ESRC Series Seminar 3:
Roundtable 'Research Gaps and Priorities', NOTES of key points/issues, June 13

Caring & expectations – what is reasonable for the family to provide? How influential are cultural differences and norms?

Re young carers: as they grow older expectations of you as a carer are greater – a 12 yr old child is expected to do more than an 8 yr old. Interestingly the most recent Census figures tell us that the largest growth in the number of carers is amongst 75 yr olds and 5 yr olds, so at both ends of the age continuum.

Once a carer becomes a teenager what is expected of them is far greater than when they were a young child and once they hit 18 yrs and are technically 'an adult' what is expected of them is considerable and they are no longer classed as a 'young carer' per se. This is an issue that is no longer that of children's rights but of human rights. Every carer has a right to have a life of their own: this issue brings into sharp relief the contrast between our view that 'children' should be offered some protection from caring whereas 'adults' are not offered the same level of protection.

Interesting question: If there are inappropriate levels of caring for children perhaps there are levels of caring that are inappropriate for everyone. Do we know about carers who decide to walk away from caring? If - even technically - carers are meant to be asked if they wish to continue with caring we should know more about those relatives who decide not to care. Maybe we have some evidence about older parents and adult sons/daughters caring for their parents and how much they do and whether they wish to share care with services or others but very little on those who wish to walk away from caring altogether.

How far do care managers ask about whether people wish to continue caring? The answer appears to be on a very limited basis. Some anecdotal evidence from the Carers Trust also suggests that feedback from carers support workers echoes these findings. One of the key problems is that carers feel they cannot walk away or even reduce their input because 'substitute' support services are so poor. The quality of alternative services is so poor which undermines any meaningful choice carers' have. If services are cut even further who are we expecting to pick up the tab for care. Carers are increasingly being viewed as free resources. Linking information about the support needs of the carer and the cared for would be a good start to developing efficient joined up models of care.

Carers often feel under huge pressure to 'do care'. One example is from a parent whose very ill child was being discharged from hospital and she was being told by health staff that 'if she didn't take her child home she'd be damaging her health and well being'. She wanted to be her daughter's 'mum' not her 'carer'. She insisted that her daughter had her care needs met by services so she was placed in a specialist residential facility; this freed up her mother to be her mother for the last years of her daughter's life facilitating the development of a more 'normal' mother/daughter relationship. But the mother had to fight hard for that level of input which she may well not have got had she not already been very familiar with the care system and the nature and extent of support to/for carers.

Reasons why providers and professionals don't do that carers want them to do: Carers are asked countless times what matters to them. Many many carers say that what they really want is to be treated as expert partners and included in decisions about the care of their relative.

And yet carers are routinely excluded from case conferences, care related meetings, decisions about hospital discharge and similar. Professionals tend to be ‘antagonistic’ or simply reluctant to engage with carers often when carers regularly aren’t going to ask for much but DO want to be listened to, their needs considered and their role acknowledged. There are some places/areas where working jointly with carers is successful and the norm and it may be helpful to look at how these models work, how outcomes for the person being cared for and the carer are improved and how care is made more effective. Some local authorities take a long view i.e. invest in prevention and early intervention and it may be useful to capture how this approach leads to more effective and cost effective outcomes. Evidence may suggest that they are saving money and achieving better outcomes for users and carers. Outcomes such as maintaining or improving health and well being of both users and carers.

New research needs to be conducted inside the policy context: the Care and Support Bill will be a reality in England in 2015 – all new research or even reported research needs to be located inside this context and not the ‘old’ legislation. Carers assessments of need are a good example.

How we take research forward: We have a lot of research out there but what do we do with it? How do we take findings forward? For research to be ‘effective’ it needs to be adopted/developed/implemented. Also funding tends to be short term or funders invest in a project and then disappear and that impetus is lost. We lose quite a lot of research along the way when funders withdraw from the field. Partners inside the carers world can help a lot in this regard. Carers Trust for example picked up a project that had ‘ended’ and ran with it on a shoestring. Sometimes the funding needed to continue with the project or implementation is not large but for it to be taken forward an agency – preferably a larger carers related agency – needs to pick up the ball.

<u>Panel round up of issues:</u>

- *Young carers*: support from schools, support from Barnardo’s – support from school is vital; some young carers are excluded from school (secondary and primary) and once out of education and at much higher risk of long term poverty, unemployment and under achievement. Young carers workers are effective. What young carers want is understanding, recognition and sometimes a break. Still an invisible population especially in local areas: young carers are children – ‘appropriate’ levels of care. We all have responsibility for young carers. Unclear in policy terms who is responsible for young carers despite their priority.
- *Two issues:*
    - *Policy differences between UK countries*: with increasingly divergent policy contexts there is now an interesting opportunity to do comparisons between the UK’s constituent countries around policy outcomes – around assessment & support for carers and cared for people.
    - *Carers resilience* – what do we mean by this, how can it be bolstered and can it be an issue that is conceptualized as both inside the individual and inside the context i.e. it is about family, community, socio-economic environment etc – a larger issue/concept that just psychological resilience.
- *Longitudinal research:* This is needed if we are to make any meaningful comments about the impact of services through time and between populations. However useful short term research is really we need a longitudinal study to capture the impact of prevention, early intervention and how combinations of services work well (or not?) for both the carer and the cared for person.

- *Loss of expertise:* There are a number of experienced researchers working in the carers field and the loss of this expertise would be a problem. Working with vulnerable groups such as young carers requires skill, knowledge and empathy and also an understanding of the wider agenda. Ethical issues are also very important. We need to be careful that we are not exploiting or taking advantage of young people.
- *A number of issues*:
    - *We need focused interventions and evaluations* of what works/what is effective
    - *There is a lot of good research out there which is not translated into better practice*: 15 yrs ago research on carers assessments was saying the same things that I am hearing today: it is as much about what happens with the research as the research itself
    - *We need new research on things we don't know the answer to* BUT we need to stop doing the same research in parallel universes whilst leaving gaping gaps in the portfolio
    - *Someone - an agency/centre - needs to take responsibility for providing an overview of carers research & for translating that research into outcomes/implementing it into practice* = translational research
    - *International/global comparisons* – need to know more about how the needs of carers are met in different countries including different groups e.g. young carers, older carers.
    - *Quality of care provided by carers*: this is a thorny area which has considerable potential to be radical in its implications for policy, practice & services & contentious!