a bureaucratic process in several countries. Associated with this, there is a significant challenge with rigidity with both completing support plans and subsequently with any changes to them:

At the moment in the municipality where I work we have to cut back on care. Instead of cleaning house every two weeks it is every four weeks. The law says it has to be an individual assessment. So before we can change how the house is cleaned, this army of office workers goes through the paperwork to find cuts in time per month. It is ridiculous duvet of admin that is growing exponentially. We have to value trust over control. It is hard. (Denmark, workshop1)

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In Wales, difficulties could arise in justifying whether support is for the cared for person or the informal carer:

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. (Senior manager, workshop 4).

However, done well, the process presents valuable opportunities to build understanding and trust. By prioritising flexibility, responsiveness, and collaboration, support planning can better address the diverse needs of families. Working together like this also corresponds with the meaning craved by formal carers, fostering relationships within care settings (Miller et al 2022).

Every part of support planning needs to be flexible, not rigid. Practitioners need to know that they can make changes without having to fill out another set of forms.

Practices

The following practices relate to relationship based practice in general as well as to support planning.

A range of knowledge exchange projects and networks exist amongst members with a focus on both promoting relational practice and policy (see policy section). Many of these use stories to help illustrate what works, and as a stimulus to encourage others to contribute stories, helping to build a fuller picture of phenomena.

In Scotland, where the current situation is one of dwindling resource, a great deal of effort is being invested in local areas to map out all the community-based supports that are available to improve the situation of carers who are not deemed eligible for statutory services.

The Triangle of Care helps mental health services support carers by providing information, advice and support that carers require to continue in their roles as expert partners in care. It is particularly focused on mental health services.

There is a version of the Triangle of Care for Children and Adolescent Mental Health Services which includes specific information about supporting young carers and sibling carers.

Mike Nolan's Senses Framework provides an excellent resource for tripartite caring – considering older people, family carers and staff.

Outcome focused support planning can help to support inclusion of the informal carer perspective (alongside that of the family as appropriate). Work from the Meaningful and Measurable project identified five criteria that can be used to develop a good outcomes plan:

- Outcomes (what the person/family wants to change/maintain) not just outputs (services)
- Outcomes should be personalised e.g. what does increased confidence mean to that person/family
- The voice of the person/family should be included
- The role that the person/family want to play should be included, not just what others do
- The plan should be action oriented (Miller and Barrie 2016)

There are additional resources available to facilitate planning with young carers, often with emphasis on a conversational approach and goals and outcomes that matter to the young person. In Scotland this is known as a young carer statement.

Discussion Point

We spent time debating whether Relationship Based Practice (RBP) should be better defined. The discussion increasingly leaned away from a prescriptive approach towards the role of policy and organisations in creating the conditions for RBP, including allowing time to talk. Practitioners also need to be able to reflect on their practice to enable informal carers to reflect on their situation, with many informal carers often lost in intensive caring roles. Reflexivity is also important in navigating the emotions involved in caring. There is also a need to acknowledge and work through tensions between standards/rules and the flexibility and responsiveness advocated by care ethicists and advocates of RBP

Questions

What are the responsibilities of different stakeholders in creating the conditions for relationship based practice?

What shifts in culture policy and practice are required to enable this in your setting?

What contribution can you make and who else can you involve?

RELATIONSHIP BASED POLICY MAKING & IMPLEMENTATION

Principle

Putting social policy into practice effectively and consistently requires continuous knowledge exchange, based on a relational and responsive approach. This should be based on honesty about the challenges and draw on the resources of all partners. Further, in implementing policy, there is a need to balance the relationships and outcomes that people value, which are less amenable to quantification than task and time, which currently predominate in policy making and evaluation

The Implementation gap and the problem of bureaucracy

Recent research on social care in the UK for last 25 years, by Needham and Hall (2023) asks why we can't 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. Echoing the concerns of care ethicists, the authors emphasise that policies often contain inherent tensions between standardisation, including processes, measurement and tools, and differentiation and personalisation which emphasise relationships. This observation has international salience. As one partner commented, in the face of the current staffing crisis across countries, there is a need to consider what bureaucracy can be removed to make space for relationships:

We want to build something, we have to build it above something. And there is rules and more rules and more paperwork and more bureaucracy which takes time away. And – if we want something new – we have to think of something we can let go. That is the conversation we are having in Finland at the moment. We have lack of staff in both health and social services. So what tasks can be taken away (Finland, workshop1)

Insights from neuroscience (McGilchrist, 2019) and care ethics suggest that transactional schemes and systems may obscure the human dimension of care, leading to a focus on procedural intricacies rather than human needs.

From care ethics, echoing many of the voices in this project: '[i]t is not just that highly mathematicised schemes are inevitably artificial ... but they tend to fix our attention on their own game-like quality. We become absorbed in the intricacies of the game instead of the plight of real people' (Noddings 2002, 60).

Throughout the project, we could see the frustrations with bureaucracy and IT systems playing out at all levels:

Government representative: *Social workers want to promote rights for people. But the system is getting in the way. The challenge of the system, the bureaucracy, the process is getting in the way of really creative practice. (Presentation, workshop 4)*

Strategic manager: *But what has been frustrating is not finding an IT system to schedule carer time that isn't driven by small time slots. We are challenging that part of the system now and we hope to get people at Welsh government level to recognise that IT systems can't be driving the system. If we can change the conditions for formal staff it will make a massive difference for families. (Group discussion, workshop 1)*

Formal carer: *We don't always ask the informal carers but likewise we don't always ask the people doing the job what would make things easier. Where I work there are lot of people with job titles like business manager for blah blah and policy decider. They may be good at their jobs, but they have never done our jobs, they have never been a carer, they have come from business school….That makes it difficult….But then we develop these systems that get add-ons and nobody stops to think first, how does that affect the people we support and the people on the frontline. Then burnout sets in. (Group discussion, workshop 1)*

Informal carer: *I have never enjoyed filling in forms. Now at age 88, as a carer for my wife who has multiple health conditions and cognitive impairment, the bureaucracy that we face on a daily basis is exhausting. I have help from different NHS and local authority staff who come into support my wife but every time there is a change or new service it means you have to sit and answer all their questions and also I have to complete exhaustive questionnaires. (Unable to attend the workshops so contributed by interview)*

These four examples illustrate pervasive experiences of bureaucracy stifling creativity, job satisfaction and wellbeing and outcomes for carers.

Policy stories illustrating challenges and strategies

Our partner policy stories illustrate that some of the complexities faced by policy makers and implementers run in parallel to those faced by formal care practitioners and managers. These include frustration with competing agendas, plus misunderstandings and conflict due to a lack of time to talk. Policy stories from all countries identified lack of resources in terms of services to support informal carers as well as lack of resource for implementation.

An example of the latter was found in Slovenia where, despite working long hours, a small team of policy staff were struggling to implement new policy on payments to family carers, with the team being very concerned about the human costs of this. The team member interviewed shared the human pain experienced by staff working 'from morning to evening and without holidays' to no avail, describing a sense of powerlessness. On the other hand, the same policy maker shared a 'magic moment,' when a longstanding conflict was resolved through a face-to-face encounter at an event, where a 'lot of bad blood was removed' and a way forward identified.

In Ireland, the introduction of a standardised carer assessment tool was viewed positively by both policy makers and our third sector partner. However, while the third sector partner was positive about the opportunities for collaboration and for raising awareness about carers needs, they were hoping for further changes to support a more conversational and flexible approach that could work better for both formal and informal carers, again illustrating the tensions between standardisation and relational and responsive approaches in policy.

In Portugal, the emphasis was on stalled implementation of recent carer legislation and recognition that the best means of translating policy into action will be through strong leadership and integration between agencies at local level. Challenges within the hierarchy of formal carers were also impeding implementation of multi-disciplinary aspects of the legislation, with nurses sometimes unable to speak to psychologists and doctors within the health unit. There is currently appetite for developing carer support planning that is not onerous, to support interagency working that improves outcomes for carers.

The EU level policy story comprised several strands including the need to be opportunistic and "find entry points for our messages in places… that do not seem comfortable at first glance." This did not necessarily mean changing the message completely, but rather reframing it or learning the new terminology. Linked to this, another strand required being ready to face unexpected adversaries. Compromise was also emphasised to avoid 'making perfect the enemy of the good', alongside patience and tenacity – such as attending more than 150 meetings over three years to influence the first legislative act explicitly supporting informal carers.

While the emphasis and content of our policy stories varied, overall they underscore the importance of relational policy making and implementation in fostering collaboration between formal and informal carers, and more broadly.

Practices

Effective policy making and implementation requires collaboration, dialogue and story, as illustrated by our policy story tellers and responses to them.

"I was struck by the policy inputs and the way they can become focused on particular solutions. There is a balance to strike between what seems achievable and what is really important, and perhaps merit in opening up the conversation to see what solutions others might bring." (Final reflections, workshop 4)

Image: G Renee Guzlas
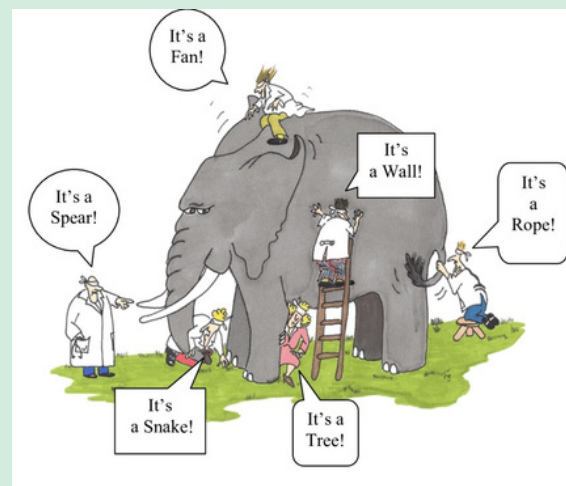
The need to use story carefully was emphasised. For people sharing lived experiences (at all levels) there was a need to ensure that they were given time to prepare and to reflect on how much they wanted to share. In all cases, story should be used not to manipulate but to open up reflection and conversation:

Use of story can be overplayed if not done right. Sometimes you can see them being used as a way of manipulation and that makes people wary. However, where they are used to encourage people to tell their own stories and as a tool for wider communication, they can help build understanding and trust. (Last words, workshop 4)

Many of our partners are involved in interdisciplinary projects and networks which aim to reimagine care relations, practices, and policies by prioritising diverse voices. These projects emphasise a dialogic and narrative approach to practice, recognising the importance of internal and external working relations in fostering effective care debates:
- Blended Learning Networks (Sweden)
- WellCare (Led by Sweden involving 5 EU countries)
- Developing Evidence Enriched Practice (Wales)
- Personal Outcomes Network (Scotland)
- Care Visions (Ireland)
- Ageing Communities (Slovenia)
- Care Visions (Ireland)
- All Wales Outcomes Focused Homecare Community of Practice

With regard to the latter, our Welsh partner explained:

An all-Wales Outcomes Focused Homecare Community of Practice is well attended. It is exploring all aspects of moving towards relational and responsive service delivery and this is being developed in a number of pioneering local authorities and provider organisations... The learning should catalyse developments in policy and practice development.

The work in Wales on outcomes focused home care has linked to national developments on a new commissioning framework. This includes seven principles with the first being "relationships matter' with further principles matching many of the themes identified in this project, including valuing what matters to people and collaboration (appendix 2).

Discussion Point

We have noticed that in communities where there are alliances between city councils and third sector, health professionals invest their knowledge. Where there is integrated care, supported by leadership, we have better quality of collaboration between informal and formal care. Our thesis is that if we invest in these fields we can really change the quality of collaboration between formal and informal care – putting the carers in the centre of the system, which they are not in the moment. (Portugal)

Questions

Can we use some of our learning about boundary setting and defining expectations to improve understanding of roles in integrated working?

What tools and methods can we use to help to define shared purpose, whilst allowing for different views to surface?

How can you show leadership in your role in promoting better partnership working?

The widespread recognition of the 'duvet of admin that is growing exponentially' begs the question – why can't we reduce this burden?

Final Discussion Point

In response to the prompt: what would help, the policy story from Finland stated: "*Care needs to be discussed as whole, not just focus on parts like informal care, homecare or long-term care. They all effect each other*".

Over the course of the project, other partners also spoke of the need to consider 'care' more holistically:

Before I joined this project I thought of informal and formal carers as two separate themes. In our local authority we have two separate teams working on them, and that would be the same at Welsh government level. Even in that short time I see them as part of the same picture. It's that synergy we need to be looking for. (Wales, workshop 4)

Questions

How might we begin to have discussions about care as a whole?

How can we create space for synergy between informal and formal carers?

CONCLUSION

This project sought to bring together diverse stakeholders from multiple European countries to address the question:

How do we promote collaboration between informal and formal carers despite enduring structural limitations?

Looking across countries, participants identified more similarities than differences.

One key difference was the extent to which policy for informal carers has developed in each country. Others linked to the level of resource devoted to supporting informal carers and to varying salary scales for formal carers from different countries. There were also differences in both the type and stage of development of supports available to informal carers, notably young carers, with varying emphases on economic and social considerations. For example, some countries have invested significantly in carer support planning with others at the very early stages of doing so. There are further opportunities for collaboration and international knowledge exchange on many of these points of difference.

Similarities between countries align with our three key themes. Notwithstanding different fiscal policies relating to carer support, care and caring are undervalued across the board – which is why care ethics was identified as relevant by researchers from different countries. As highlighted by care ethicists, relationships are necessary to generate good care, and consciously making space and time to build these.

While the project initially focused closely on the interface between informal and formal carers, we recognised the need for a tiered approach to support better working relationships and mitigate any tensions at the 'frontline'. In our project the need for relationship-based practice and relationship-based policy making and implementation generated overwhelming consensus.

When the project started, there was interest in defining relationship-based practice. This interest shifted as the workshops progressed, to focus on principles and creating the conditions for relationships rather than adopting a prescriptive approach.

Some important principles and practices included investing the time in developing mutual understanding from the earliest stage. Opportunities for building connections and sharing experiences, such as joint training initiatives were also highlighted, along with defining roles, expectations and boundaries – based on honesty and trust. One of the key barriers to positive relationships between formal carers and those involved in family caring situations was the 'duvet of admin' identified by one of our EU participants. While good data are essential to plan and evaluate services, a lot of associated processes are superfluous and crush the potential for meaningful connection which requires a flexible and responsive approach.

For any formal carer to practice responsively requires organisational support and the right policies in place. However, **policy-making and implementation are social processes which need to be relationship based too**. There is a tendency to assume that implementation is an administrative chore, requiring organisations to put the right tools and processes in place. This leads to the well-known characterisation of implementation as the process between "great expectations" and "ruined hopes" (Pressman & Wildavsky, 1974).

A fundamental principle of DEEP is that all perspectives should not only be included but also equally valued. We can't develop support and services well if we don't understand what good looks like from each perspective. DEEP also emphasises the importance of story and dialogue at all levels. This involves using story to prompt dialogue and to generate further stories; exploring different perspectives at the level of practice on the ground and in creating and implementing policy at organisational, regional, national and, as with this project, EU level.

The concept of 'the middle ground' was mentioned frequently in our workshops. This relates both to practice and policy-making. The need for honesty, trust and compromise was threaded through the policy and practice stories shared. Consistent with this, the idea of progressive realisation comes from international human rights law and focuses on implementation. Underpinning this, there is a sense that, when the circumstances are as challenging as they are just now, 'good enough for now' may be a good place to aim for short term, backed by continuing negotiation to achieve 'as good as we can get' longer term.

ACKNOWLEDGEMENTS

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APPENDIX 1: PROJECT PARTNERS

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APPENDIX 2

National [commissioning, planning, procurement and contracting] standards for care & support in Wales:
Report of National Framework Task & Finish Group (November 2022)

Principles

Central to the principles of consistent, transformative commissioning, planning and securing effective care and support is the statement of what matters to individuals in need of care and support detailed within the Codes of Practice for the 2014 Act, which has been adapted by the Task and Finish Group in consultation with key stakeholders:

"My care is planned by me, with people working together, to understand me,
my family and carers (and our needs), with my best interests central,
giving me voice, influence & control, bringing together services and
support networks that will achieve the outcomes important to me"

The following principles of effective commissioning were coproduced with key stakeholders,
(see Appendices for Task & Finish Group membership and a summary of engagement).

	Principles	Values and ethos
1	**Relationships Matter**	Caring, compassionate, inclusive, and equitable relationships come from inclusive co-production.
2	**Effective leadership is inclusive transparent & honest**	Effective leaders create positive cultures. System leaders and commissioners: - Must be accountable. - Should make best use of digital and technological systems to collect, share and understand data, to inform decisions. - Must establish a shared understanding of risk and implement actions to mitigate such risks.
3	**Collaboration: share risks, resources and assets**	
4	**Value is "what matters"**	Value is *more than* cost; it is good quality, safe care and support that delivers outcomes that matter to people, maximises positive risk enablement and enhances social value. Public value is derived from meeting all legal and regulatory responsibilities including, equalities, human rights, economic, social, technical, environmental, and legal (procurement) considerations.
5	**Sustainable care and support is built on fair work and fair pricing**	Support employers to improve status, well-being and working conditions in social care to achieve parity across (statutory, private & third) sectors.
6	**Plan for current need *(including unmet need)* and future generations**	Commissioning for better outcomes is a medium to long term activity; planning requires forecasting, delivery should focus on prevention and sustainability (including carbon commitments).
7	**Evidence what works through stories *and* numbers**	Research and share the perspectives of individuals receiving care and support, their carers, and care & support workers about what works. Use evidence to establish clear, consistent outcome frameworks that focus on supporting people to have a good life. Focus on what's strong, not what's wrong, *improve* not prove.