

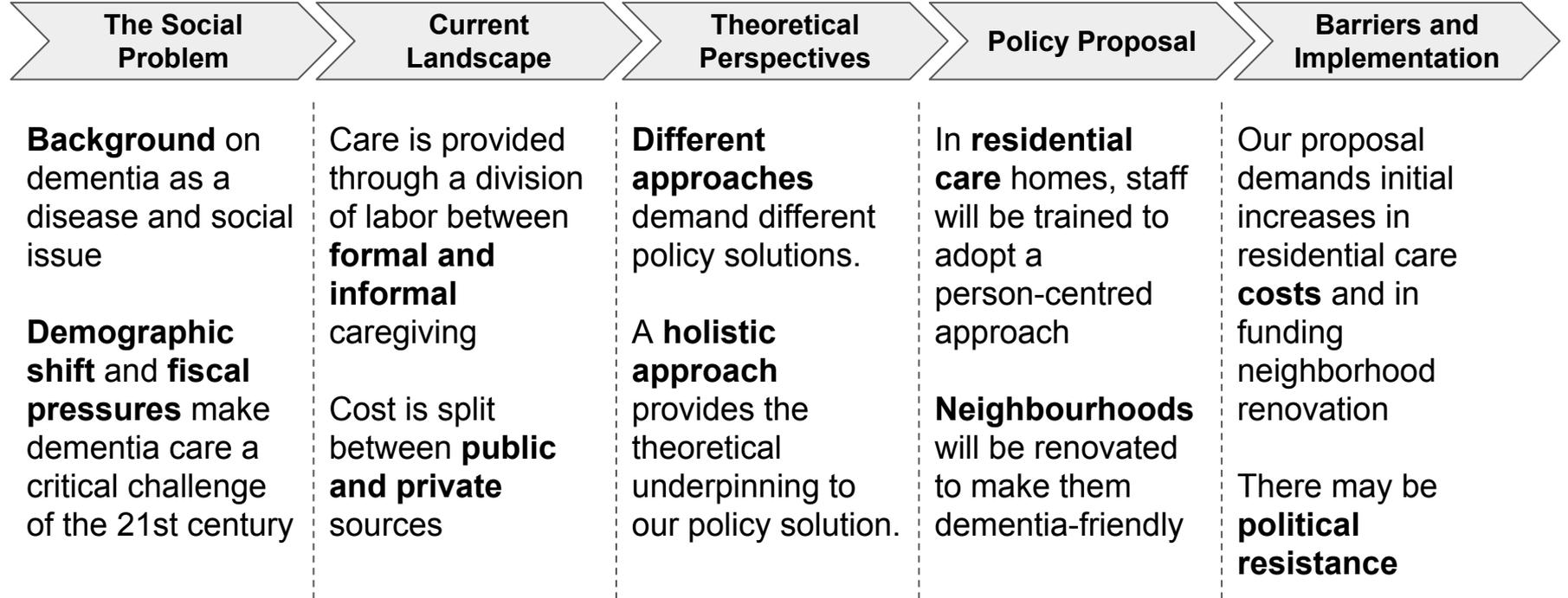
A Person-Centred Approach to Dementia: A Policy Proposal for Improving Dementia Care in the U.K.

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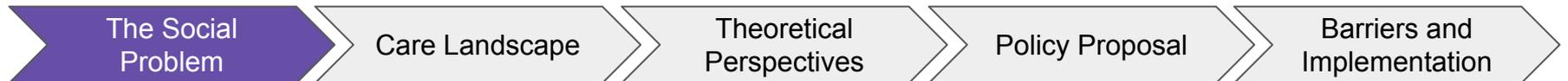
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Proposal Overview



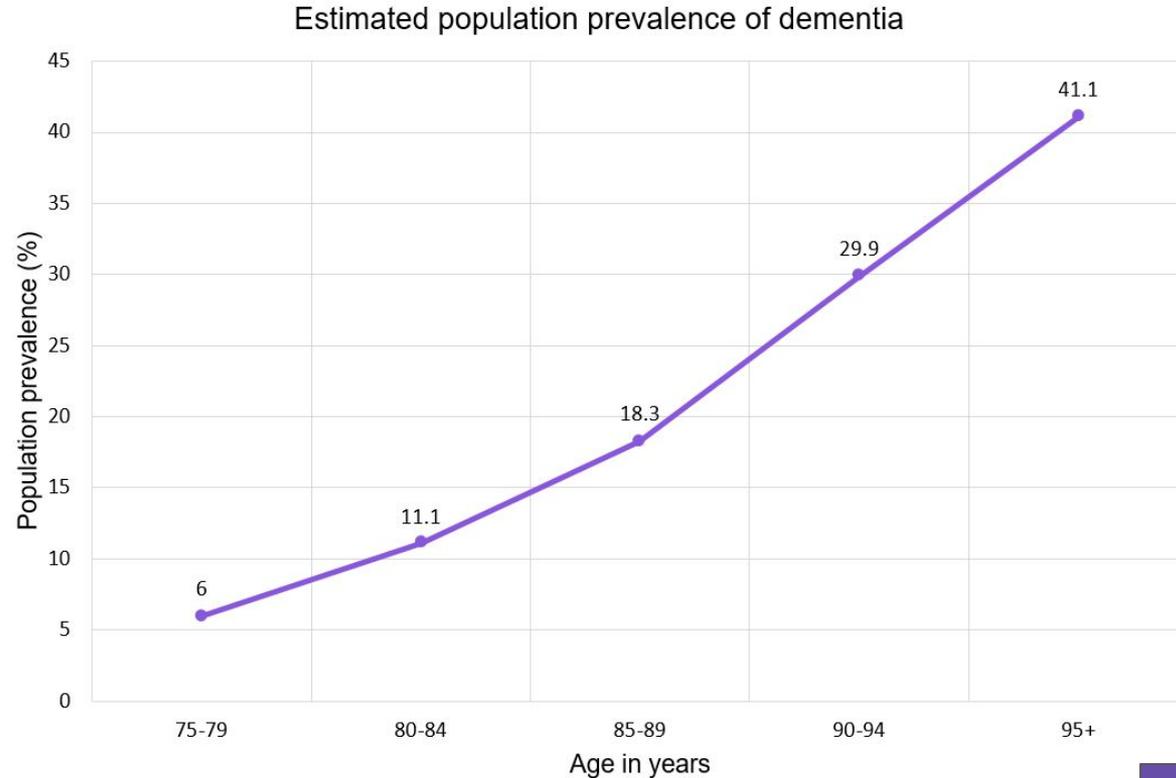
The Social Problem: Demographic shift and fiscal pressures make dementia care a critical challenge of the 21st century



Dementia is a cognitive disorder resulting from a number of diseases

- Group of related symptoms indicative of decline in brain functioning (NHS Choices, 2017)
 - Memory loss
 - Language impairments
 - Judgement problems
 - Mood problems
 - Movement problems
 - Difficulties carrying out daily activities
- Some subtypes:
 - Alzheimer's disease (62%)
 - Vascular dementia (17%)
 - Mixed dementia (10%)
- Leading cause of death for females, 2nd leading cause for males (ONS, 2017)

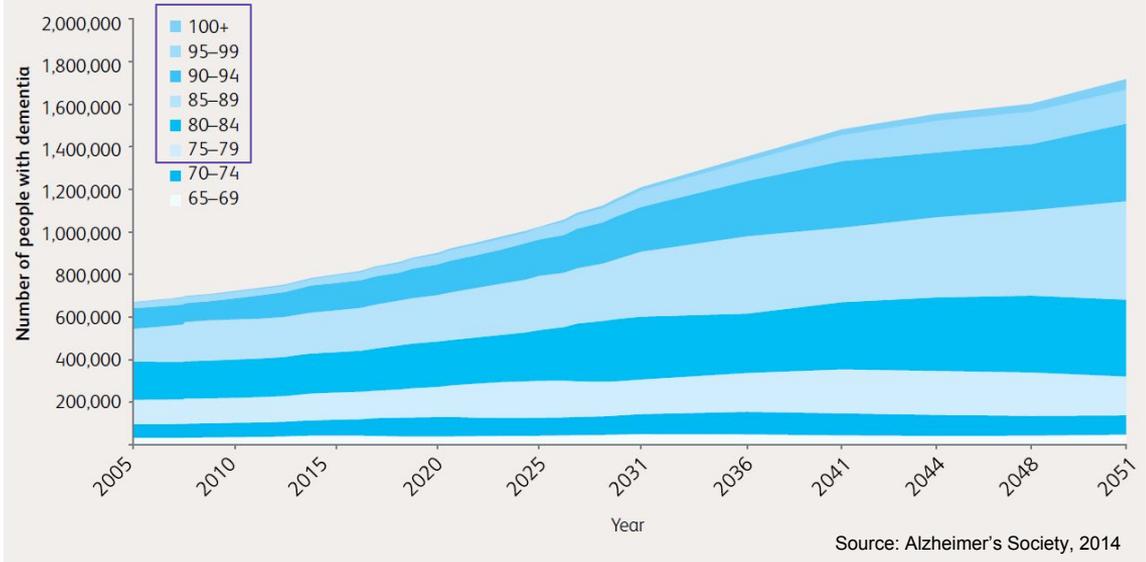
The prevalence of dementia increases sharply with age



Population aging will cause a doubling of the U.K. dementia population by 2050

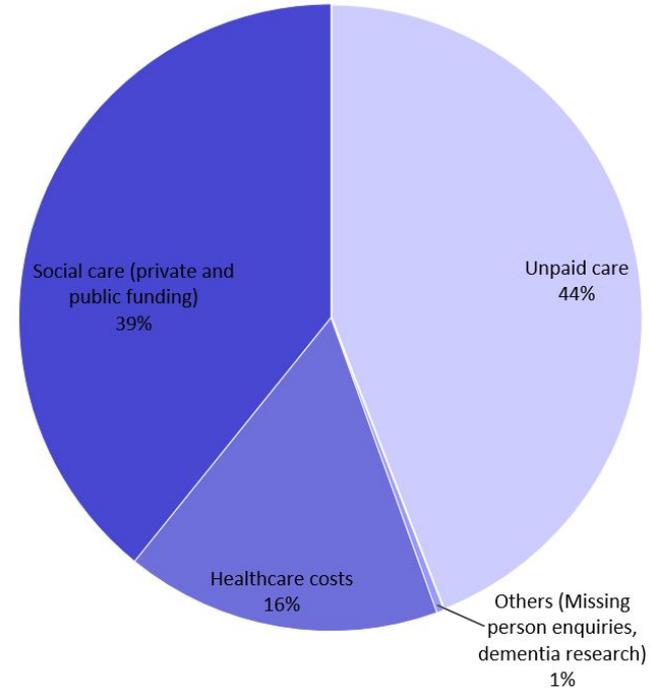
- Demographic ageing
- Estimated increase in dementia sufferers: **32%** by 2025, **147%** by 2051

Figure B: Projected increases in the number of people with dementia in the UK, by age group (2012–2051)



The increasing dementia population will lead to an increasing financial burden

- According to the Alzheimer's Society (2014), currently £26.3 billion a year
 - More than costs of cancer, heart disease, or stroke
 - 'Enough to pay the energy bills of every household in the country'
- Costs expected to be tripled by 2040



Dementia patients currently have poor quality of life

- A large UK study revealed that 20.5% of dementia patients had depression, compared to 8.6% of those without dementia (Winblad et al. 2004)
- Results of recent inspections on 725 care homes: around 44% rated as 'inadequate' or 'requiring improvement' overall (Care Quality Commission, 2017)
- 1 in 4 ratings of care homes on the Good Care Guide are 'poor' or 'bad' (Knapton, 2017)
 - For instance, there were complaints of inadequately trained staff who did not know how to lift patients or care for people with dementia
- Although they value being able to walk outside, they get anxious and disoriented in complex, busy or loud places (Mitchell & Burton, 2010)

The U.K. government recognises the issues posed by dementia and is attempting to address them

“the new Challenge aims to make England, by 2020, the best country in the world for dementia care, support, research and awareness”

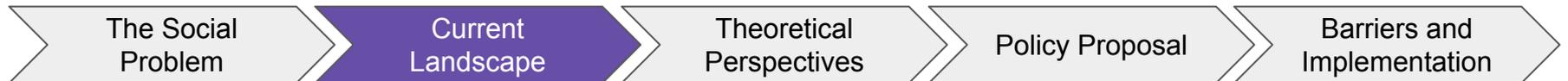


Prime Minister's Challenge on Dementia 2020

Implementation Plan



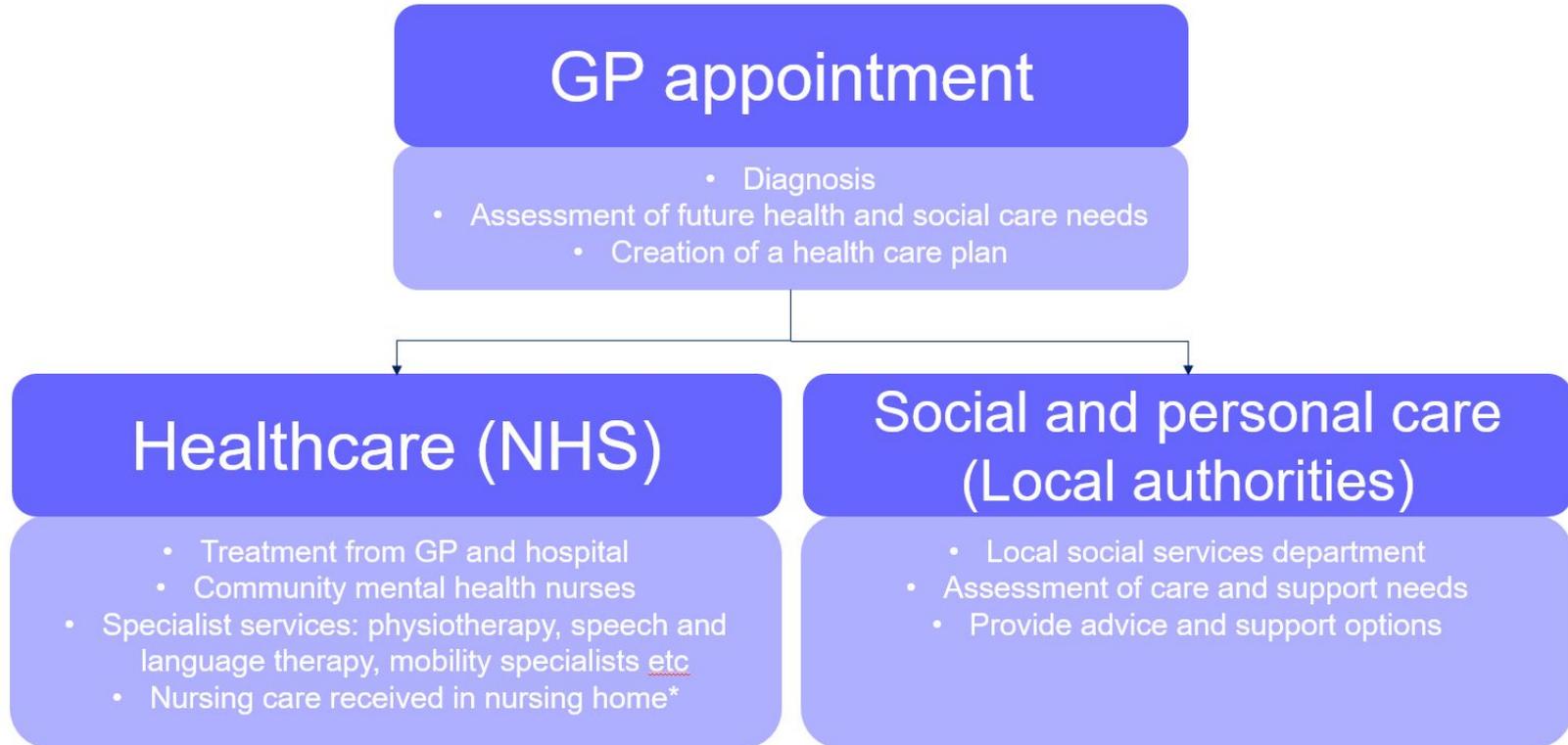
Care Landscape: A division of labor between formal and informal caregiving



Policy is formulated and implemented via various structures

- Devolution:
 - England, Scotland, Wales and Northern Ireland all have separate powers to introduce policies concerning dementia
- Policy implementation overseen by Department of Health
 - NHS: GPs, nurses, specialists, medical staff
 - Local authorities: social services department
 - Private businesses: residential care homes

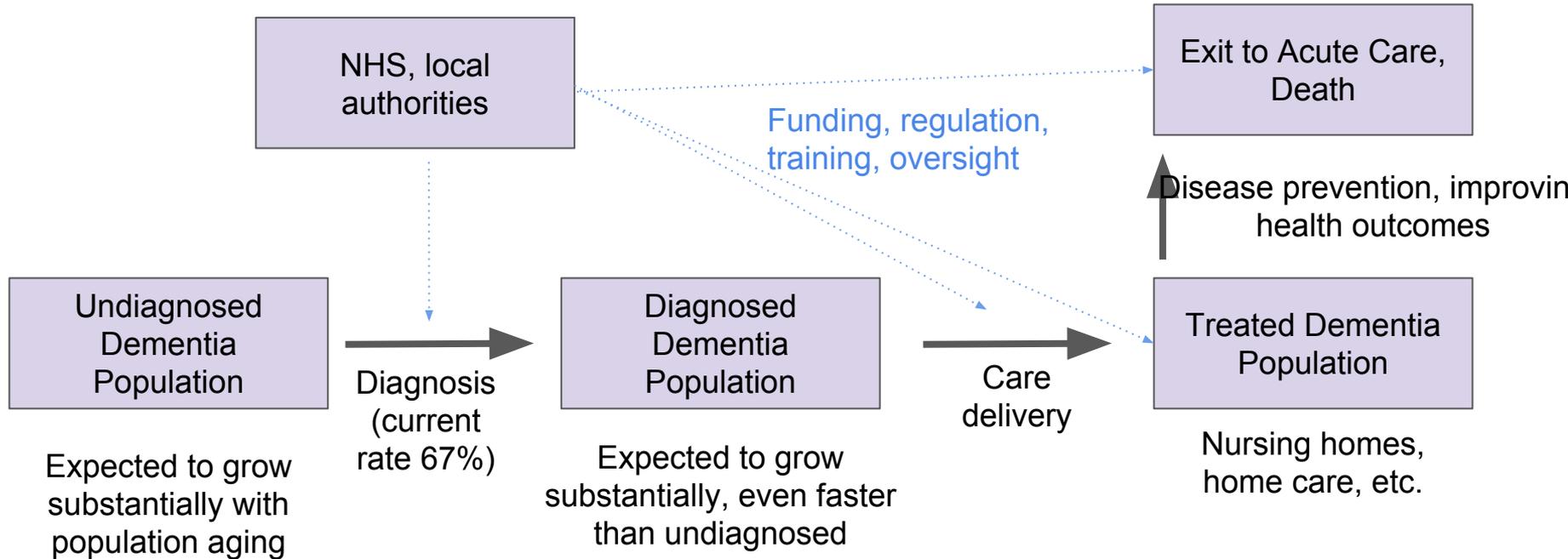
Healthcare is administered by the NHS and social care is taken care of by local authorities



There are five key types of social care available to people with dementia



Dementia is a complex problem with many potential areas for intervention



Theoretical Perspectives: Different Approaches to Dementia

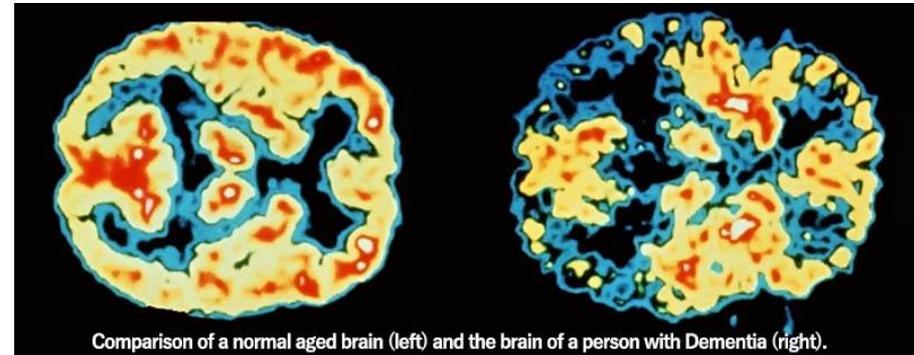


Theory and Dementia: The framing of policy and discourse

- Multiple theoretical ‘starting points’
- Due to the multidisciplinary nature and multiprofessional nature of dementia, the discourse around dementia care practice is such that the underlying assumptions of recommendations are blurred or implicit.
- It is vital to not only to understand how particular perspectives shape policy, practice, and research directives...
- *...But also* to be aware of the multiple theories that shape dementia discourse.
- ‘Confused professionals’
- Aim: To ‘untangle’ the different theoretical models, perspectives, and approaches often used when discussing dementia.

The biomedical perspective: emphasizing the disease process

- For over a hundred years there has been interest in dementia from biomedical disciplines and health professions, where the key concern was around understanding the disease process.
- The biomedical model has three main propositions:
 - Dementia is a pathological, abnormal condition.
 - Dementia is organic in aetiology and progresses through stages
 - Dementia is diagnosed using biomedical assessments.



Biomedical Perspectives: Benefits and Limitations

Biomedical Perspectives: evaluation

Benefits	Limitations
<ul style="list-style-type: none">● Provides a way to cope with the challenges of caring for a dementia patient.● Provides a differential diagnosis.● Reduces the stigma often associated with conditions seen as mental health conditions.	<ul style="list-style-type: none">● What is missing: the views and experiences of the person with dementia.● ‘Cause: unknown; diagnosis: very difficult until after death’ (Harding and Palfrey, 1997, p.34)

Addressing the gap: Social-Psychological Perspectives

The introduction of personhood: ‘a status or standing bestowed upon one human being, by others, in the context of the social relationship and social being. It implies **recognition**, **respect**, and **trust**.’ (Kitwood, 1997, p.8)

- A focus on the self and awareness.
- A person-centred care approach provides practitioners with a framework of values that are **ethical**, **humanitarian**, and **respectful** of the person with dementia.

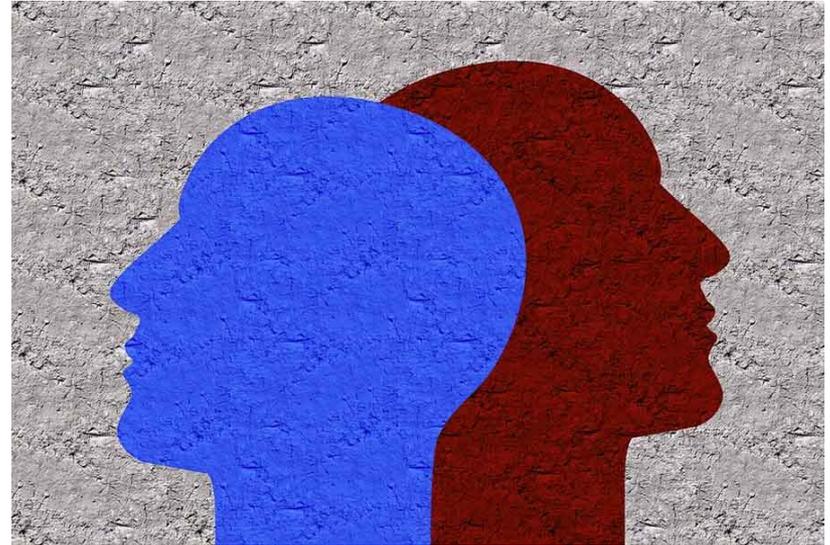
Psycho-social Perspectives: Benefits and Limitations

Psycho-social Perspectives: evaluation

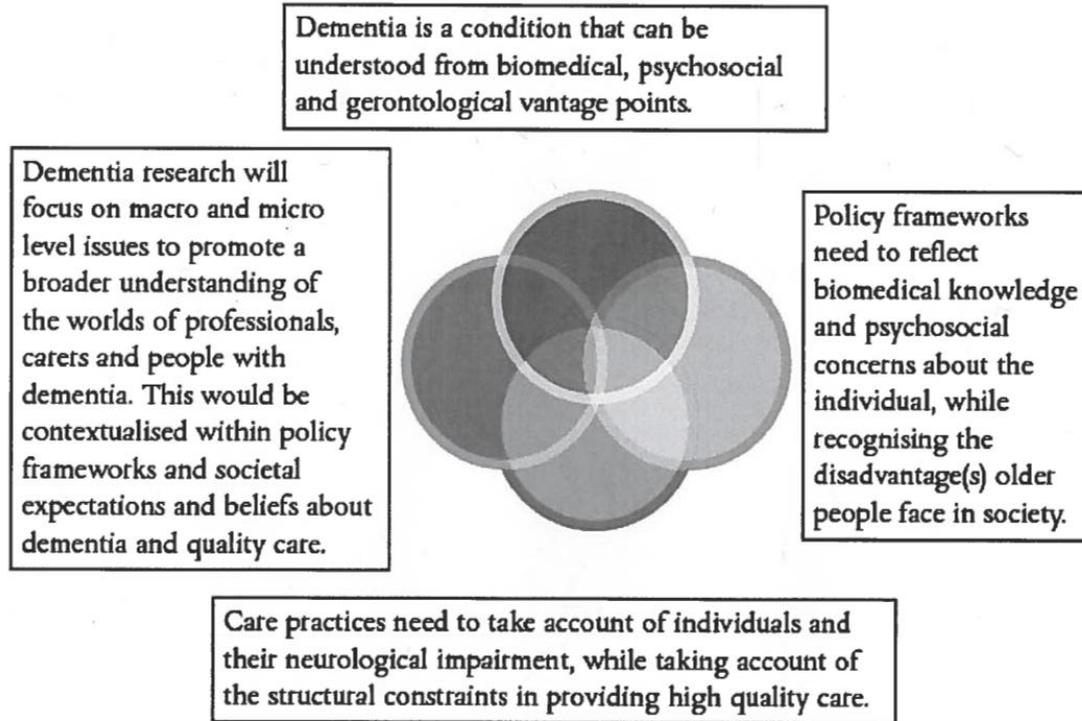
Benefits	Limitations
<ul style="list-style-type: none">● Reminds carers and professionals of the importance of focusing on the individual person with dementia.● Highlights possible therapies and interventions that might be useful for the individual, or for their family to help support.	<ul style="list-style-type: none">● Outcome measures for person-centred care remain elusive;● As does widespread change in care practices.● A failure to locate analysis of experiences of individuals within wider social, political, cultural and economic concerns.

Critical Social Gerontology: looking at the disadvantages faced by older people in society

- The **wider social and structural factors** that shape an individual's experience of dementia must be utilized.
- A consideration of life with dementia that can remain fulfilling: there is '**life beyond the illness**'.
- Goes **beyond the individualism** promoted by social psychology;
- Goes **beyond the disease labelling** of biomedical perspectives.
- Our policy solution: **straddling the intersection**.



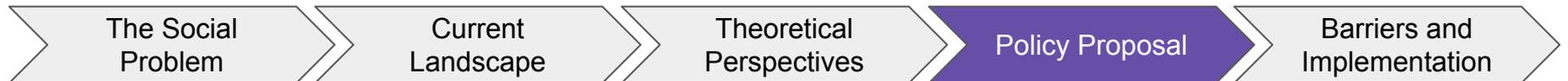
Taking a Holistic Approach to Dementia Care and Treatment



Innes, 2014, p.36

Figure 1.1 A web of understanding dementia using an integrated perspective

Proposed Policy: Person-Centred Approach to Neighborhoods and Residential Care



Person-Centred Care is an integrative approach to improve Quality of Life

What is person-centred care? (PCC)

- Kitwood: person-centred care (PCC) as distinguishable from medical care, importance of contact and communication (Kitwood, 1997)
- In dementia, patients have selfhood, rights, and need for sensitive interaction

PCC in the U.K.

- PCC for elderly is Standard 2 of the National Service Framework, with reporting towards this standard required (Brooker, 2003)
- Nonetheless, person-centred care remains an ambiguous term, and although widely advocated, specific practices have not been implemented (Edvardsson, 2008)

Person-Centred Care remains an ambiguous term, with recent efforts seeking to refine measurement tools (1/2)

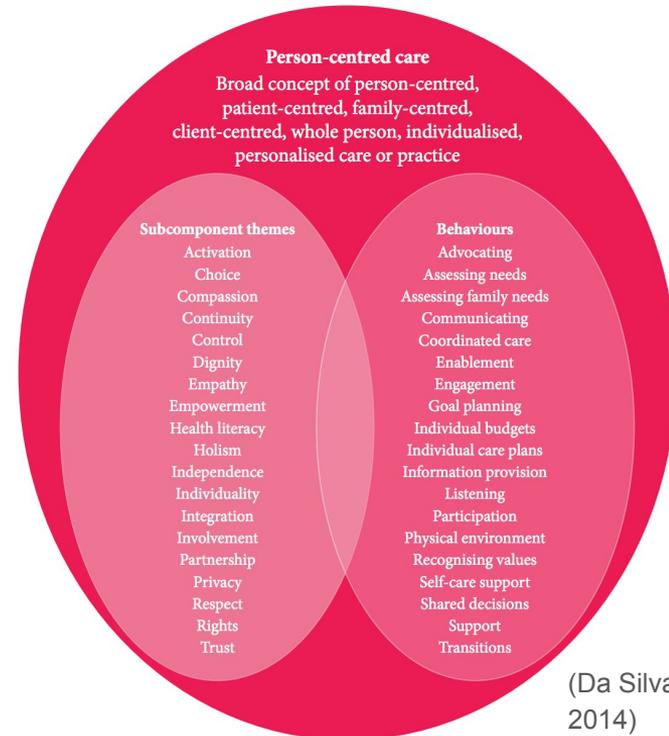
“Person-centred care is a philosophy that sees **patients as equal partners in planning, developing and assessing care to make sure it is most appropriate for their needs.** This involves patients and their families being at the heart of all decisions. Services are reorientated to be user-focused, to promote control, independence and autonomy for the patient and the carers and family, **to provide choice and be based on a collaborative team philosophy.** ”

- Debra De Silva, The Evidence Center, in a systematic review of PCC (Da Silva, 2014)

Person-Centred Care remains an ambiguous term, with recent efforts seeking to refine measurement tools (2/2)

Measuring PCC (Da Silva, 2014)

- No universally agreed-upon measurement criteria (holistic vs specific)
- Techniques include **surveys** of clinicians and patients as well as **direct observation** of caregiving by evaluators



PCC shows improved care quality in residential homes, and reduced burden on health services, broadly

Experimental outcomes from PCC training in residential care homes:

- Reduced **agitation** and **aggression** (Sloane, 2004; Chenowith, 2009)
- Reduced administration of **antipsychotic medication** (Fossey, 2006)
- More **gentleness** and greater perception of **ease** in caregivers (Hoeffler, 2006)

Systematic reviews of PCC & related practices find:

- Increased self-management of care **reduces health service visits, improves clinical outcomes, quality of life, and care behaviors** (Da Silva, 2011)
- Shared decision-making improves **patient satisfaction**, and may improve clinical outcomes and resource use (Da Silva, 2012)

Policy: Transitioning to PCC in UK Residential Care Facilities

- In 2013, there were 12,848 registered residential care homes (with 244,232 beds) for adults and older people in England, as well as 4,664 nursing homes (with 218,678 beds) (NICE, 2015)
- We propose **annual training, observation, and surveying** of PCC in 1000 residential care facilities across the UK
- We would also intend to make additional money available, through research grants, for researchers looking to improve the implementation and measurement of PCC

PCC in U.K. Residential Care Homes will Improve Care Quality

Based on the literature previously referenced, the following are the intended outcomes of increasing PCC training and research:

- Reduced **agitation** and **aggression** of dementia residents
- Reduced **antipsychotic drug use**
- Reduced medical care **costs** per dementia resident (more theoretical)
- Improved **outlook** of caregivers
- Improved **measurement and implementation** of PCC

Neighbourhood

- Existing approaches to person-centred care “fail to locate the person with dementia as an active participant in their community/neighbourhood”.

(Keady et al 2012)

- A respect for personhood is incompatible with social isolation.

- Less than half (47%) of dementia sufferers feel a part of the community.

(Alzheimer's Society Survey, 2013)

Findings from the review: social capital

- Social capital, as applied to older people:

“the array of social contacts that give access to social, emotional and practical support”

(Gray 2009)

Building on the review

“Regular interaction with the same people in the same places builds familiarity and a broader sense of belonging.”

(Ward et al 2017)

Store keepers, hairdressers, joggers → improving sense of belonging.

- Psychologists have developed “self determination theory” (see Ryan and Deci 2002)
 - Mental wellbeing is improved by a sense of: autonomy, competence, belonging.

Findings from the review: walking

Walking around the community helps to...

- maintain cognitive functioning in those with dementia
- maintain the sense of self and well-being of a person with dementia

Findings from the review: walking

Higher rates of walking prompted by:

1. Feelings of safety
2. Trust of neighbours
3. Access to greenery

And “negative aspects of the built environment that are traditionally associated with disadvantaged areas” correlate with “reduced walking and lower levels of mental well-being”.

Findings from the review: walking and shopping



New technology causes problems (Brorsson et al 2011)

Walking clubs

R. lit up when we walked by the dog park today...

She spent the next 15 minutes or so handing out dog cookies, patting the odd dog, clearly loving it.

Later....she said “They ... you know ...” She paused. “...respond to me.’

(Phinney et al 2016)

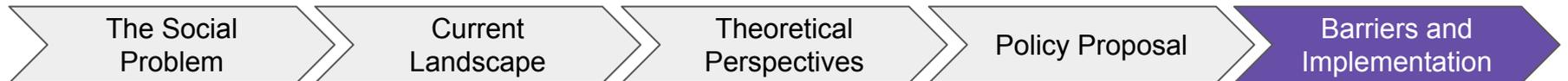
Council-led intervention

Empower local authorities through a **dementia community fund**.

To be spent on targeted:

1. Signage
2. Walking groups
3. Greenery
4. Dementia-proofing of shops
5. Recruitment of dementia friends

Barriers and Implementation: Cost and Politics



Implementation will require funding From the NHS or Dementia/Alzheimer's groups

- Total estimated cost for PCC training and observation, appx. **£3 million annually**
- The NHS and NICE regularly engage in similar types of surveys to those proposed, so including questions on PCC would represent **little incremental cost** (Da Silva, 2014).
- Costs associated with dementia-friendly neighborhoods are likely to be **highly variable and difficult to calculate**, but represent a large **up-front cost**
- Better Care Fund, **£5.9 billion pounds**

PCC Costs

Residential Training: £1.5 million per year

1000 facilities * £1400 = ~ £1.5million
(Chenowith, 2009)

Observation: £1.5 million per year

Assume similar costs for similar staff as residential training

Total: ~£3 million per annum

There are political barriers...

Political Barriers

Residential Care PCC	Dementia-Friendly Neighborhoods
<ul style="list-style-type: none">● Difficulty of expanding health care costs in climate of austerity● Strong regulation of private/public facilities reverses trend of increasingly privatized provision of health care in the U.K.	<ul style="list-style-type: none">● 59% of UK adults surveyed in the YouGov poll feel that the inclusion of people with dementia in the community is fairly bad or very bad● Initial implementation costs● Difficulty in making structural changes to privately owned land

...but also strong interest groups and a central position on the current political agenda

Interest Groups

- Alzheimer's Society is well-funded and influential

Political Agenda

- London pushing to become dementia friendly
- 1.4 million people becoming Dementia Friends and 142 communities to date across England signed up to be Dementia Friendly Communities
- Prime Minister's Challenge on Dementia 2020: clear goal to ensure best care is provided to every person with dementia, with focus on staff training.

There are possible gaps and pitfalls in implementation

Implementation Challenges

Residential Care PCC	Dementia-Friendly Neighborhoods
<ul style="list-style-type: none">● Caregiver buy-in (previous studies have shown little difficulty with this, however)● Logistical challenge of oversight across so many facilities	<ul style="list-style-type: none">● Local authorities and contractors may not have a clear idea of what is needed, in terms of the structural changes (e.g. dementia-friendly signage)

Conclusion

PCC as a proposal to improve outcomes and care delivery for dementia patients

- Dementia is a major challenge for the 21st century due **population aging**, rising **medical costs**, and increased **diagnosis**
- **Person-Centred Care (PCC)** focuses on treating dementia patients as **autonomous individuals** who (along with their families) can and should be involved in the caregiving process
- Improving PCC through **residential care staff training** and through better equipping **neighborhoods** to handle dementia patients has the potential to **improve health outcomes, quality of life, and cost**
- There is likely to be a substantial **fiscal barrier** to incomplete implementation of this proposal, and there may be an **attitude barrier** towards dementia-friendly neighborhoods

**Thank you for
considering our
proposal**



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