

A wide-angle landscape photograph of a coastal region in Ireland. The foreground and middle ground are dominated by rolling green hills and large, moss-covered rock formations. The sea is a deep blue, extending to the horizon under a bright sky with scattered white clouds. The overall scene is vibrant and scenic.

Ireland

Nikki Dunne

Towards a Participation Income for Family Carers

Present

Carer's Allowance – a means-tested taxable weekly payment (anti-poverty measure)

Future

Income support that socially values care

Problem

Means testing inaccessible for many and inadequate for most, with significant restrictions that limit capacity to advance in life

Solution

Introduction of a Participation Income for Family Carers (acknowledge that the solution more centrally requires significant investment in services)



Finland

Kaisa Parviainen



Training for informal carers?

- Informal caring is not a profession
- Carers have a need for information concerning caretaking and guidance about different social and health services.
- Helps carer to recognize his/her life situation and find resources. Focus on mental well being.
- Those informal carers who receive care allowances have the right to training from public services.
- Carers Finland provide training specially those informal carers without care allowance

Tools for Caring

- The characteristics of family care
- Caregiving as a part of life

Tools for social and healthcare services

- Services to support family care
- How to assist someone with disabilities

Tools for change

- Change as a part of life
- Tools to caregiving

Tools to preparing for the future

- Towards tomorrow
- The strength of peer support, the joy of participation

Ovet- training

(8 x 1,5 h)

Outcomes

- I take better care of my mental well being 4,2
 - I don't feel lonely with my thoughts and feelings 4,5
 - I know more about services and support for informal carers 4,7
-
- Year 2022: 488 participants, 336 answers
 - Scale: 1= completely disagree 5= completely agree

An aerial, high-angle photograph of a dense residential area in a German town. The buildings are multi-story, featuring a variety of architectural styles. Many are half-timbered, with dark wooden frames and light-colored plaster. The roofs are steep and made of dark tiles or shingles, with several dormer windows. The houses are painted in various colors, including pink, yellow, green, and white. The scene is captured from a slightly elevated perspective, showing the intricate layout of the streets and the way the buildings are packed together. The lighting is bright, suggesting a sunny day, and the overall atmosphere is one of a well-preserved, historic neighborhood.

Germany

Seb Fischer

wir pflegen!

Interessenvertretung und Selbsthilfe
pflegender Angehöriger e.V.



Improving the interface between formal and informal carers

Wissenstransfer (knowledge transfer)

Thesis

Lebensqualität (quality of life)

is best provided by the right care mix consisting of

- **Selbstbestimmung** (self-directed support)
- **Betroffenenexpertise** (empirical expertise)
- **Fachwissen** (professional expertise)



Predictions

1. Over the next 10-15 years, demand for care will increase faster than the availability of professional support.
2. It follows: more care will have to be shouldered by unpaid, informal carers.
3. *Fachkräftemangel* (skills shortage) necessitates greater skills investment to strengthen those who provide most of the care, i.e. carers and communities.
4. The stress and burden of informal caring can be relieved by improving caring confidence and knowledge – and by validating and endorsing *Betroffenenexpertise* (the expertise of unpaid carers)
5. Lowering the high bar of ‘professionalism’ opens the way to wider societal participation in community care, and can release *Fachkräfte*



Knowledge transfer

Bridging *Betroffenenexpertise* und *Fachwissen* will help overcome a 'knowledge divide' and false dichotomy between formal and informal care. It will lead to improved collaboration, greater care confidence and competence for both informal and formal carers, and thus to sustainable collaboration.

Wissenstransfer (Knowledge transfer) is also critical to supporting unpaid carers as *gleichberechtigte Partner in der Pflege* (equal partners in care), and for opening new pathways into care and for stimulating new *zivilgesellschaftliche Entlastungsangebote* (greater societal involvement through community care initiatives).





Sweden
Elizabeth Hanson





Northern Ireland

Sasha Gillespie



An empirical study of parent-carers' social citizenship experiences in Northern Ireland.

Sasha Gillespie

‘Caring’ citizens

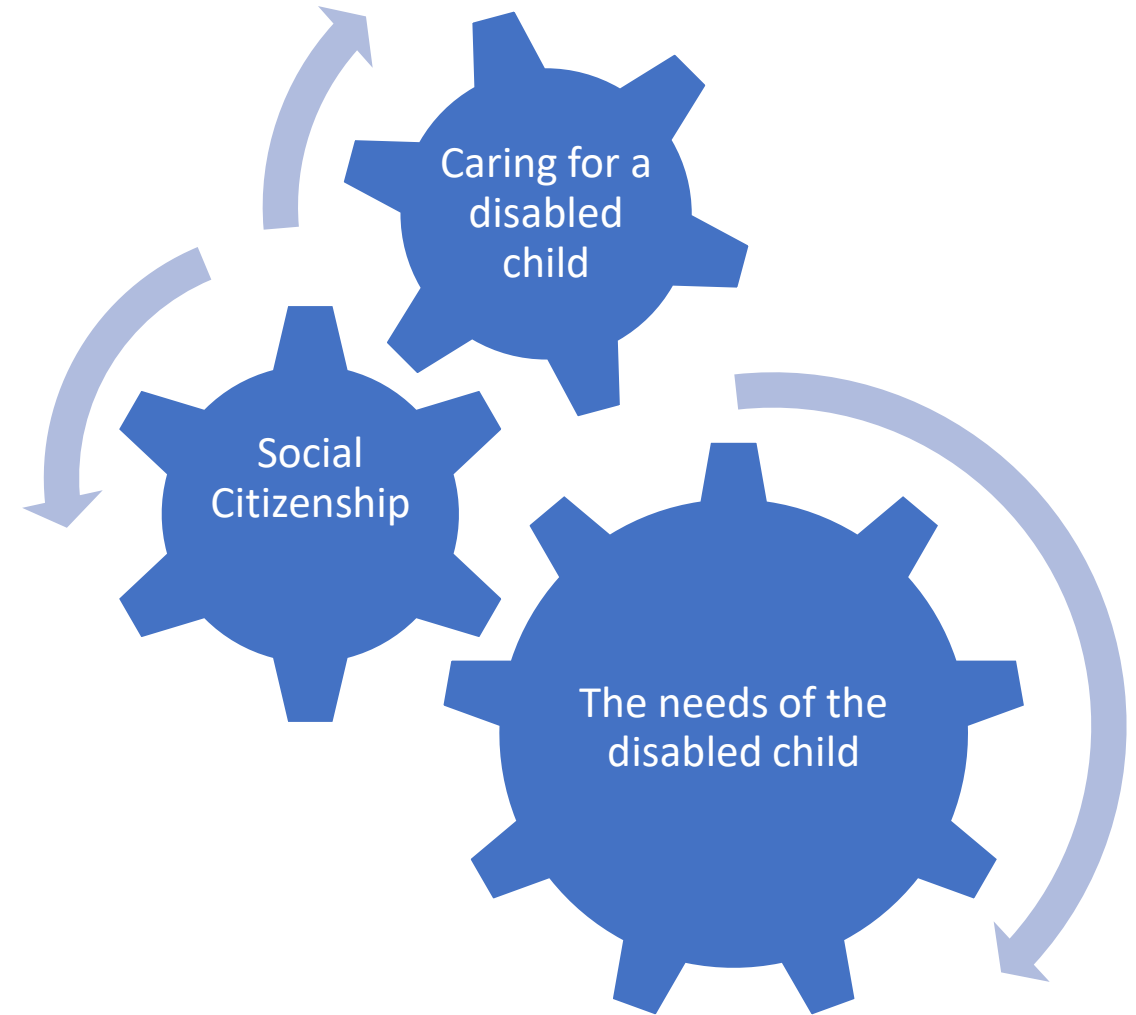
Experience highlighted in the research:

Experiences and challenges far extend beyond money worries, to isolation and discrimination.

Caring role is demanding and multi-faceted and includes advocating, organising treatment and therapies, access to justice.

Many sources of discrimination – work, society, and the built environment – leads to exclusion.

Lack of participation across the life course, disabled children’s care needs often remain or increase as they become adult dependants.



Rights in their 'own right'?

- Carers and parent-carers – defining/understanding/**valuing/recognising** their role.
- Protected group/characteristic in equality law...
- Focus on carers as citizens with social citizenship rights.



	Child 1	Child 2
ball pm	Physio	
	Hospital Appointment	Swimming Practice 2pm
	ART Therapy	
book club 7.30	Phyio	
	Speech + Language	
BARBERS 11am		Birthday Party 1.30pm

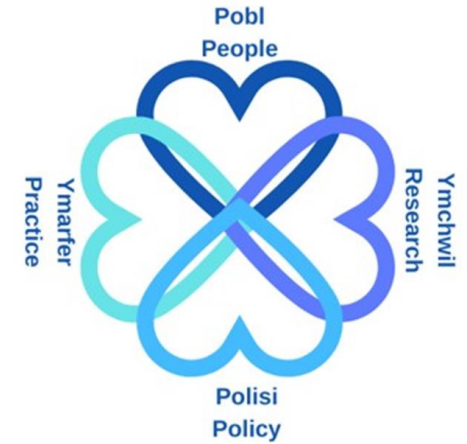
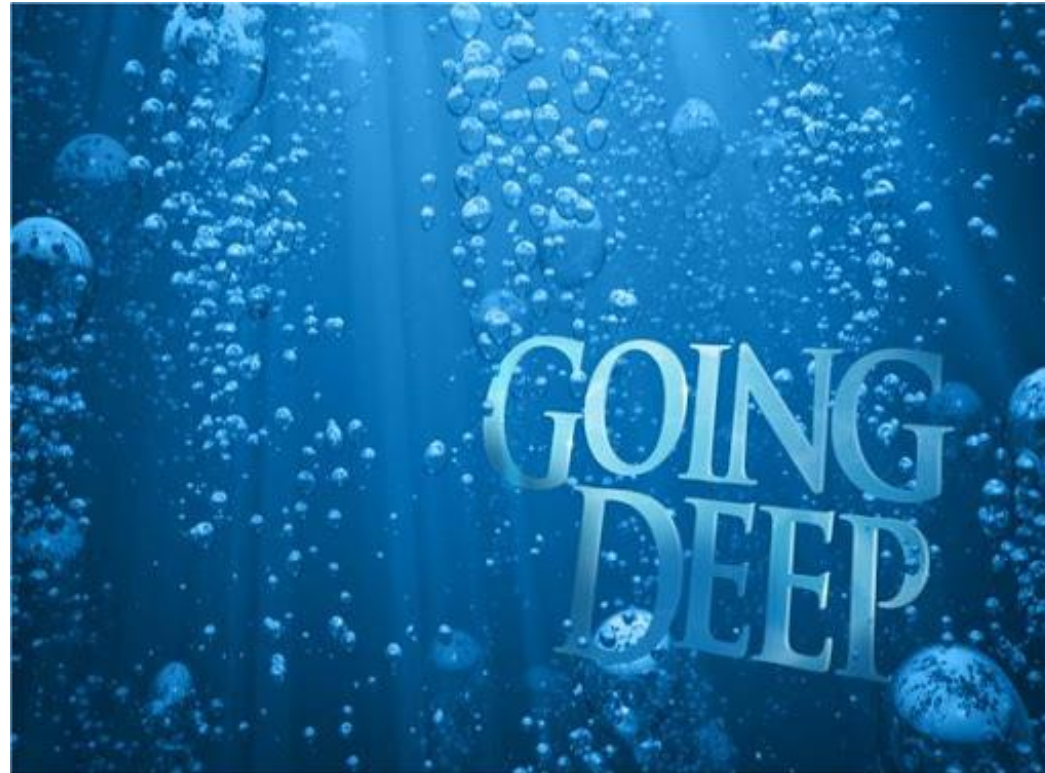


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Wales

Nick Andrews

War on wisdom? – thoughts from research in Wales



DEEP: A fo ben bid bont



Swansea University
Prifysgol Abertawe

Nick Andrews, Swansea University n.d.andrews@swansea.ac.uk

A 'magic moment' and a 'tragic moment'

"I was providing care to an older lady and had noticed that she had a lot of cross stitch samplers on her walls. One day when I visited her, I 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. As soon as she had finished it, 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"

"I have worked as a nurse for many years and was looking forward to working with the homecare workers to look after my husband who had motor neurone disease. On their first day I remember welcoming them at the door and taking 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"

Our research - discovering the world of 'undercover kindness'



Supporting a shift from *compliance* with rules to *responsiveness* with people

A focus on Ethics of Care:

- Attentiveness
- Responsibility
- Competence
- Responsiveness

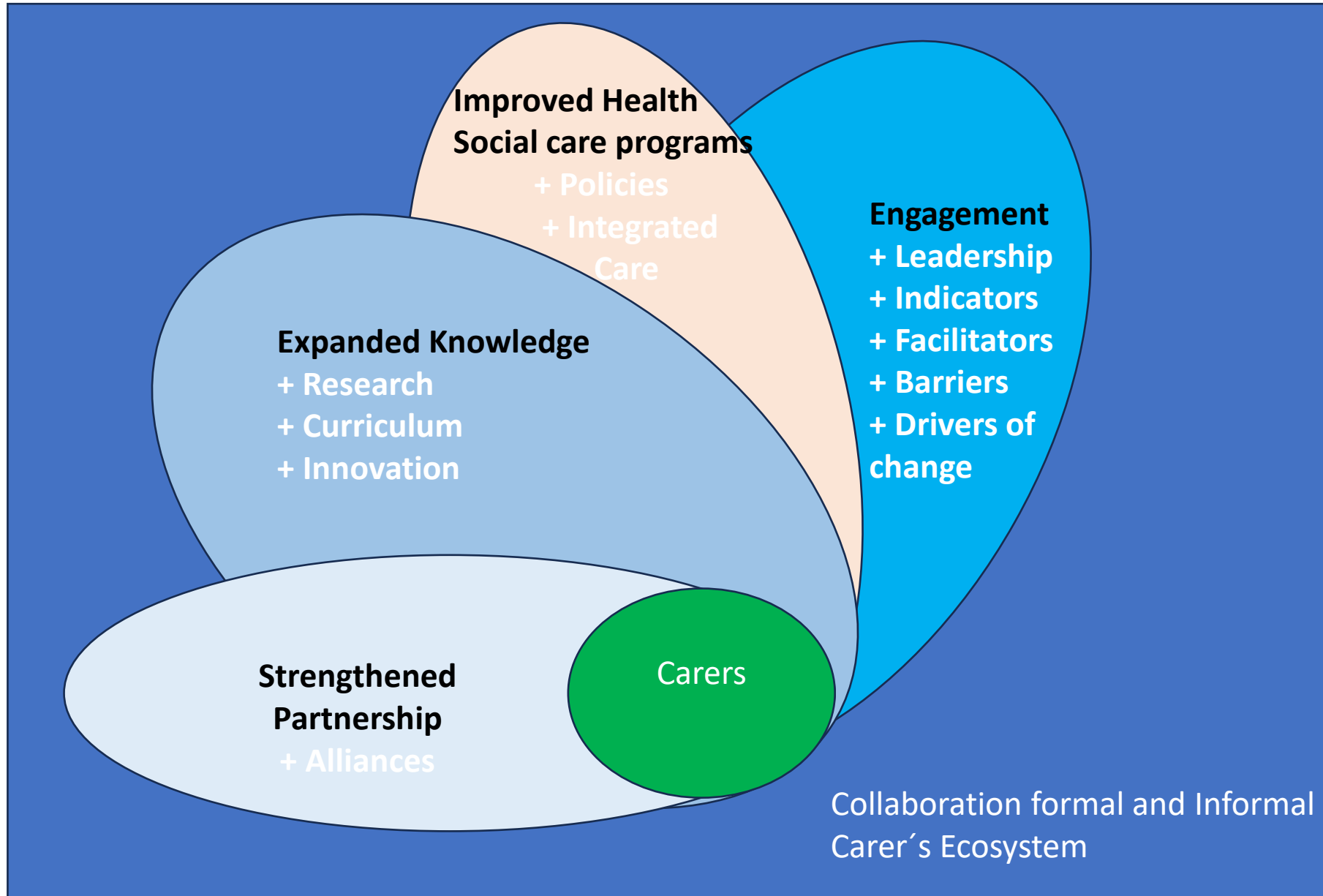
Tronto, J. (1994) *Moral Boundaries: A Political Argument for an Ethic of Care*.
New York, Routledge

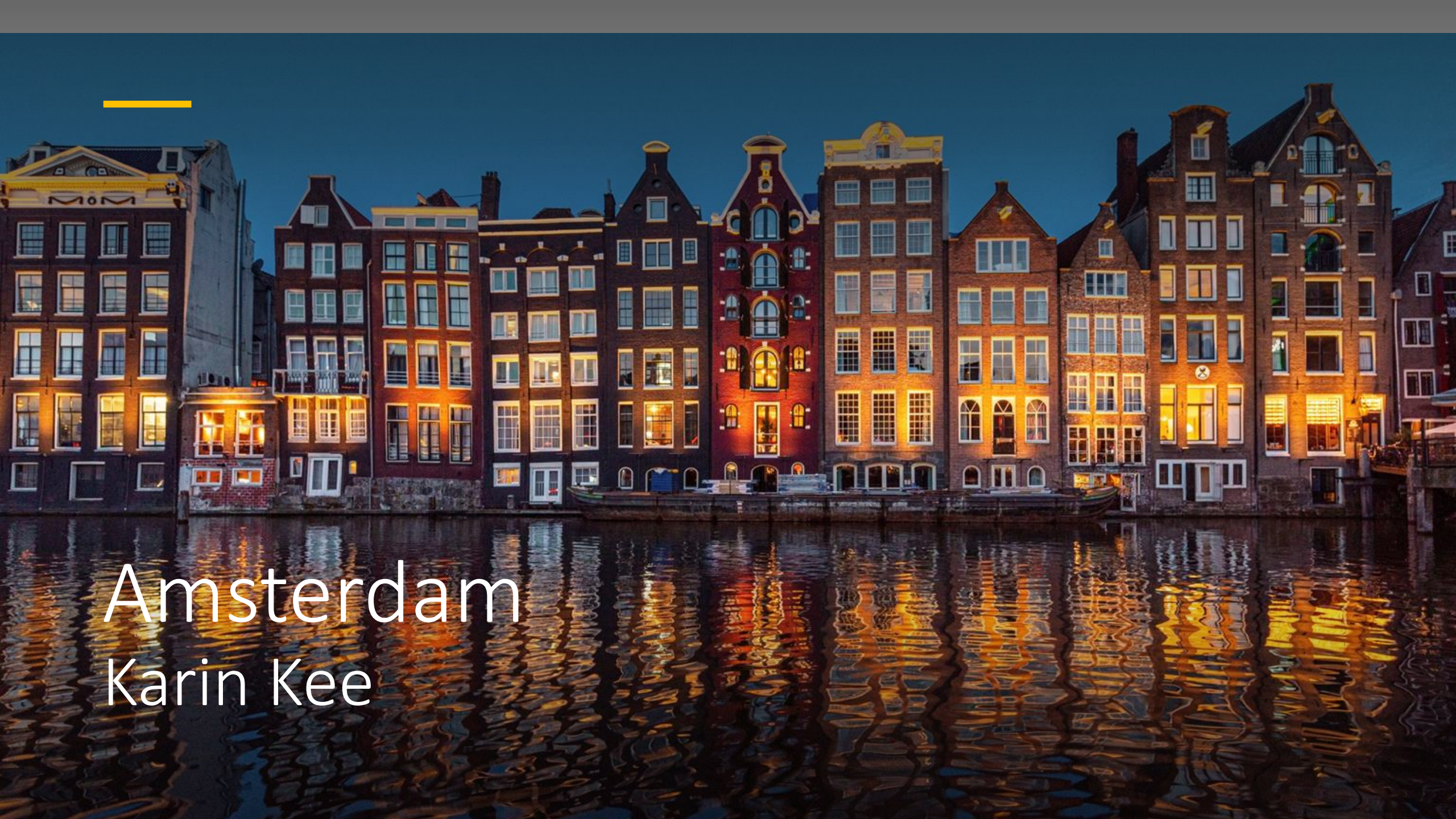
The All-Wales Outcomes-focused
Homecare Community of Practice



A low-angle, upward-looking photograph of a street in Portugal. The sky is a deep blue with scattered white clouds. Numerous strings of pennants, alternating in color between bright green and golden yellow, are strung across the sky from the buildings. The buildings themselves are multi-storied and feature a variety of colors: a prominent yellow building with white architectural details and arched windows, a light green building with dark shutters, and a blue building on the left with a yellow door and ornate balcony. The perspective creates a sense of height and festivity.

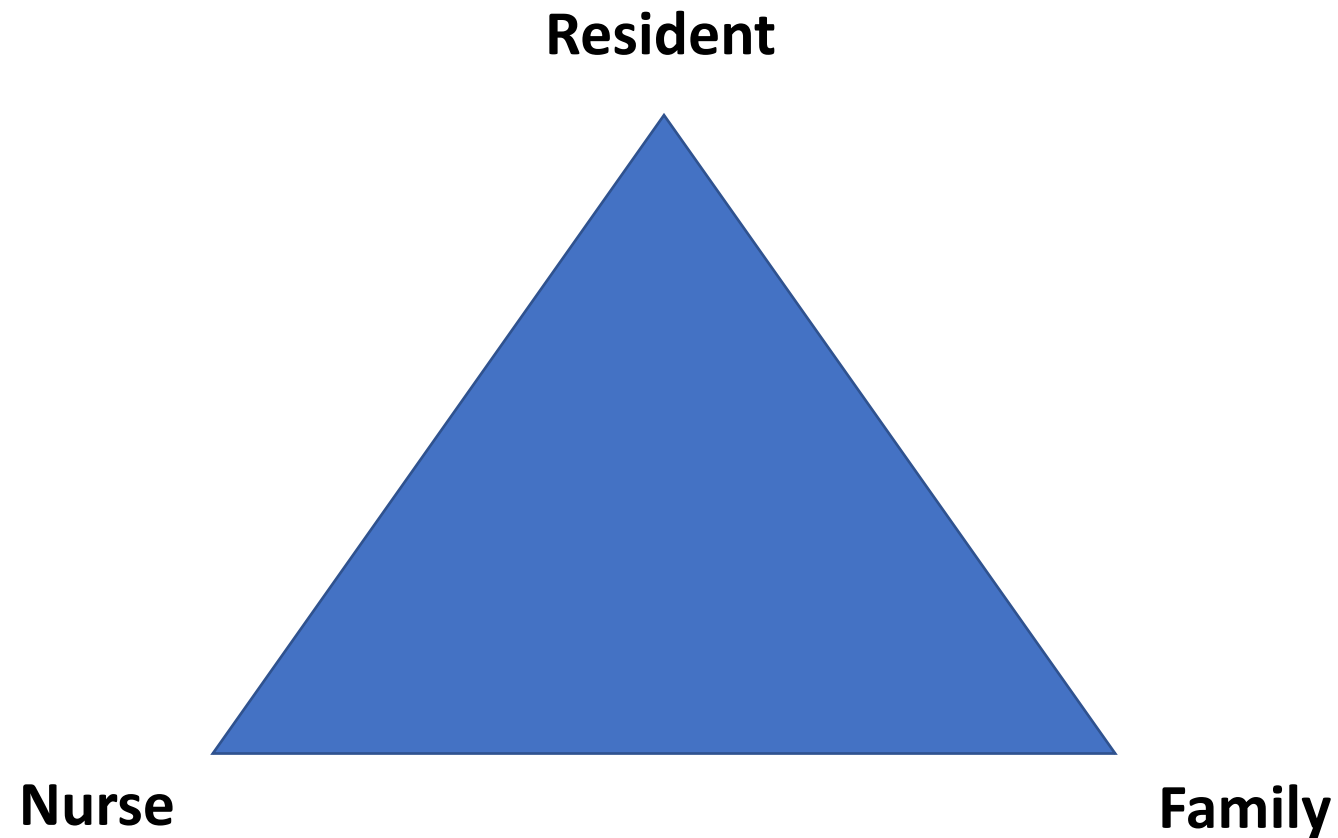
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Portugal
Bruno Alves





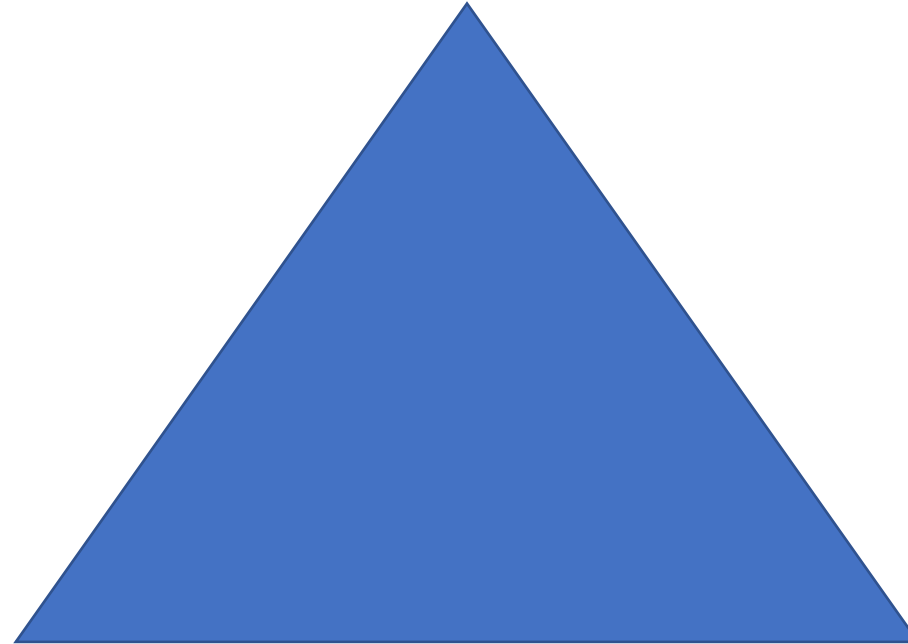
Amsterdam
Karin Kee

Which hat are you wearing? An exploration of identity positionings in care



Resident

- Care recipient
- Vulnerable person
- Home owner



Nurse

- Care expert
- Shoulder
- Socializer

Family

- Expert of experience
- Companion
- Helper



Scotland

Emma Miller



Importance of
partnership /
relationships and when
things get stuck

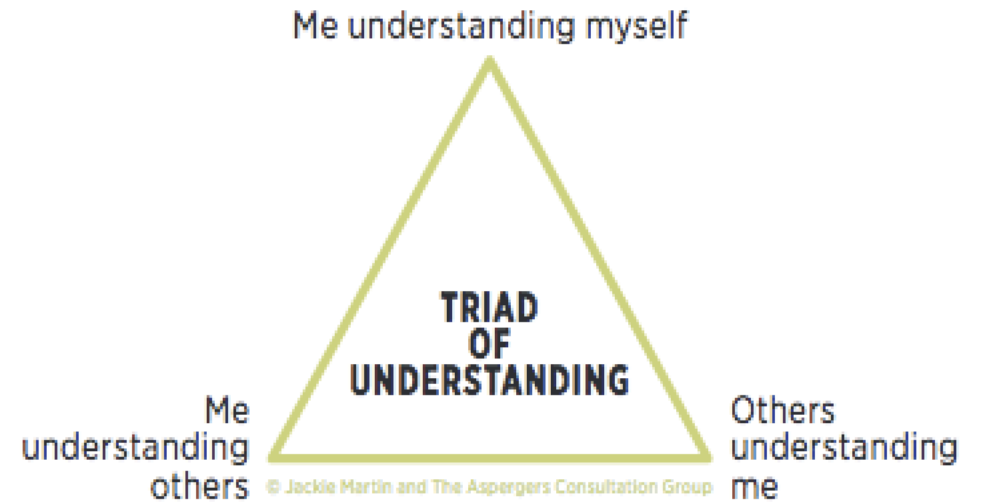
Importance of partnership
/ relationships and when
things get stuck

Lesley, Occupational Therapist

I'm an OT in a local authority. Recently I was interviewing carers for my Masters dissertation, about carer outcomes. I recorded my first interview and thought it was a good interview until I played it back. I realised I wasn't listening to the carer, was focused on our processes and I was defending my colleagues if she said anything negative about the service. It was a real wake up call!

I realised I was going to have to wear a different hat if my research was going to be of any value. I had to take off my usual professional hat and learn to really listen. I learned so much once I did that.

Assessing / processing versus understanding



Sure glad the hole isn't at our end.



Tackling the implementation gap

- Social Care in the UK's Four Nations: Between Two Paradigms (Needham and Hall 2023)
 - Partly about changing the funding model
 - Partly about inherent tensions within and between policy – standardisation and differentiation/personalisation
- Efficiency and/or effectiveness?



A misty forest landscape with a white text box overlaid on the left side. The background shows a dense forest of evergreen trees, with a thick layer of white mist or fog rising from the ground and partially obscuring the trees. The sky is overcast and grey. The text box is white and contains the title 'Slovenia' and the author's name 'Ana Ramovs'.

Slovenia

Ana Ramovs



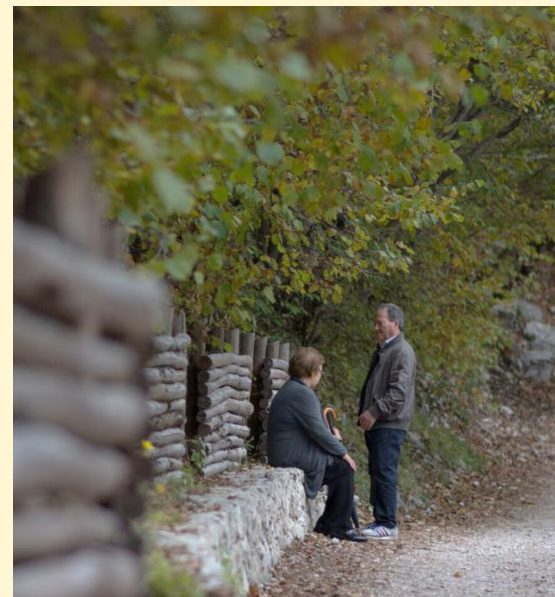
SLOVENIA – INTERFACE BETWEEN FORMAL AND INFORMAL CARERS:



to each their own work
tactful understanding
same direction



a fight for supremacy
lack of understanding
opposite direction



helping each other
empathy and solidarity
same journey



Tenerife
Idaira Cabrera

FOR THE RIGHT TO CARE AND BE CARED FOR WITH DIGNITY



Acufade



A STUDY ON FAMILY CAREGIVERS IN THE CANARY ISLANDS (2021)*

85% of caregivers are women who feel obligated to perform caregiving tasks

95% are not registered in the Social Security System

50% receive less than 400 euros and 20% no income at all

80% of family caregivers do not receive any benefit from the Dependency Act, and 46% are assisted by caregivers under an irregular status

50% of family caregivers work 9 to 12 hours daily, 40% work for more than 40 hours per week

9 out of 10 caregivers claim that care work has been detrimental to their quality of life, both emotionally and physically

1 out of 3 caregivers devotes less than 1 hour/day to self-care activities

WHO IS RAQUEL

Caregivers
don't ask for
applause,
they ask for
resources

And for a state law that
recognizes, regulates and
protects care work

