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Carer Participation in England, Wales and Northern Ireland

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SCIE Carer Participation Research 2005

- Study completed by the University of Sunderland and Sunderland Carers Centre and the network of Princess Royal Trust Carers Centre
- Literature and Practice Review of England, Northern Ireland and Wales
- August 2004-July 2005
- Adopted carer-led methodology
- Carer Participation Review Group (10 carers)
- Research Review Group (12 national attendees)

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Carer Led Methodology

- Once the focus and Knowledge Review template in place...
- Carer Participation and Review Group formed to: formulate research tools, identify key issues in carer participation, review and reform all aspects of research as required and now primary role is commenting on research findings and SCIE feedback

Research Population

- All Social Service Departments and Care Boards in England and Wales (74)
- All Health and Social Care Boards (5)
- Selection of PCTS and Health Authorities (32)
- Selection of Learning Disability Partnership Boards (9)
- Carers and Carer's Centres (25&15)

Research Methodology

- Systematic Literature Review (Sift of circa 30,000 sources)
- Policy Review
- Practice Review in 3 stages: questionnaire, interview and data triangulation
- All methodological and research roll out issues carer-led

Policy Context

- NHS and Community Care Act 1990
- Carer's Recognition Act 1995
- Caring National Strategy 1999
- Cares and Disabled Children Act 2000
- Carers (Equal Opportunities) Act 2005
- Northern Ireland Consultation on Standards to Improve Quality in Health and Social Care

Literature Review Findings 1

- There is much carer participation (CP) taking place
- However there are very diverse interpretations of just what CP is-ranging from consultation through Board memberships to direct involvement in services planning, monitoring and review, research and influencing service outcomes

Literature Review Findings 2

- There is no consensus on what CP is taken to mean at a theoretical level, whilst the main schemes and ideas shaping the academic and practice literature (Arnstein, Smale, Manthorpe) do not filter through into practice guidance.
- There is a sound if not substantial body of literature dealing with carer participation, however certain issues such as carer diversity, for example BME, lifetime carers are quite unusual

Literature Review Findings 3

- Most research on CP is small scale and tell us little about the broader picture of carer's involvement in services.
- Much research subsumes carers under the rubric of research on 'users and carers' which often treats the latter as an add-on feature of a study

Literature Review Findings 4

- The bulk of CP research looks at carers in terms of the 'impairment group'-users with learning difficulties, dementia. Mental illness
- There is some important work on needs assessment and the need to take carers' views and expertise more fully into account
- Health service insights (e.g Expert Patient Initiative) are being creatively deployed to build CP into health and social care contexts

Literature Review Findings 5

- There remains little work which looks at CP as an empowerment issue (c/f user empowerment)
- There are however good example of joint working and commissioning which provide promise as to future CP potential
- Some best practice examples are discussed in the literature for example carer's being fully involved in major programme review, carers on carer support worker interview panels...

Practice Review 1

- Many examples claimed for creative CP activity and these straddle statutory and voluntary sectors
- Most statutory organisations had got CP on the agenda, however the extent of application was very patchy
- Carer consultation was common, as was Board membership of carers, for example LDPB

Practice Review 2

- Carer Participation in service planning and review was less common and measured outcomes of involvement very uncommon
- Key role of carers' centres in activating CP, making it happen.
- Most established CP activity involved carers in a range of activity including strategic and street-level service activity

Practice Review 3

- There were a small number of CP activities which successfully targeted traditionally hidden carers
- Despite legislative presence and the Caring about Carers guidance-there was felt to be a need for greater clarity and action adherence measures for best practice assessment

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