Reaching out or missing out?
Approaches to outreach with family carers in social care organisations

JO MORIARTY
Outline

► What we did
► What we found
► What we think might help
► Important to recognise that although this was an exploratory study, a lot of findings will be only too familiar to family carers and practitioners!
What we did

METHODS
Concurrent mixed method design

- Analysis of Carers Workers in NMDS-SC (Hussein & Manthorpe, 2012)
- Care plans
- Leaflets and brochures
- Websites
- National survey of councils with social services responsibilities
- National workforce data
- Interviews
- Survey
- Documents

Analysis of Carers Workers in NMDS-SC (Hussein & Manthorpe, 2012)
Interviews most important component

- Commissioners: 24
- Voluntary organisations: 8
- Carers workers: 16
- Family carers: 38

Commissioners: Red
Voluntary organisations: Orange
Carers workers: Brown
Family carers: Green

Joint SSRG NIHR SSCCR event
30 January 2014
What we found

BARRIERS TO SEEKING SUPPORT
DIFFERENT APPROACHES TO OUTREACH
We know that....

Many carers report difficulties in finding out about services, meaning that they are sometimes caring without any other sources of support.
‘Classic’ approach to problem solving

Identify problem  input  outcomes

But .... recognising a problem doesn’t always mean that solutions are achievable!
Multiple sources of information and support
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.

But many people don’t see themselves as carers.
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.

They may feel guilty about asking for help.
And, again, people say stigma is not out there, but it is and it’s massive.

Some may feel stigma about asking for help.
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?’

Information not always accessible or useful (overload and absence)
So called ‘hidden’ or under represented carers

- Even less likely to access support:
  - Carers from black and minority ethnic groups (Katbamna et al, 2004)
  - Lesbian, gay, bisexual and transgender carers (Willis et al, 2011)
  - Young carers (Children’s Society, 2013)
  - Working age carers in paid employment (King and Pickard, 2013)
General approaches

- Around 80 percent of councils responding kept Carers Register
- Leaflets in libraries and contact centres
- Link up to national events (Carers Week)
- Working with supermarkets

Daily Mail 13 June 2011
But....

- Council websites very variable
- Carers wanted more timely and specialist information
- Registers only include a small proportion of carers
Types of outreach

‘High street’
Visibility

Integrated primary care
Familiarity

Self help
Minimal infrastructure
Types of outreach

**Specialist**

‘Heineken effect’
‘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

Joint SSRG NIHR SSCR event

30 January 2014
in truth, when most of them do just pop in without an appointment they’re normally at crisis point to be honest, so we get quite a lot of people in up to here, a room full of tears here

Enables rapid response
Potential & challenges

- Carer involvement in centre signage and decor and in designing website helped one centre be more ‘visible’
- Challenge in rural areas because of cost
  - Rolling programme seen as better than one off visits
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
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

Helping with prevention agenda
Potential & challenges

- Appeared to exist only in one study area
- But much bigger body of work in NHS aimed at improving carer recognition in primary care
  - Not clear how this would/could link to carer assessments and other social care support
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
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 ... 

Combine credibility and flexibility
Potential and challenges

- Requires minimal resources
  - Small grant from council for meetings and publicity
  - Potential to link with other carer led initiatives (for instance, forums)
  - But very dependent on individuals
  - General trend away from grants to contracts may hinder expansion of this model
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
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

Cultural and language barriers around ‘caring’
You won’t get [carers of substance misusers] to realise they are carers or accept it. The chance of them walking into a carer centre or an NHS ... place and saying, ‘One, my son is a junkie. Two, I’m his carer. Three, I need help.’ Not a chance in hell!

Stigma and sense of failure accentuated.
Potential and challenges

- Clear way for services to demonstrate they are meeting requirements of Equality Act 2010
- Vulnerable to cutbacks as resource intensive
  - Even more so in rural areas
I haven't got a husband, a boyfriend, a partner, whatever. I never had a big social life. I have a few friends, but not friends that I would regularly go to the cinema with or go out for a drink ... One of my neighbours has become a good friend and she brings over a bottle [of wine] every now and again ... That's about the extent of my social life, apart from any carers meetings that I go to.

CARER07

And what happens when identified?
Discussion

WHERE DO WE GO FROM HERE?
Discussion

- Carers are very diverse
  - Need different types of outreach to reach different types of carer
- Potential for adult social care departments to link up outreach and prevention strategies
  - Context of Care Bill
- Risks of assuming information provision is enough
  - Not enough social care research on effectiveness of information strategies
Disclaimer

The preparation of this presentation was made possible by a grant from the National Institute for Health Research (NIHR) School for Social Care Research on social care practice with carers. 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.
Thanks to ....

Everyone who was interviewed or who returned a survey
Lizzy, Jenny, Mark, and Carolyn who helped with interviewing
Lizzy for help with data entry and coding
Virtual Outsourcing, Laptop Confidential and Voicescript who did the transcribing
The Project Advisory Group and the Unit Service User and Carer Advisory Group
To NIHR SSC R for funding
To you for listening!