More than tea and sympathy? Social care support for family carers

SOCIAL CARE WORKFORCE RESEARCH UNIT

Jo Moriarty
Jill Manthorpe
Michelle Cornes

KING'S College LONDON

Outline

- Aims
- Methods
- Role of carers' workers
- Social workers
- Continuity and change
- Eligibility tensions
- Discussion

Why do this research?

- Support for family carers is an important national and global policy objective

- Long term care policies predicated on assumption that better support for family carers will reduce demand for long term care

Image from Guardian 12 June 2012

Most carers want to care but….

- Intensive caregiving affects people's lives in multiple ways
  - Support for carers in their own right
- Context of fiscal austerity
  - Choice/cost imperatives to reduce expensive long term care options
    - 40% admissions to care home attributable to 'carer related factors' (Darton et al., 1997). Old research but not replicated
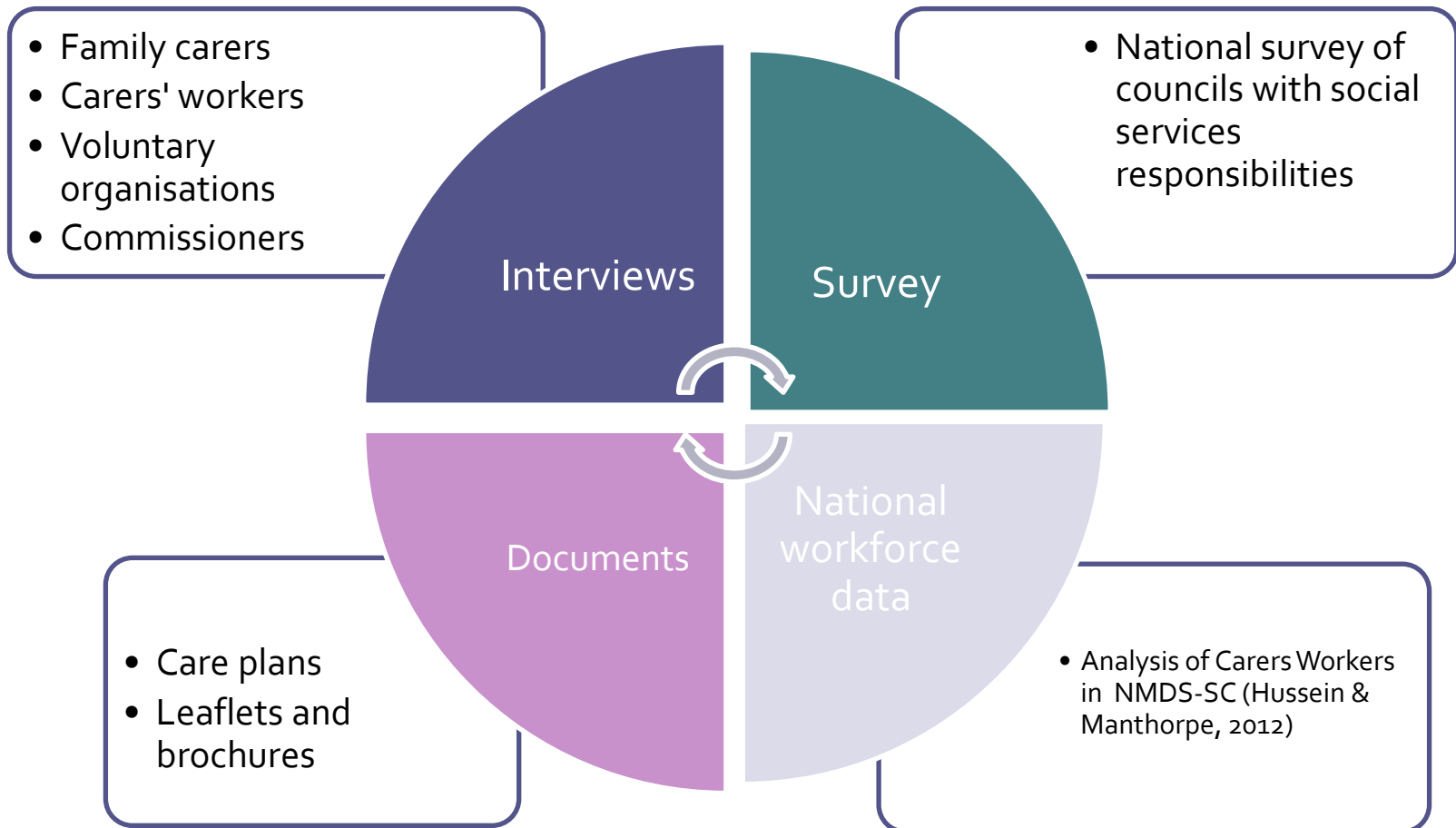

Photograph for Carers Week by Zoe Childerley for Richmond Carers Centre

Need for new research

- Long history of research into caregiving in UK
- UK one of first countries to recognise carers' rights
  - Through benefits system (1992)
  - Through rights to an assessment (1995) and services in their own right (2004)
  - Central government strategies (1999, 2008, 2010)
  - Range of different services
  - But most social care research undertaken in 1990s/early 2000s

Concurrent mixed method design

- Family carers
- Carers' workers
- Voluntary organisations
- Commissioners

Interviews

Survey

- National survey of councils with social services responsibilities

Documents

National workforce data

- Care plans
- Leaflets and brochures

- Analysis of Carers Workers in NMDS-SC (Hussein & Manthorpe, 2012)

Results based on….

Data	
Interviews with over 80 participants	☺
Surveys from over 50 per cent of local councils	☺
Difficulties with care plans – ended up talking through carers' assessments with social workers in two teams	😐

Routes into the work

Advice work (e.g. CAB)

Personal experience of caring

Other social care role (e.g. day care)

Professional (e.g. nursing or social work)

Unrelated
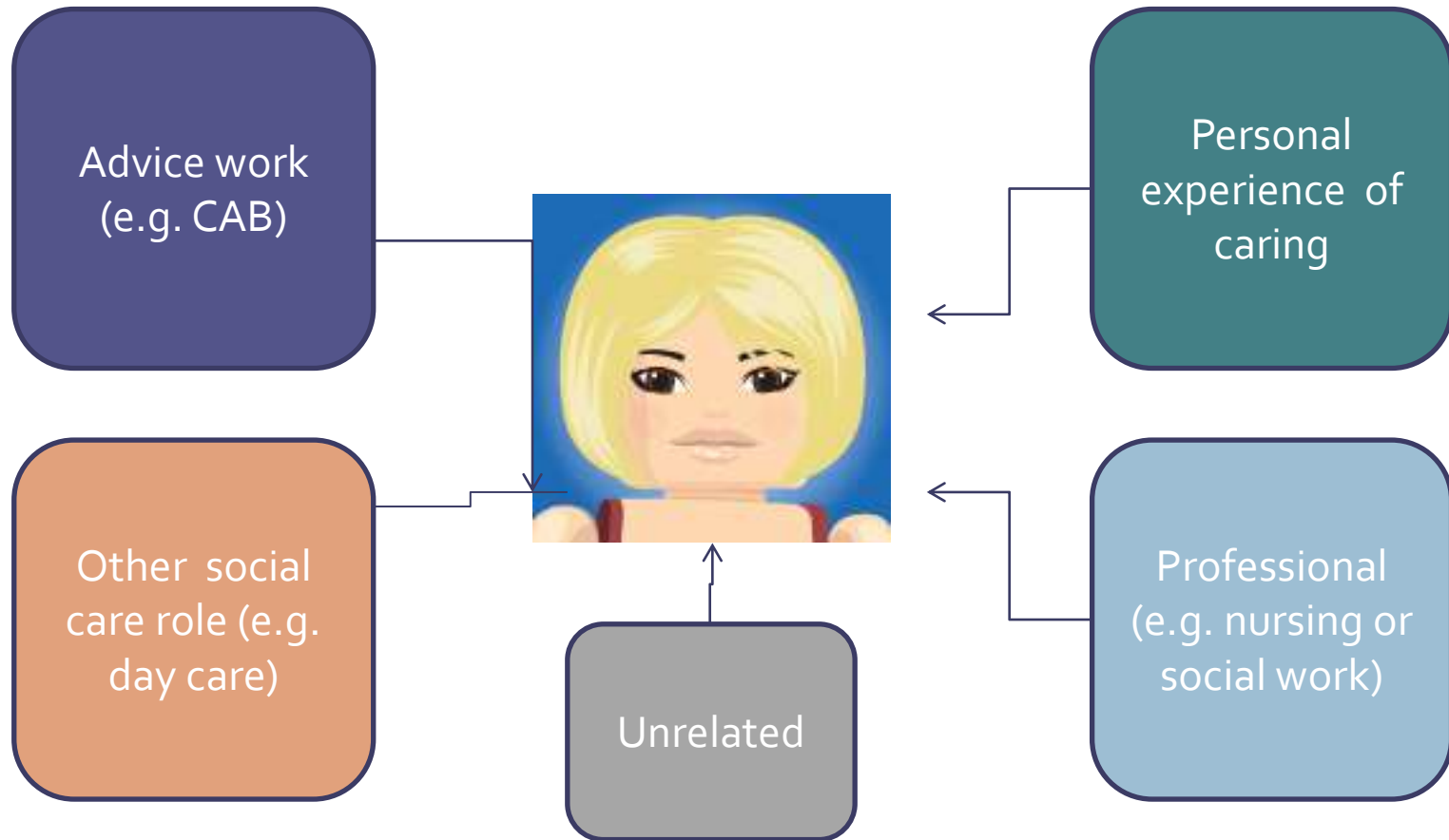
Different models of support

- Interviews suggest carers' workers offer different types of support
  - Outreach
  - 'Drop in' – mainly to give information or 'signpost'
  - Advocacy – for example, attending assessments/meetings
  - 'Being there' - 'being a listening ear' support
  - Counselling
  - Community development
  - Co-worker with other professionals
  - These roles often combined – comparisons with social work where becoming more segmented

Outreach work

- [BME carers] role is not just to the service user that they're looking after, it also extends to other members of the family. So [instead of a] structured carers group….that's why we've had to put in the drop-in session (WORKER22)

Photo by Mark & Jenny

Advice & information

- And we'll go out and just have a chat and go from there really, to see if there is anything that we can help with or anything that we can signpost them to, or if we think that they should be referred to services, or if the service isn't working and they need to be looked at again. (WORKER1)

Advocacy

- 'If someone wants help to do something then that's part of my role too, as an advocate. I can help. At the moment I'm dealing with a couple of things for one particular family. We've got a Continuing Care appeal on the go, plus at the same time we're doing the paperwork for the Courts to apply for Deputyship, because they never got Power of Attorney and the patient has now lost capacity, so we've got to go for Deputyship. So we're doing the forms, well we've just… They've just been posted off, and we're hoping we're not going to get too many back to say we haven't done it right. So we've been doing that, and at the same time trying to deal with the NHS for Continuing Care. So it's sort of a bit of everything, really, yes.' WORKER23

'Being there'

- Just being there. Sometimes it's just being there and just smiling and saying, hello to somebody who might not have seen anybody for a few days. I think it's just being round people ... I think sometimes it's just sitting and listening and just giving people your time. I think that one is the best thing really (WORKER29)
- Some overlap with befriending but offer other support

Counselling

- We offer individual counselling. We typically offer 12 sessions with a review afterwards so if at that point the client and the counsellor both feel that there is still work to be done…then it's possible to extend it…We have two groups in addition to that (WORKER11)

Community development

- One of the carers who started coming into the Wednesday morning group … was looking for friendship, because she was caring for her husband who was about twenty years older than herself. She wanted also to pal up with somebody to go on holiday with them. It wasn't just any sunshine and sand holiday, it was specifically a walking holiday. She did meet and those two ladies actually now no longer come to the group, but they visit with each other at home and they get the newsletters and they come along to some of the gentle exercise or flower arranging classes that we've had. But they go on a walking holiday together. They share their little personal budgets so their husbands can have some joint care (VOL13)

Co-working

- Work with social worker to arrange personal budget for carer to be spent on driving lessons

- The good thing was that the social worker I was with managed to take responsibility for the personal budget, so that was going to be set up immediately…. She feels confident…that she can contact us and that things will be done (WORKER30)

Social workers

- Extensive literature on care management
  - Administration and assessment (Weinberg et al, 2003)
  - 'McDonaldization of social work (Dustin, 2007)
- Talked through last carer's assessment with them
  - Comparatively little direct work with carers
  - Work mainly care co-ordination
  - Assumptions will do more safeguarding
  - Some trends in outsourcing assessments
- Will take a lot to help them community development
  - Role of social work curriculum?

Future role for social work?

Paul Burstow before leaving his 'dream job' talking at *Community Care Live* in May 2012

Social workers' roles will shift from care managing and brokering services for those who meet eligibility thresholds towards helping people avoid the need for formal care and support altogether. This would be through working with older and disabled people to build community networks and use their strengths and assets to reduce isolation, build resilience and help people live active, fulfilling lives.

Old debates, different situations?

- Twigg (1988) highlighted the ambiguous nature of carers in the social care system
  - Carers as *resources*
  - Carers as *co-workers*
  - Carers as *co-clients*
  - Tension between *prevention* and *substitution*
- Early research based on experiences of spouses and adult children
  - Study highlighted role of parents and grandparents for people with overlapping conditions or complex needs

Falling between two stools

- I just think as [my husband] said, [the mental health crisis team] should change their name. Because you can't get them in a crisis. They actually came out one night and [when] they got there [daughter] wanted me out of the room. They spoke to her downstairs and then while I went downstairs it was a total waste of time, because [they said they were for mental health and not alcohol misuse]....[but support service for carers] I think they have been absolutely fantastic (CARER22)

The dilemma: eligibility criteria (1)

- And so you get this really wide spectrum of somebody believing that caring is nothing to do with me and yet they might be [caring] round the clock through six or five days a week .....through to somebody who is just you know, popping in and looking after their neighbour.... I think it does need more focus about saying, looking after your neighbour is kind of the social contract that we all have as ...human beings and ...and that doesn't make you a carer, it makes you a decent human being...I don't know that there is a really well understood recognition of what is substantial at that point' (COMMISSIONER1)

The dilemma: eligibility criteria (2)

- The difficulty with FACS, as anybody who understands a business will tell you, is that we probably have a certain amount of people in the community who are vulnerable. Any social worker doing an assessment on a vulnerable person who thinks they need a service will describe them as critical. So you will get some councils that have nothing but critical eligibility criteria and have the same percentage of people on the books as places like [us]....because people [ratchet it up]...to make them entitled.... So what we've done is created this intellectual vaulting, which you would then need another system set in place to challenge the vaulting. So you would then need your managers to be more street savvy than the social workers. What a waste of public resource. (COMMISSIONER4)

Implications

- Almost all councils moving towards
  - Universal services available to all carers as local citizens
  - Targeted services for those with substantial/critical needs
    - Not always clear as to whether this relates to the carer or the person for whom they care
  - Commissioners in one area said they had a more preventative model
- Not clear what effects this will have in terms of support for carers
  - This study can't answer this question but suggests that we need to consider if this is the case

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