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Citation

Larkin, Mary (2014). What do we know about carer perspectives in mental health and disability services?". In: National Conference: What Works? User and Carer Perspectives on Mental Health and Disability Services., 11 Jun 2014, Leicester, UK.

URL

<https://oro.open.ac.uk/41098/>

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



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11th June 2014

Outline

1. What do we know about carers?
2. Policy recognition of carers
3. Effectiveness of policies
4. Why aren't carers needs being adequately met by services?
5. The use of carers' perspectives in service delivery
6. Carers and services in the future
7. Towards a better future for carers

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

1. What do we know about carers?

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 making 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

and

- embedding carers' perspectives into every stage of service development and delivery
