

Scrutiny Inquiry

'Making Southampton a Dementia Friendly City'

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Insights from a Gerontologist's research

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Outline

- Emerging story on dementia prevalence
- University of Southampton news on dementia
- Take-home messages from my research with:
 - Croydon Memory Service
 - Southampton, Portsmouth & Hampshire social services

Dementia prevalence estimates & predictions

- In **2007** there were estimated to be **683,597** people in the UK who had dementia (Knapp & Prince, 2007)
- ***Due to the ageing population =>***
 - By **2051** there are expected to be over **2 million** people in the UK with dementia (Prince *et al.*, 2014)

Prevalence of dementia slowing over time?

- Multi-centre longitudinal study of cognitive ageing in England & Wales (MRC CFAS)
- In 1994 they estimated that there would be **884,000** people aged 65+ with dementia by 2011
- *However*, the later data allowed an estimate of **670,000** people aged 65+ with dementia in 2011
- **A cohort effect** – the numbers of people with dementia are not increasing as quickly as was once predicted
 - *Potentially due to healthier lifestyles, better education, improvements in care, etc.*

New developments at the University of Southampton

- In 2015, the Alzheimer's Society funded eight **Doctoral Training Centres (DTCs) in Dementia** around the country
 - This is the single biggest funding commitment to support early-career dementia researchers in the UK (almost £5million)
- The University of Southampton was successful in its bid to win one of these centres
 - Bowling, Bartlett, **Willis**, Addington-Hall, Green, Bridges & Roberts
- Southampton's Doctoral Training Centre in Dementia Care focuses on *Researching patient safety and risk enablement* in different care settings (own home, care home, hospital)
- *Southampton DTC Launch event 15th December 2015*
(contact: events.hs@southampton.ac.uk)

Support services for dementia

- Evaluation of the Croydon Memory Service
- Participant views on experiences with the support provided:
 - The memory service
 - Carer support groups
 - Day centres for people with dementia

“It did help me because we spoke to other people with similar problems and you learn that you are not alone.” (Carer)

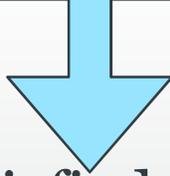
“It’s [the memory service] one of the pillars you can lean on if it gets to the stage where you need to, you know, you’ve always got a chance of ringing them, you’ve got a voice at the other end that you know and who’s in a situation where they understand and that makes a big difference.” (Carer)

**“Going to the day centre and so on and it was quite helpful, you know, and it made me feel better that there were other people and, you know, it was nice to be with other people and not to feel the pressure as you do sometimes with normal people [laughs], you know, so on the whole it was very good.”
(Person with Dementia)**

Satisfaction surveys

- National surveys have consistently shown lower satisfaction levels among Black/Black British and Asian/Asian British groups compared with the White group

Overall, how satisfied or dissatisfied are you with the care and support services you receive?



- 7-point scale from extremely satisfied to extremely dissatisfied
- The survey approach did not allow for an explanation of why this pattern occurred

Local social care research

- In-depth interviews (n=121)
 - **Service users** (n=46)
 - South Asian
 - White British
 - **Informal carers** (n=36)
 - South Asian
 - White British
 - **Service providers** (n=39)
 - A range of ethnic backgrounds
- Southampton, Portsmouth, Hampshire
- Two interviewers: British Indian (PK) and White Irish (RW)



Similarities across ethnicities

- **Staff who really care**
 - Appreciation of the caring manner of staff: *angels, charming, empathetic*
- **Continuity of care**
 - Importance of continuity for confidence of client
 - If can't have continuity, then it is vital to have read the care plan, particularly for culturally specific needs

Differences between ethnicities

- **South Asian:**
 - The right time to contact services
 - How to access services
 - Experiences of discrimination
 - Language
 - Food
- **White British:**
 - Staff abilities and interpersonal skills
 - Time

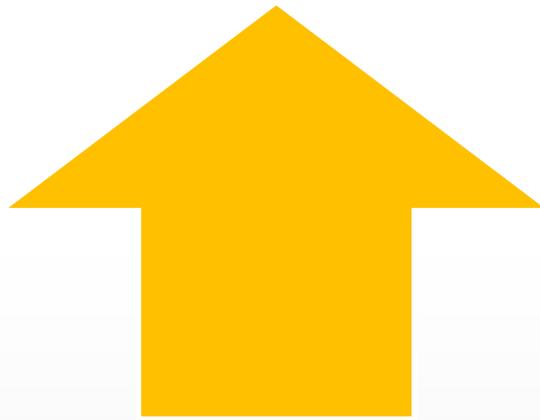
'The right time to contact services'

*Our culture is built, our foundation, our culture is built on the basis that **we try not to take help from outsiders** ... and this is what was happening in my case that because my wife was working, I was working, although I was working from home, I still needed support from somebody to look after her [my mother] in terms of her daily wash and care and then, perhaps, maybe take her out for a while, so that sort of things, for that support we need it ... Although we go, what I'm saying is, **we go to social services** ... but I don't think we as much **don't want to take advantage of it and we wouldn't have asked for help unless we were really, really desperate**. And it's when the desperation comes, **that's when you go and seek the help**. (Carer 20, SA)*

‘No help offered if you don’t ask’

*There was never any talk
of any kind of additional care
or respite or anything like that.
We just took that as normal.
(Carer 26, SA)*

Key theme: Understanding the system



Clearer
understanding,
higher satisfaction



Unclear
understanding,
lower satisfaction

Summary

- Carers who had familiarity with the social care system were more satisfied
 - *These people tended to be ‘insiders’ or to have long experience with the care system, and included both WB and SA participants*
- Many South Asian carers viewed social services as fulfilling an important role, and something to be used when absolutely necessary (at crisis point)
 - *Formal social services are not incompatible with British Asian cultural values*

Recommendations

- ‘One-stop-shop’ memory clinics can provide access to a range of helpful services (joined-up care)
- Continuity of care is valued and important in dementia care
- Need to improve communication between social services and carers/service users at every stage of the process:
 - Outreach
 - Assessment
 - Meet language needs at all stages
 - More follow-up calls / visits (not dropped from caseload)
- These issues are particularly problematic for the South Asian group, who had additional barriers to knowledge about social care services

Thank you



References

- Health and Social Care Information Centre (2013) Personal Social Services Adult Social Care Survey, England - 2012-13, Final release, Leeds: HSCIC.
- Knapp, M. and Prince, M. (2007) Dementia UK: The Full Report, London: Alzheimer's Society.
- Matthews, F.E., Arthur, A., Barnes, L.E., Bond, J., Jagger, C., Robinson, L., Brayne, C. and CFAS, M. (2013) 'A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II', *Lancet* 382: 1405-1412.
- Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., Wittenberg, R., Adalaja, B., Hu, B., King, D., Rehill, A. and Salimkumar, D. (2014) Dementia UK Update: Second Edition, London: Alzheimer's Society.

Some of my journal articles

- Banerjee, S., Willis, R., Matthews, D., Contell, F., Chan, J. and Murray, J. (2007) 'Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon memory service model', *International Journal of Geriatric Psychiatry*, 22 (8), 782-788.
- Willis, R., Khambhaita, P., Pathak, P. & Evandrou, M. (2015) 'Satisfaction with social care services among South Asian and White British older people: The need to understand the system', *Ageing and Society*. Early view available online.
- Willis, R., Evandrou, M., Pathak, P. & Khambhaita, P. (2015) 'Problems with measuring satisfaction with social care', *Health and Social Care in the Community*. Early view available online.
- Willis, R., Chan, J., Murray, J., Matthews, D. and Banerjee, S. (2009) 'People with dementia and their family carers' satisfaction with a memory service: a qualitative evaluation generating quality indicators for dementia care', *Journal of Mental Health*, 18 (1), 26-37.

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