What do we know about carer perspectives in mental health and disability services?”

Conference or Workshop Item

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What do we know about carer perspectives in mental health and disability services?

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1. What do we know about carers?

Profiles
12% (6.4 million) of UK adults are carers

- 26% of all carers care for a spouse or a partner
- 52% care for their parents/in law
- 13% care for a disabled son or daughter
- 70% of the cared-for population are aged over 65
- 25% of carers are aged over 65 years
- 2% of carers are young people
- just under 50% provide care for 20+ hours per week
- 20% care for 50+ hours
- 14% care for two people
1. What do we know about carers?

**Impact of caring**
- full-time carers are twice as likely to be in bad health as non-carers
- 40% of carers experience ‘significant levels’ of distress and depression
- carers of those with mental health problems experience higher levels of stress and anxiety than many other carers
- intensive levels of care are associated with a 23% higher risk of stroke
- nearly 3/5ths of carers give up paid work to care (loss of £11,000+ pa per carer and £5.3 million pa to the UK economy)
- quality of life
- risk of poverty
- sense of giving back and higher levels of subjective well-being

**Valuing carers**
- carers save the UK economy £119 billion pa - a rise of 37% since 2007
- demographic change coupled with a reduction in public sector support means that both the number of carers and the intensity of care will increase
- there will be 9 million carers by 2037
- 3 in 5 adults in the UK will become a carer at some point in their lives
- it is predicted that the ‘tipping point of care’ - when the need for family care for older people outweighs the supply of carers - will be reached by 2017

2. Policy recognition of carers

- policy recognition of carers’ contributions has increased over the last 20 years
- policies (e.g. Carers Recognition and Services Act 1995 and the cross government ‘Carers Strategies’) have explicitly focussed on carers’ rights to:
  - have their needs assessed,
  - protect their health and well-being,
  - access support, training and employment
  - ‘live a life outside caring’
3. Effectiveness of policies

- many carers are still profoundly disadvantaged
- carers are routinely overlooked and feel unsupported, powerless and marginalised
- access to services
  - only 6% of all carers in England receive a needs assessment,
  - 31% of carers providing 35 hours+ per week reported receiving “no practical support”
  - in 2013 only 1 in 10 carers received Carers Allowance
- the evidence relating to service effectiveness is mixed

4. Why aren’t carers needs being adequately met by services?

- exploring users perspectives been an accepted feature of policy marking and practice since the 1970s
- the use of carers perspectives was much later
  - concept of ‘carer’ only brought into legislation in 1990
  - lack of conceptual clarity
  - only half of all carers self-identify
  - some carers may be service users too
  - Disability movement 1960s v Carers movement 1990s

5. The use of carers’ perspectives in service delivery

- carers perspectives are sought in professional training and assessment
- understanding of the carers’ perspective is an integral part of professional training
- invited to take part in Department of Health consultation events for policy changes
- SCIE co-production network
- involved in the co-production of practice guides e.g. Think Local Act Personal guides (TLAP)
- more research aimed at understanding carers’ perspectives (SPRU, PSSRU, Carers Trust)
- carers as co-researchers
- carers assess research proposals (NIHR SSCR)
6. Carers and services in the future

- health and social care is unsustainable without carers
- the demand for carers is likely to outstrip supply
- carers will have to cope with new demands
- carers will have to cope with more intensive caring

Therefore we need to:
- support carers to stay in work whilst caring
- keep carers well
- improve their quality of life
- provide the right support for them to meet changes in the challenges of caring

7. Towards a better future for carers

Integral to the way forward is using carers’ perspectives:

- using carers’ perspectives to identify carers
- embedding carers’ perspectives into every stage of service development and delivery