Support for family caregivers: global issues and local solutions

Jo Moriarty

Jill Manthorpe

Michelle Cornes

KING'S College LONDON

SOCIAL CARE WORKFORCE RESEARCH UNIT

Outline of presentation

- Presenting early results from a project 'Social Care Practice with Carers'
- Funded by the National Institute for Health Research School for Social Care Research
  - ❖ Methods
  - ❖ Key issues
  - ❖ Discussion
    - ▪ Transferability
    - ▪ Scope and significance of research for practice development

Background (1)

- Support for family carers (caregivers) is a global issue
- 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)
  - ❖ Network of Carers Centres in most towns and cities
  - ❖ But issues still remain in terms of support for family carers

Background (2)

- Bulk of research on impact of government policies undertaken 1995-2005
  - ❖ Major changes to social and health sectors since then
- New roles developed in carer support
  - ❖ Information and advice/outreach
  - ❖ Unevaluated
- Impact of fiscal austerity on public expenditure
- Identified need for new research looking at how family carers were being supported
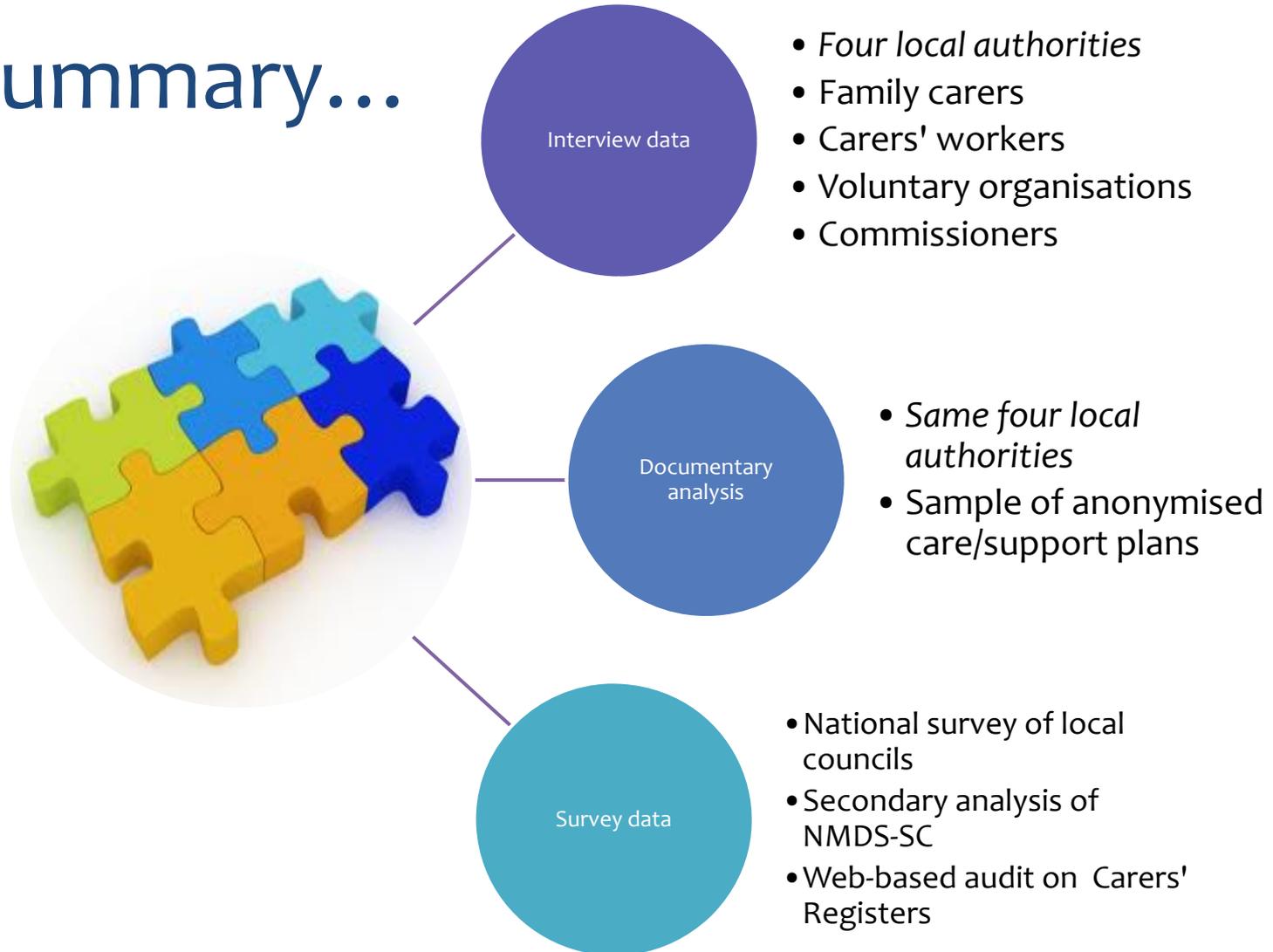
Design (1)

- Concurrent mixed method design
  - ❖**Advantage** is that different forms of data can inform the other
  - ❖**Disadvantage** is that new/interesting issues are hard to follow up (as would be the case in sequential designs)
- In depth information
  - ❖Four local areas
  - ❖Interviews with 'carers workers', carers, commissioners, and representatives from the voluntary sector
  - ❖Documentary analysis of a sample of care plans

Design (2)

- Contextual information
  - ❖ National survey of councils with social services responsibilities
  - ❖ Secondary analysis of National Minimum Data Set for Social Care (NMDS-SC) http://www.kcl.ac.uk/content/1/c6/08/21/82/SCWPIssue10web.pdf
  - ❖ Web based audit of Carers' Registers (data collected by local councils on the number of carers in their locality)

In summary…

Interview data
- *Four local authorities*
- Family carers
- Carers' workers
- Voluntary organisations
- Commissioners

Documentary analysis
- *Same four local authorities*
- Sample of anonymised care/support plans

Survey data
- National survey of local councils
- Secondary analysis of NMDS-SC
- Web-based audit on Carers' Registers

What makes a difference?

- Survey respondents think access to breaks and an emergency card are what carers value most
- Survey respondents think information and a named contact are the most important services they provide

But….(1)

- Confirms existing research about difference between knowing *about* carers and knowing you *are* a carer
    - ❖ *I [was] on an [information] stall and the amount of people that walked past and you said to them, 'Are you a carer?' and they said, 'No, but I look after so and so and so and so. Because it was a relation they just didn't think of themselves as a carer. It's surprising and it's something you come across all the time….They think a carer is professional or someone who gets paid or a stranger that looks after someone'* (Family carer)
    - ❖ Pre-supposes people recognise they are carers

But….(2)

- The 'named contact' model does not seem to be evidence-based
  - ❖ Assumes stability in terms of post holder
  - ❖ *Unfortunately, at the moment with all these cuts coming up next year a lot of them are very iffy about their job*
- There is an extensive literature on the impact of poor social support. Is this being ignored?
  - ❖ *[name] has been a huge emotional support to me. Being a trained counsellor, she's been able to give me a lot of sort of support and just someone to talk to who is … just there for me and I know that I can call and she's never … she's always ….got time to talk, which is lovely. She's been a real rock*

Outreach (1)

- Survey respondents reported work to reach 'seldom heard' or 'hidden' carers
- Two models of information provision
  - ❖ Through general publicity and awareness raising
    - Often linked to Carers Week or Carers Rights Day
  - ❖ Through specialist workers or teams

http://www.national-awareness-days.com/carers-rights-day.html

Outreach (2)

- Survey respondents identified issues identifying
  - ❖ 'Working' carers
  - ❖ Carers from minority ethnic groups
  - ❖ Carers of people not eligible for social care support
- Different themes emerged in interview data
  - ❖ *I don't think people who are supporting someone with an eating disorder, I don't think they identify with carers organisations or realise the kinds of benefits they might be entitled to perhaps as much as I dare say people who perhaps slightly more clearly see themselves as carers do* (Voluntary organisation)

Outreach (3)

- Outreach is not just about engaging with 'seldom heard' or 'hard to reach' carers
  - *There's the outreach work going out to speak to different teams. With some teams it is like bashing my head against a brick wall. [Colleague] will probably tell you this…. I tackle social care, she tackles health care and it's about trying to engage with the professionals in each of those sectors. Very difficult to do. The culture is sometimes really hard set (Carers worker)*

Different models of support

- Interviews suggest carers' workers offer different types of support
  - ❖ 'Drop in' – mainly to give information or 'signpost'
  - ❖ Intensive 'being a listening ear' support
  - ❖ Advocacy
  - ❖ These roles often combined – comparisons with social work where becoming more specialised

Way support is delivered

- Carers workers reported they offered support in different formats
  - ❖ By phone, text, face to face
  - ❖ Liked face to face work best
- 'Cascading' effect of support
  - ❖ Facilitating family carers to offer support
    - Peer support through group for carers of substance misusers
    - Encouraging a carer to volunteer at a local 'carer café'

Examples of personalised support

- Mediating role in terms of accessing different organisations
  - ❖ Personal budget for carer living in a rural area to spend on driving lessons
  - ❖ Substitute care for a couple to spend a few days away visiting friends from abroad who were holidaying in the UK
  - ❖ Welfare rights and benefits an important aspect of work

Trends

- Integration and outsourcing are happening together
  - ❖ Integration with health
    - Example of learning difficulty/mental health/local council jointly funding Asperger's service
  - ❖ Outsourcing of council posts to the voluntary sector
    - Funding posts in voluntary organisations such as carers centres
    - Contracting with voluntary organisations to do carers' assessments
- Rise of personal budgets
  - ❖ Majority of councils have *policies* to allow carers to be paid for supporting the cared for person
  - ❖ Carers may also receive direct payments but variation in terms of whether they are means tested

Discussion

- Looking specifically at two conference themes
  - ❖ Transferability of locally collected research
    - ▪ Don't always know if results are representative of England!
    - ▪ However, certain themes recur across research undertaken in different countries
  - ❖ Scope and significance of research for practice development
    - ▪ Variation in role of practitioners/organisations across countries
  - ❖ Examples of some theoretical debates that studies such as this could contribute to

Theorising about caring/caregiving

- Substantial literature now exists
  - ❖ Distinctions between paid and unpaid caring becoming more blurred
    - Emerging policies for giving carers 'cash for care' payments
  - ❖ Early work assumed homogeneity among carers
    - Now there is more emphasis on heterogeneity
    - But carers still often defined in terms of problems faced by person who they care or their demographic or personal characteristics
    - Canonised or stigmatised?
      - Under-researched substance misuse/eating disorders

Convergence versus divergence?

- Developing literature looking at whether welfare states are converging or diverging (e.g. Achterberg and Yerkes, 2009)
  - ❖ Methodological challenges in comparative studies of support for family carers in different countries
    - Social attitudes towards the roles and responsibilities of families differ
    - Levels of professional long-term care services for older and disabled people vary widely (Glendinning et al, 2009)
  - ❖ Do carers provide a 'telling case' or lens for examining how policies and practice are conceptualised in different countries?
    - Example of flexible working policies (Hegeswisch, 2009)

Outreach versus information provision?

- Outreach work often presented as conceptually simple and easy to define
- In reality….
  - ❖ Under theorized
  - ❖ Dependent on context (Andersson, 2011 advance access)
    - ▪ 'Outreach' often used to describe roles that are more about control or surveillance
    - ▪ Here, emphasis is on 'under served' communities
    - ▪ Research highlights links and tensions between outreach and 'information provision'

Implications for social work

- Few UK studies investigate social work contribution to supporting family carers (outside context of parenting/grandparenting)
    - Studies tend to focus on assessments (e.g. Arksey, 2002; Seddon et al, 2010) and not on whether/how they differ between professionals
    - Focus has been on identifying needs and not on models of long term support
    - Trends in adult social care may mean that more social workers seek employment in third/voluntary/not for profit sector

Acknowledgements & disclaimer

Thank you for listening!

- Contact details:
jo.moriarty@kcl.ac.uk
jill.manthorpe@kcl.ac.uk