

# Family carers - national differences, similar problems. What can we learn from each other?

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# Starting point

- ▶ Carer/caregiver divide
  - ▶ UK and European research tends to use term 'carer' rather than 'caregiver'
  - ▶ Both concerned with unpaid care by family members or friends
  - ▶ Similar intellectual origins in work by US & UK researchers looking at women's unpaid work within the family in the 1960s and 1970s

# What is a carer?

- ▶ 'A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support'
- ▶ Anyone can become a carer
- ▶ Carers generally don't choose to become carers; it happens



Carers Trust Website

# Our chances of becoming a carer



## Women

- ▶ Women have a 50:50 chance of becoming a carer by the age of 59
- ▶ Women more likely to be 'sandwich' carers
- ▶ Women more likely to give up work to take on caring responsibilities

## Men

- ▶ Men have a 50:50 chance of becoming a carer by the age of 74
- ▶ (From Carers UK Facts about Carers 2014)

# Why it's important for health and social care professionals

- ▶ In EVERY area of practice you will be working with carers
  - ▶ A young carer supporting a parent with a mental health problem
  - ▶ An adult child supporting a parent with dementia
  - ▶ A person supporting his or her partner with a long term condition
  - ▶ A lone parent supporting a child with autism

# Policy context

- ▶ 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)
  - ▶ 'Equal footing' with person for whom they care in Care Act 2014

# But we know that....

- ▶ Many carers report difficulties in finding out about services, meaning that they are sometimes caring without any other sources of support



Image from care.com website

# Increase in number of posts aimed at supporting carers



Carers Support Merton (CSM) values and listens to unpaid carers of all ages from our diverse community and provides high quality services and advice.

CSM wants unpaid carers of all ages to have real choices to improve their quality of life and to receive the respect, support and recognition that they deserve.

This project will fully integrate a Dementia Carer Outreach Support Worker (DCOSW) into the Older Peoples Home Treatment Team (OPHTT) with South West London and St. George's, which cares for patients in crisis in the community, keeping people out of hospital from the first awareness of symptoms.

## Overall Purpose of the Job

Working within clients' homes to promote independence through greater choice and control. To provide support and assistance to carers and people with care needs in a whole family approach. This will involve the provision of personal and social care, respecting confidentiality at all times within an equal opportunities framework and in compliance with our quality assurance standards. Also support to achieve personal goals and positive outcomes.

## Box 3. Helping families make the most of personal budgets

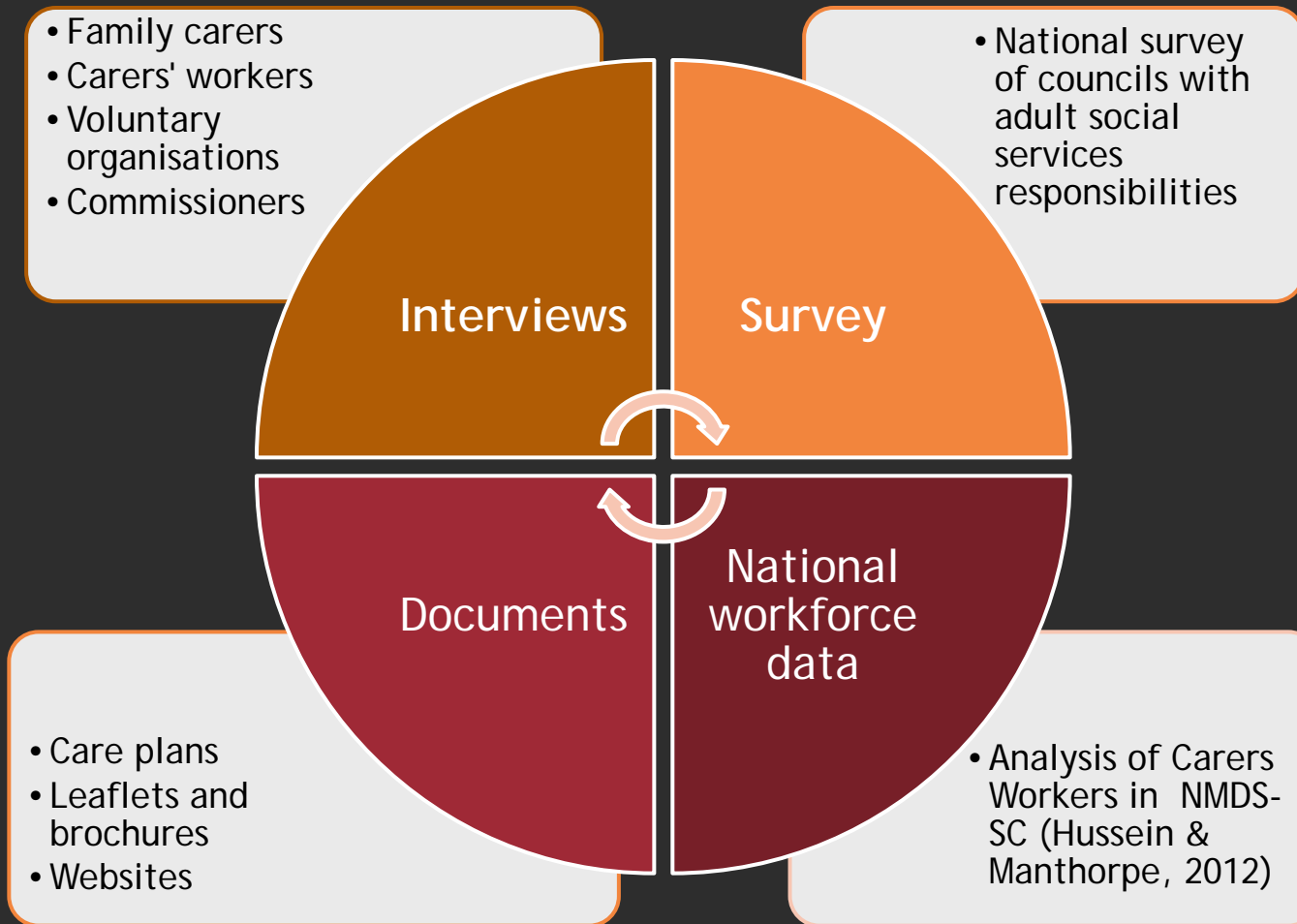
### Carers' Support Bexley, funded by The Princess Royal Trust for Carers

The scheme supports carers who are responsible for managing personal budgets on behalf of the person they care for, by offering ongoing support around managing budgets, accounting, insurance, and employing care staff. It also provides support for people who are self-funders. Importantly, control remains with the personal budget holder.

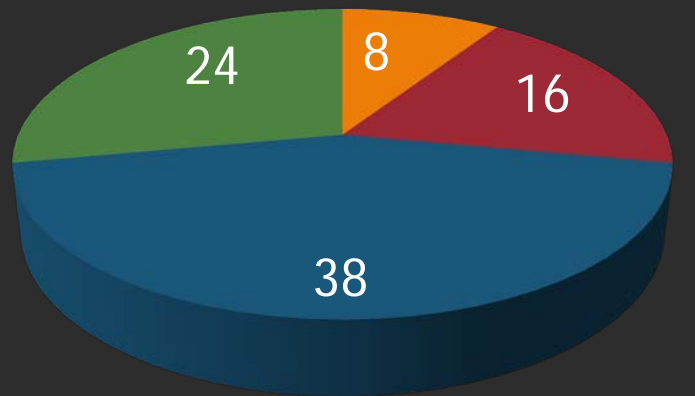
<http://www.carershub.org/node/161>



# Concurrent mixed method design



# Interviews



- Commissioners
- Voluntary organisations
- Carers workers
- Family carers

- ▶ Sampling covered different types of caring experiences:
  - ▶ Relationship to person cared for
  - ▶ Reason why person cared for needed support
  - ▶ Other factors (e.g. rural)
- ▶ 'Information rich' informants (Patten)

“ If I’m taking [my husband into the [public] toilet, it’s very challenging when I come out of a disabled toilet with a middle-aged man ... And then once you’re in the disabled toilet facilities, there’s nowhere to put your handbag or anything, it has to go on the floor [as does the] change of clothes and pads and what have you

”

CARER08

## Practical difficulties

“

My mother's condition means she is living more in the past than the present most days and is unable to remember what I tell her or what is planned for the day. This makes some days very lonely and also frustrating as I repeat for the tenth time what I have planned for dinner. But she is also sometimes a complete joy

”

CARER20

# Can be lonely

“ He’s a big lad ... and he went really aggressive and I thought, ‘I can’t do this anymore.’ But basically he was sectioned and then they just sent him home. I was saying to the services, ‘I need help. I cannot care for him anymore,’ and they just ignored it. He relapsed again within days and I’d got to start all the b\*\*\*\*y palaver there of trying to get services to kick in, to get him to hospital

”

CARER16

## Hard to get services to listen

“

It's there 24/7 and ... there [are] lots of mental health issues for [carers]. Lots of carers get stressed out and end up on anti depressants or their health takes a toll

”

WORKER13

## The long term effects of caring

# Help generally assumes people recognise themselves as carers

- ▶ People more likely to see themselves as partner/child/parent and so on
- ▶ Some consider it's because concept of 'carer' is flawed (Forbat, 2005, Molyneux et al, 2011)
- ▶ O'Connor (2007) talks about people 'positioning' themselves as carers

“

It was only when we made contact with the Carers Centre, and we explained a few things that the assistant manager [said] ... you are all carers ... When we say to [other parents], do you know you are a carer ... and they say, no we are not. I'm just a mum. You cannot get them to come out

”

CARER02

Many people don't see themselves as carers



“

I wouldn't have any clue about the wording of a carer at the time. I didn't see myself as a carer, even if I [had known] that word

”

CARER05

## Cultural and language barriers around 'caring'

“ I first found about carers' support by picking up a leaflet when [my husband] went to the ... clinic one day. And up until then I had no idea that there was anything out there for carers ... It was probably, I would say, five years ago at the most

”

CARER11

Often find out about support by chance

“

Other times I just feel really frustrated that we can't do more. And that might be because the carer's so ... driven by guilt and won't take a step to break off from the caring role

”

WORKER15

They may feel guilty about asking for help

“

Adult mental health is quite different in some respects, I think, to other caring roles. I'm not saying that it's worse or more intense or any of that but because of the whole stigma thing around adult mental health and the prejudices around it that, in itself, brings its own problems,

”

WORKER17

## Stigma can be a barrier too

“

There is such a lack of communication or information from professionals ... the parents' groups are very, very good, because you'll go along and people will say, 'Haven't you got this yet?' or, 'Do you know about such and such?'

”

CARER24

Information not always accessible or useful  
(overload and absence)

# Publicising information

- ▶ Around 80 per cent of councils responding to survey kept a Carers Register
- ▶ Leaflets in libraries and contact centres
- ▶ Link up to national events (Carers Week)
- ▶ Local developments e.g. working with supermarkets

# Types of outreach



'High street'

Visibility



Integrated primary care

Familiarity



Self help

Minimal infrastructure

28 May 2015

# Types of outreach



## Specialist

Aimed at specific groups



# 'High street'

- ▶ Carers Centres (mainly run by The Carers Trust)
- ▶ Carers Hubs (local partnerships)
- ▶ Carers cafés
  - ▶ More rural areas
  - ▶ 'Travelling' advice sessions
  - ▶ Hosted in another venue



Photo by Jenny & Mark

# Integrated outreach in primary care

- ▶ Carers much more likely to have seen their GP than any other health and social care professional
- ▶ Carers may have dual role
  - ▶ As 'partners' in someone's care
  - ▶ As someone with health needs of their own

**Information about a patient's health & consent**

- Where appropriate ask patients who have carers whether they are happy for their personal health information to be given to their carer
- Give carers information about the diagnosis, the treatment – including medication and its side effects – and progress for the people they care for
- Obtain consent from all parties involved eg:  
*I agree to information about my health being discussed with my carer. I will contact the practice if this information changes.*

**Patient and carer signatures**

Carer's name:

Patient's name:

Patient's illness or condition:

**In the presence of**

Health professional:

Name:

Role:

Date:

Phone:

Signed:

Signature of patient:

Date signed:

**What can I expect from my general practice to help me improve my health and quality of life?**

Once your practice knows you are a carer, should you need additional support you can be referred to specialist carers agencies or social services.

You are entitled to ask your local social services department to assess your needs as a carer. They will take into account how they can help you to continue in your role as a carer so that you are best placed to make your own choices about recreation, work or study.

Do not neglect your own health. If you need to see your GP they may be willing to provide a home visit or to take other steps to make it easier for you to keep your appointment.

**Sourcing support from Community/District Nurses**

If you are caring for someone needing a level of nursing care, you can ask for assistance from your Community/District Nursing Services. This can be organised through your general practice.

**The most commonly-asked questions by carers tend to focus on:**

- Welfare and benefit entitlements
- Understanding benefits and health rights for carers
- Sourcing breaks and respite care
- Sourcing practical support in the home
- Advising on medicine
- Assistance with transport/personal care
- Finding further advice from charitable or carer-led agencies

**To find your nearest Carers' Centre contact**

The Princess Royal Trust for Carers Head Office  
142 Minories London, E32 7AB 7788 or info@prtrn.org  
Wales, 104 Mansel Street, Swansea, 01792 472 908 or info@carers.org

Scotland, Charles Dalry House, Glasgow 0141 221 5566 or info@scotlandcarers.org

Northern Ireland, St-Faxi Carers' Centre  
028 93434700 or info@northernirelandcarers.org

**CARERS IN PRACTICE**

A partnership between the Royal College of General Practitioners and The Princess Royal Trust for Carers to support the health needs of carers. If you are looking after someone, this leaflet may help you.

www.rcgp.org.uk  
www.carers.org

“

Part of the [carers support worker] role was to help GPs identify carers and a recent survey of the carer's registers ... has ... indicated that those practices that engaged most with that support worker have a higher number of carers on their register

”

COMMISSIONER08

## Helping with prevention agenda

# Self help

- ▶ Creates sense of mutual support
  - ▶ Not being alone
  - ▶ Doesn't demand major infrastructure
- ▶ Research on peer support but this does not appear to consider self help outreach

The screenshot shows the NHS Choices website interface. At the top, the NHS logo is followed by 'choices Your health, your choices' and a search bar. Below this is a navigation menu with tabs for 'Health A-Z', 'Live Well', 'Care and support' (which is selected), 'Health news', and 'Services near you'. The main content area is titled 'Help for you' and includes social sharing options. Below this, there are tabs for 'Overview', 'Peer support', 'Advocacy', and 'Legal help'. The 'Overview' tab is active, showing the 'Self-help for carers' section. This section contains text about feeling overwhelmed, advice on setting expectations, and suggestions for support groups. A callout box on the right provides contact information for Carers Direct (0300 123 1053) and lists supported languages. At the bottom, there is a 'Services near you' section with a location search field.

“

Carers are hard to find ... It's just a question of talking and talking and more talking until I eventually found one and I found another one and then it spread from there, really ...

”

CARER18

# Combine credibility and flexibility

# Specialist outreach

- ▶ Fits most closely with other models of outreach in other research
- ▶ Especially important where stigma and/or lack of awareness an issue



Image from Rushcliffe BME  
Carers Support Service

# But

- ▶ No one study area had every type of outreach
- ▶ Need multi pronged approach
  - ▶ Recognises diversity of carers and caring situations

# Closing thoughts

Starting point for discussion



# Family carers are and will be increasingly important

- ▶ Increased number of older people
- ▶ More people aged under 65 with severe disabilities surviving
- ▶ Carers UK estimate that we will need another 3 million carers in the next 40 years to deal with increase in the older population and population with disabilities

# Contested concept (1)

- ▶ Some would argue that dominant approaches to 'caring' minimise its complexities
  - ▶ Forbat (2005) distinctions between carers and those they care for are not always clear
  - ▶ Takes a mechanistic approach to caring - focus on heavy physical labour
  - ▶ Lloyd (2006) many 'carers' do not recognise themselves as carers

# Where are we in research terms?

## US literature

- ▶ Similar findings
- ▶ Better on intervention studies
- ▶ Better evidence base on cultural and ethnic differences & role of spirituality in caring

## UK literature

- ▶ Similar findings
- ▶ More mixed methods studies
- ▶ More on carers' own experiences

# Disclaimer

- ▶ This presentation includes independent research funded by the NIHR School for Social Care Research. The views expressed in this presentation are those of the authors and not necessarily those of the NIHR School for Social Care Research or the Department of Health/NIHR

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## Social care practice with carers: What social care support is provided to family carers? What support do family carers want?

**KEY POINTS FROM THE RESEARCH**

- Most social care support for carers is delivered through the voluntary sector, although most councils still directly undertake carer assessments.
- Changes in commissioning and contracting arrangements have created additional opportunities for the voluntary sector but also some uncertainties.
- Carers have mixed views on the extent to which they feel their social care needs are met. However, they are positive about the help provided by carers' workers with a specific remit to provide them with support.
- Activities by carers' workers are varied and include outreach work, information provision, counselling, advocacy and ongoing support.
- Different ways of improving carers' access to information, such as websites, carers' cafes and outreach workers, have been developed, although these rarely seem to be evaluated for their effectiveness.
- Identifying carers in need of additional support seems mainly to take place when the person for whom they care is assessed. This disadvantages those caring for someone who is not eligible for, or who refuses, social care support from their local authority.
- The Care Act 2014 has implications for the way that social care support to carers is delivered. Currently,

The Care Act 2014 strengthens the rights and recognition of carers in the social care system, including new rights for carers to receive services. In the run-up to implementation of the Act, this study maps different types of social care support for family carers across England.

Using information from commissioners, carers' leads, voluntary organisations, social care workers with a specific remit to support carers, and family carers themselves, this mixed methods study used interviews, surveys and secondary data analysis to ask:

- How do carers access information about social care support?
- What are carers' experiences of assessment?
- What support is provided by carers' workers whose tasks involve providing specific support to family carers?

carers caring for someone not meeting the eligibility criteria for social care support may have substantial or critical unmet needs of their own.

- Carers' organisations argue that an important part of their role is to encourage carers to complete self-assessments but they are concerned that not enough support is then available to those carers who have been assessed.
- Some local councils are working with local clinical commissioning groups on integrating support for carers, though these developments have yet to become established everywhere.

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Improving the evidence base for adult social care practice

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