

# WICKING

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**Co-production: building bridges between carers and dementia health services**

**(A Start Point for Service Redesign)**

Dr Christine Stirling

## Overview

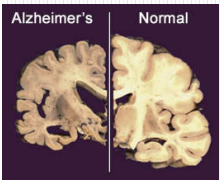
- Co-production and Service Redesign
- Dementia Carers – A case study of carers' experiences of community services
  - Finding out what's wrong.
  - Getting help when you need it.
  - The down-side of health services in the home.
- Bridges to better services
  - Freeing up access
  - Increasing shared decision making
  - Ensuring voice



## We need to redesign health services


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**Dementia – a disabling disease**



HACC, Community Packages and residential place costs to increase between 450% - 749% from 11 billion in 2010 to 60 - 94 billion in 2050

Access Economics 2010 – Projected figures rounded

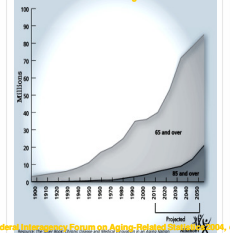


## Dementia as one example


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Number of People Age 65 and Over, by Age Group, Selected Years 1990-2000 and Projected 2010-2050

1. The year 2010 marks the first of the baby-boomer generation turning 65 years of age.
2. Change from just over 1% of population have dementia in 2010 to more than 3% by 2050



(Access Economics 2009 and 2010 – Projected figures rounded)



## Co-Production – service redesign

Services produced in a reciprocal relationship between professionals, service users, families and neighbours.

- Service users are resources
- Services need to interact with neighbourhood level support
- Family, neighbourhood, community and civil society are the 'core economy' – social capital
- Services need to promote idea of equal partnership
- Focus on effectiveness not efficiency

(Boyle and Harris 2010)

## Co-Production Benefits

'Co-production changes all this. It makes the system more efficient, more effective and more responsive to community needs. More importantly, it makes social care altogether more humane, more trustworthy, more valued – and altogether more transforming for those who use it.'

Phil Hope – then Minister of State for Care Services UK 2009

'Co-production shifts the balance of power, responsibility and resources from professionals more to individuals, by involving people in the delivery of their own services.'

(Boyle and Harris 2009).

### BUT for Service Volunteers?

Sharing Power, Responsibility and Resources?

- Deep seated power remains unchanged
- Seen as a solution that ignores/hides inequity
- Limited resources – no budget
- Capacity not equal but ‘Blame the Victim’
- Government encroaching on the social
- Communities and families competing against each other.

### A warning: lack of collective agency

- Volunteers have agency to enter and exit services
- But volunteers were unable to articulate new directions and lack structures (Archer 2000):
  - Constrained by the cultural framework of ‘helping’
  - Small and geographically distant groups
  - Managers control representations of volunteers
  - Communication systems all top-down
  - The focus of volunteer interests – local, service –not attracting activists

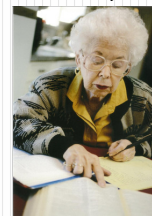
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**What service redesign would be needed to trial co-production with a group who are already providing enormous resources:**

**Carers of People with Dementia?**

### Who Cares?

- In 2010 PWD received 210 million hours of informal care
- Around 73% of PWD in the community have a carer
- Most carers aged 50-70 years
- Average hours of care provided is 38 - 42 hours per week.
- Carers suffer from stress, lack of sleep, neglect of own health problems, high level of disability



### Carer stress and burden

#### Stress Reduction Kit

**How bad can it get?**  
An excerpt from Benbow et al. (2009).



- Directions:
1. Place kit on FIRM surface.
  2. Follow directions in circle of kit.
  3. Repeat step 2 as necessary, or until unconscious.
  4. If unconscious, cease stress reduction activity.



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### Carers' Experiences of Community Services

*without the services I couldn't cope, simple as that. I wouldn't even attempt to cope. It would mean a home for him and the odds of getting into one of those is near impossible.*

## Carers Experience of Diagnosis

- Difficult to get a diagnosis
- Difficult to get information
- Referral onto other services inconsistent
- I'd say, "Mum's memory isn't too good"; try and not make her look silly in front of them, but, she'd say, "Oh, it's better than yours", and they'd just laugh with her and that would be the end of that. You know, you couldn't get anyone to take it very seriously.
- 'The biggest problem for carers is -where do you get the information?'

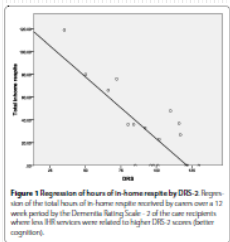
## Getting help when needed

Assessments not capturing need

"Well there's been five actual assessments and three interviews... over the last four months... then there was the day care lady came and assessed her and that was fruitless"

**Table 2: Objective and subjective clinical characteristics of the 20 carer and 20 care recipient participants.**

Subjective and Objective measures of burden	Statistic (mean (range) SD)
DRS-2, mean (SD) = 6.0(2)	61.2(6) 10(7) 13.0(5)
BDQ-5 Total, mean (SD) = 6.6(2)	74.1(4) 4(10) 1.8
Care Recipient Age at Diagnosis,	74.0(5) 4(0) 9.9
Female/Carer, Yes/No	8/12(16) 8(2) 1(6)
<b>Measures of Care Burden</b>	
GHQ-16, mean (SD) = 6.0(2)	43.1(2) 2(5) 7.9(7) 13.0(5)
CCQ-12 Subscale where most possible = 12	19.3(9) 3(7) 8.8
CCQ-12 Care stress where most possible = 12	10.2(5) 3(2) 8.8
CCQ-Overall Burden	3.2(5) 0-11
CCQ-Physical Burden	3.2(5) 0-11
CCQ-Emotional Burden	4.0(5) 0-11
CCQ-Financial Burden	2.1(5) 0-11
CCQ-Social Burden	3.2(5) 0-11
CCQ-Care recipient by service needs	2.8(4) 0-11
<b>Services Provided</b>	
Total of in-home respite hours over 3 months receiving RRP hrs	12.0(2) 2(6) 1-22.8(7) 14.7(8)
Total in-home respite over 3 months receiving RRP hrs	29.0(11) 0-34.8(7) 11.2(5)
Total practical help over 3 months receiving RRP hrs	22.0(12) 0-33.8(7) 12.6(8)
CCQ-career help need score	3.9(4) 0-12
Need more help from services than I am given - yes	8/16(13) 0(5)
Need more information than I am given - yes	8/16(13) 0(5)
Services should work together & communicate more - yes	8/16(13) 0(5)
Need better access to services - yes	8/16(13) 0(5)



**Figure 1** Regression of hours of in-home respite by GHQ-16. Regression of the total hours of in-home respite received by carers over a 12 week period by the GHQ-16 scores. Carers with lower GHQ-16 scores were related to higher GHQ-16 scores (better cognitive).

A statistically significant rank correlation ( $p = 0.01$ ) between carer's use of in-home respite and the care-recipient's cognitive and functional status. Otherwise, there were no statistically significant relationships between carer burden or stress and level of service provision.

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**A simple one-item measure of carers' felt need for more services was significantly related to carer stress as measured on the GHQ-30.**

65% of carers would like more help from services than they were currently receiving (*felt need*). The statement- 'I need more help from services than I am given' was positively related to carers' GHQ-30 (Spearman's rho = 0.625, p = 0.01).

Qualitative data showed that there are many potential stressors for carers, other than those related to the care-giving role.

## Getting help when you need it

Rigid boundaries around service provision

"I was totally happy. I had had support from all sorts of organisations – respite care, day care, in home respite, but at the critical moment it totally collapsed on me. The system collapsed. I was very, very desperate, and I needed help and this is the letter I got."

## Confusing array of services

Fragmentation causes confusion

- 'We need more co-ordinated services, rather than people all over the place who have never heard of one another all doing assessments'.
- "About twelve months ago now, a group of youngsters came and they washed all the windows outside and the boys... and that was wonderful... They said "Will you ask for us again next year?" And I thought yes, I will, but I don't know where they came from."

## Confusing array of services

### A stream of different people and organisations

- Carer: They got a lady to come and assess Mum and talk to Mum and she said yes, she's got dementia.
- *Interviewer: Was that an ACAT assessment? Aged Care Assessment Team?*
- Carer: I don't know. It was just some, some woman that came. I couldn't tell you what it was.

## Home is no longer the castle

- A stream of strangers entering the home
- Routines must change to fit the service
- Ambiguous gain (Lloyd and Stirling 2011 – in print)

“He's had four [carers] and this gentleman will be the fifth **today**. So he gets very confused about who is coming and I have to explain each week.”

## Fearful gratitude

- “I have to leave it, I can't ruffle anybody anymore, you know I have got to take my turn.”
- “I'm extremely grateful for the fact that it's available. It's just that it seems rather strange to me that ... I shouldn't have mentioned that. I'm extremely grateful.”
- They say that they want to keep you in your home, but ... That [kind of service] has all been cut out now. They have cut down staff. We are just lucky that they will come and cut the wood for us, which is a great help.



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Service ReDesign

## Improving Access to Diagnosis

### The Brain Check Clinic

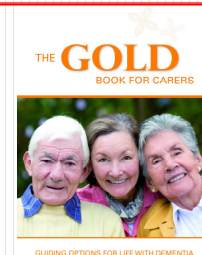
- Free or small charge nurse-led cognitive assessments
- Accepting GP AND self-referral
- Follow-up visit to facilitate appropriate referrals to community supports such as Alzheimer's Australia, HACC
- Funding from the ANZCT-The Mason Foundation Award: Grant-Judith Jane Mason & Harold Stannett Williams for 12 month pilot

Supporting GP and Practice Nurse Education on Dementia Diagnosis

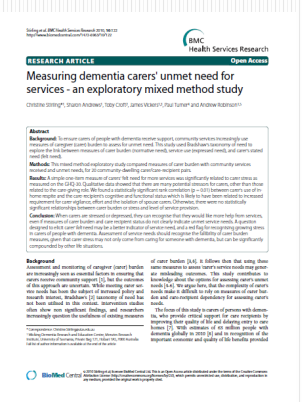
## Facilitating Carer Voice in Service Negotiations

### Development and Trial of the GOLD Book

- To increase the knowledge of carers about the trajectory of dementia.
- To improve carer participation in decision-making about community services
- To reduce decisional conflict and anxiety for the carer when making care decisions, and
- To increase the early use of community services by carer/PWD dyads



**"Felt Need" providing a better indicator for dementia services need than expert assessment?**



**Measuring dementia carers' unmet need for services - an exploratory mixed method study**

**Abstract**

**Background:** In many cases of people with dementia, the caregiver is the primary person with knowledge of caregiver needs to inform services for carers. This study used a Bayesian mixture of need for services to help determine measures of carer burden, unmet needs, and carer engagement and support needs.

**Methods:** This mixed methods exploratory study included measures of carer burden with community services, unmet needs, and carer engagement. The data were analyzed using Bayesian mixture models.

**Results:** A single case study analysis of carer felt need for services was significantly related to carer burden as measured by the GDS-15. Qualitative data showed that there are many perceived reasons to believe that the felt need related to the caregiver. We found a statistically significant relationship ( $p < 0.01$ ) between carer use of home support and carer engagement, support and help needed. Qualitative data showed that there are many perceived reasons for carer engagement, support and help needed. Qualitative data showed that there are many perceived reasons for carer engagement, support and help needed.

**Conclusions:** When carer use services are perceived to be low, this may suggest that there would be more help from services, such as respite care and carer support. This study indicates that carer felt need is a better indicator of carer burden. It suggests that qualitative data can be used to help determine the perceived need for services and help for caregiver support. It also suggests that carer use of services may not only come from caring for someone with dementia, but can be significantly correlated with the caregiver.

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## Assisting interactions with services - navigators

At least 24% of those with dementia living in community households live alone (AIHW 2007).

They are a vulnerable group and are more likely to be admitted to Aged Care Facilities (Yaffe et al. 2002)(Martikainen et al., 2009).


Developing a research project to better understand the care decision needs of this group and assist them to maintain independence.

**How does advocacy help people with dementia living alone?**

PhD Candidate – Corinna Dwan


**Project Partners**

Dementia Advocacy Service



## Service design from the carer perspective

- Timely diagnosis – GP or clinic easily accessed
- Pertinent information – several formats
- Link to appropriate combined, multi-disciplinary service
- Ongoing respectful relationship with access to help and services when needed.
- Services that fit the pattern of their life



## Strategies to develop and maintain equal relationships

- Continue to capture the experiences and voices of carers – feed-up from the grassroots.
- Develop and use tools to facilitate partnerships
- Safe avenues for grievances
- Carers' need adequate representation in policy making
- Carer umbrella groups and associations need to be supported to provide advocacy - not just services


## In Conclusion

There is a lot of work to be done to change culture so that we have more equal relationships with a sharing of power.





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**Thank You**

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