Chapter 1
BACKGROUND AND CONTEXT

1.1 Introduction
- Numbers of dependent older people will increase nearly threefold fold from 101 million in 2010 to 277 million by 2050.
- Nearly half of those older people with needs for care are likely to be living with and experiencing the effects of dementia.
- Dementia and cognitive impairment, along with other conditions of the mind and brain, are by far and away the leading chronic disease contributors to dependence, and, in high income countries, to transitions from independent or supported living in the community, into care homes.
- In this report, we consider the extent of the increase in numbers of older people needing care, the regional distribution of the problem, and the reasons for this, including the contribution of the global epidemic of dementia to these trends.
- We will map out the key components of a comprehensive system of continuing care and support for people with dementia, addressing some of the challenges in optimising quality of care, and the quality of life of those most affected.

1.2 A world in transition
- In the last century the world’s more developed countries have undergone profound shifts in their population age structure (the demographic transition) and in the profile of health conditions that are responsible for most of the disease burden (the epidemiologic transition)
- Ageing of the population leads to increases in the size of the older population relative to that of children and working age adults. As infectious diseases, reproductive and nutritional health problems are controlled, chronic diseases, including dementia, become more common and burdensome.
- These transitions are already well under way and gathering pace in low and middle income countries, with profound societal consequences
  - There are fewer working age adults to provide support for rapidly growing numbers of older people with needs for care.
  - The traditional system of unpaid ‘informal care’ by family, friends and community is increasingly coming under threat.
  - Health systems are not yet organised, trained and funded to manage chronic diseases in an increasingly frail older population.
  - Social protection, particularly for older people, is not yet well established, with low pension and health insurance coverage, and a reliance on children or charity for income support.

1.3 Future Challenges
• In High Income Countries, governments are struggling to find ways to sustain high levels of social protection in the context of stagnant economic growth, ageing populations, and rapidly increasing demand for cost-intensive services.

• Rapid economic growth in developing countries provides some fiscal ‘breathing space’, but also increases demand for social protection. Formal care systems (including paid homecare, and care homes) are very little developed, with reliance instead on the unpaid support of family and community. Governments have often resisted the development of the formal care sector, but demand-led growth seems both necessary and inevitable.

• Countries worldwide need to develop comprehensive and sustainable plans for long-term care and support for older people. Financing is the key to sustainability. In developing long-term care policies and systems governments of low and middle income countries and other stakeholders will want to learn from the experiences of the past. As pointed out in a recent OECD report (1) “In many countries, LTC policies (are) being developed in a piecemeal manner, responding to immediate political or financial problems, rather than being constructed in a sustainable, transparent manner.”

1.4 Conceptual issues

• Dependence (needs for care) is defined as ‘the need for frequent human help or care beyond that habitually required by a healthy adult’. The nature of care has been further defined as ‘beyond what would be expected by virtue of family or social ties’.

• There is naturally a close relationship between dependence (needing help and care) and caregiving (the provision of that help and care).

• Dependence arises from disability, but disability represents only a limitation in the performance of activities of daily living, and does not necessarily mean that help is needed. Disability may be experienced without dependence, but dependence always implies a degree of disability, usually of a more advanced and severe form.

• Since disability arises from a health condition, then dependence also requires the presence of health problems to account for the underlying disability.

• What people habitually do is modified by cultural expectations, and gender, and changes with age. This complicates the definition and assessment of dependence, and its comparison across countries and cultures.

1.5 The course of dependence

• Dependence may get worse, remain stable, or get better over time.

• For people with dementia, the onset of needs for care typically begins early, and escalates over time, from support for instrumental activities of daily living (IADL – household, financial and social activities), to personal care (core ADL – bathing, dressing, toileting, feeding), to what may be almost constant supervision and surveillance.

Chapter 2.
PREVALENCE OF DEPENDENCE

2.1 The global prevalence of dependence, in the general population

• The prevalence of dependence increases markedly with age, from 1% among children aged 0-14 years, to 4.8% among adults aged 15-44 years, to 6.9% among those aged 45-59 years, and 13.2% among those aged 60 years and over.

• In 2010, the proportion of the whole population who were dependent varied narrowly among world regions, from 4.7% to 5.6%. This represents 349 million people worldwide with needs for care, of whom 101 million (29% of the total) were aged 60 years and over.
• By 2050 it is predicted that there will be 613 million dependent people worldwide of whom 277 million (45%) would be aged 60 and over.

• Increases in overall numbers will be modest in high income countries (a 31% increase between 2000 and 2050), but much higher in China (70%). India, Latin America, the Middle-East, and other parts of Asia (over 100%), and sub-Saharan Africa (257%).

• Proportions of dependent persons who are aged 60 and over will increase between 2000 and 2050 from 29% to 45% overall; from 21% to 30% in sub-Saharan Africa, from 23% to 44% in India, from 23% to 47% in Latin America, and from 30% to 60% in China, compared with from 45% to 61% in high income countries.

• Numbers of dependent older people are forecast to quadruple in most low and middle income countries, while numbers of dependent younger people in those regions remain relatively stable.

• Dependence is therefore increasingly concentrated in low and middle income countries, while in all world regions it is rapidly becoming a problem concentrated among older people and linked to ageing processes, particularly chronic disease morbidity.

• These changes are mainly driven by population ageing. The 'dependency ratio' (the number of number of dependent people (needing care because of a health problem) divided by the working age population, is a useful indicator of the fiscal impact of population ageing and the health transition upon economies worldwide.

• The dependency ratio will increase slowly in high income countries, from 7% to 10%, but from 8% to 14% in China, and from 9% to over 12% in India.

2.2 The prevalence of dependence among older people

• Population based studies of dependence among older adults in high income countries provide fairly consistent estimates of between 12% and 17% needing regular care.

• Data from the 10/66 Dementia Research Group’s population based surveys in eight Middle Income Countries (Cuba, Dominican Republic, Puerto Rico, Venezuela, Peru, Mexico, China and India), suggest a somewhat lower prevalence, ranging from 2.9% in urban India to 15.7% in urban China. Prevalence was lower in rural and less developed settings, but particularly high in rural Nigeria, where 24.3% needed care. Prevalence of dependence doubled with every five year increase in age, and was generally lower in men than in women, and in those with more education.

• The lower prevalence among older people in less developed, and, especially, rural settings might be explained by underascertainment of dependence among older people living with their families who routinely provide high levels of care and support; a high mortality rate, and hence a shorter survival of those who develop needs for care; or, a lower prevalence of chronic diseases that contribute to disability and dependence.

• An optimistic future scenario is that future generations of older people will enter old age in a better state of health, and that there will be ‘compression of morbidity’. Increases in life expectancy would comprise additional years of healthy life, and not life lived in a state of disability and dependence. Alternatively older people might live longer in a state of ill health, and we might instead experience an 'expansion of morbidity'.

• The evidence on compression versus expansion of morbidity is very mixed. The authors of an OECD report on disability trends concluded that

  “it would not be prudent for policymakers to count on future reductions in the prevalence of severe disability among elderly people to offset completely the rising demand for long-term care that will result from population ageing”.
Chapter 3.
THE CONTRIBUTION OF DEMENTIA TO DEPENDENCE

3.1 The impact of dementia, across the course of the illness
- Unlike most other chronic conditions, people with dementia can develop needs for care in the early stages of the disease, and become increasingly reliant on caregivers throughout the course of the disease. Progression in needs for care over time is linked to deterioration in cognition, function and behaviour
  - In the early stages, those affected become forgetful, have problems with orientation, making decisions, and carrying out household tasks. Caregivers often need to provide emotional support, remind the person about events and tasks, and help with complex tasks (for example managing finances and shopping).
  - In the middle stage, all of these symptoms become worse. Difficulties in communication increase, and need for help with personal care often extends to personal hygiene. Hence living alone can be challenging even with support from family or paid caregivers. Behaviour changes (including wandering, clinging, agitation and aggression) can occur, leading to extensive needs for supervision.
  - In the final stages of the illness people with dementia can be unaware of time and place, unable to recognize relatives, friends, or familiar objects, unable to eat without help, severely restricted in their mobility, and sometimes bed-bound. Care, support and supervision needs are more or less constant, and full physical care has to be provided

3.2 The prevalence of dementia, among older people who need care
- In the 10/66 Dementia Research Group population-based surveys in Latin America, China, India and Nigeria, 49% of all older people who needed care were living with dementia. This proportion varied from 39% in urban China to 67% in Cuba, but was just over or just under half in most sites. The proportion of those needing care that have dementia increased with age (from 30% of those aged 65-69 to 66% of those aged 90 and over), and was nearly twice as high among those needing much care (62%) compared with those needing some care (34%)
- In the USA, people with dementia account for 37% of older people who use non-medical home care services, at least half of attendees at adult day centres, 42% of residents in assisted living and residential care facilities, and 64% of Medicare beneficiaries living in a nursing home.

3.3 The contribution of dementia to dependence, taking into account the effect of other common chronic diseases
- The fact that older people who need care commonly have dementia does not necessarily imply that it is dementia, or dementia alone, that is giving rise to dependence. Older people often have multiple health conditions, the effects of which combine to result in disability and needs for care.
- One approach for disentangling the independent contribution of different, comorbid chronic diseases is to use statistical models to identify the independent contribution of each condition, controlling for the effects of others. Such studies concur that, among older people, cognitive impairment and dementia make the largest contribution to needs for care, much more so than other types of impairment and other chronic diseases
- In a study of Medicare recipients in the USA those who developed dementia were 7.5 times more likely than other to have developed needs for care two years later. While psychiatric disorder, stroke and obesity also made important but lesser contributions, the onset of coronary heart disease, cancer, hypertension, lung disease, diabetes and hip fracture did not predict dependence. Dementia was also identified as the main risk factor for the onset of functional dependence in a three year follow-up of a population-based cohort study in Sweden.
In the 10/66 Dementia Research Group baseline prevalence surveys (in Latin America, India and China), those with dementia were four and a half times more likely than others to have needs for care, and around 34% of needs for care were accounted for by dementia, compared with 9% accounted for by limb impairment, 8% each by stroke and depression, 6% by eyesight problems, and 4% by arthritis.

In a US study of older people needing help with activities of daily living, those with cognitive impairment were over twice as likely as others to receive paid home care, and used services twice as intensively as did cognitively normal users of paid home care.

A meta-analysis of predictors of transition into a care home in the USA indicated that cognitive impairment was the health condition that most strongly predicted transition, (RR 2.54, 95%CI 1.43-4.51), with smaller contributions from cancer and diabetes, and no association with other chronic conditions including cardiovascular disease, arthritis or lung disease. In a study conducted in Sweden, dementia was the main predictor of moving into a care home, independently accounting for 61% of such transitions.

Chapter 4
LONG-TERM CARE SERVICES AND THE JOURNEY OF CARE FOR PEOPLE WITH DEMENTIA

4.1 What is ‘long term care’

Long-term care is defined by the World Health Organization as

“the system of activities undertaken by informal caregivers (family, friends, and/or neighbours) and/or professionals (health, social, and others) to ensure that a person who is not fully capable of self-care can maintain the highest possible quality of life, according to his or her individual preferences, with the greatest possible degree of independence, autonomy, participation, personal fulfillment, and human dignity.”

Long-term care is a complex system with broad boundaries. Care can be provided at home, in the community, or to a resident of a care home. Many different tasks and functions need to be performed, and the needs of each individual and family are specific. Different agencies are involved in providing, supporting, organising and financing care. The family will always have a central role, supported to a greater or lesser extent by formal professional or paraprofessional care services.

4.2 Options for long-term care provided for people with dementia

Health vs. social care

Long-term care requires both health and social care services. Health care services include; long-term nursing care; health services in support of family care; and personal care services (supporting core activities of daily living); and palliative care. Relevant social services include; home help (for example, domestic services); care provided in residential care or assisted living facilities; care assistance (supporting instrumental activities of daily living); and other social services.

The boundaries between the two systems are not distinct, and the integration of health and social care components into a single structure for the purposes of funding and delivery of services is a current policy priority for many OECD countries.

Family (informal) vs. paid (formal) care

Unpaid care provided by family, friends and community is generally referred to as ‘informal’ care and paid care as ‘formal’ care. Paid care workers can be employed by the government, private (for-profit or not-for-profit) nursing homes or community social care agencies, or directly by families. They face a difficult and demanding job, often with little training, and modest remuneration. There is a high turnover of staff, to the detriment of care.
• Family caregivers can, and commonly do provide all of the regular 'hands-on' care provided by paid care workers, but they also have an important role in advocating for the person with dementia, and organizing their care, sometimes from a distance.

• Data from surveys of those aged 50 years in OECD countries (in Europe, the USA, South Korea and Australia) suggest that between 8% and 16% of those aged 50 and over are informal caregivers providing support for core activities of daily living. 15.4 million Americans aged 18 years and over provide unpaid care for a person with dementia, contributing an average of 21.9 hours of care per caregiver per week, or 17.5 billion hours of unpaid care annually.

• Studies from the USA, Dominican Republic and China concur that, compared with caregivers of those with other conditions, caregivers of people with dementia provide more high intensity care with an increased requirement for assistance with personal care, and experience greater strain.

• There is a large literature attesting to the strain that caregivers experience, which is practical (time spent caregiving detracting from other activities, particularly leisure and socializing), psychological (emotional strain, with a high prevalence of anxiety and depression), and economic (increased costs, coupled with cutting back on work to care).

• The distinction between formal and informal care is one that matters to governments that finance long-term care through public expenditure. While formal care at home or in care homes accounts for an average of 1.5% of GDP in OECD countries, informal care is often considered not to have any fiscal impact. However, in the USA, the Alzheimer’s Association costed replacing the 17.5 billion hours of unpaid care by family caregivers by paid caregivers at US$216 billion per year. In other ways the distinction is unfortunate.

- Many dependent older people receive care exclusively from family or other informal caregivers. However, it is rare for long-term care to be provided exclusively by paid caregivers, even for care home residents. Paid caregiving may either substitute some of the functions of family caregivers, or supplement what they have been able to do.
- Paid caregivers help to alleviate the strain experienced by family caregivers including the practical demands of caring; coping with behavioural problems; and restrictions on the caregiver leaving the home, socializing or going to work.
- Paid, and unpaid family care providers work side-by-side with an important interface between the two systems requiring sensitivity, collaboration, discussion and planning. They have a lot in common, notably their shared commitment to provide the best possible quality care to the person living with dementia.

Home care, or care in a care home?

• Care homes for people with dementia typically comprise; residential care or assisted living facilities; nursing homes and dementia special care units. In high income OECD countries, more than half of all care recipients aged 80 years or over receives care at home in most countries, and only a third of all long-term care users receives care in care homes. Nevertheless, 62% of total direct costs of long-term care are incurred in care homes, reflecting the intensity of care in those settings.

• Estimates of the proportion of all people with dementia living in care homes in high income countries vary from 30-40% in the USA, 35-50% in the UK, and 50% in Canada. In the worldwide questionnaire survey conducted by ADI for its 2010 World Alzheimer Report the mean proportion estimated to live in care homes was 34% in high income countries, but only 6% in low and middle income countries.

• Studies show that transition into a care home is predicted, mainly, by factors linked to needs for care (cognitive and functional impairment). Also, transition is more likely to occur; when the care recipient and caregiver are older; and when the caregiver experiences psychological distress or strain. Interventions that support, educate and train caregivers can reduce or delay transition into a care home, as shown in several randomized controlled trials. In the USA one such intervention maintained over a longer period was associated with a 28% reduction in the rate of transition into a care home, and care home admission was delayed by a median of 559 days.
Transition from home into a care home setting often represents a ‘forced choice’, associated with escalation of needs for care beyond what family and community care services can manage. All too often, the transition occurs at a time of crisis, or following admission into acute hospital care.

There are theoretical benefits of transition into a care home, both for the person with dementia, and the caregiver. However, the transition can be traumatic. Health and psychological status can deteriorate significantly after admission, with a high mortality risk. This may be explained by the reasons for the transition, and the fact that this often occurs at times of crisis.

The important question of whether, over the longer term, the quality of life of people with dementia is better preserved by remaining at home, or moving into a care home, is difficult to resolve. Although more research is required, there is as yet no evidence that the quality of life of people with dementia is any lower for people living in care homes, and it may actually be slightly higher for those with more advanced dementia.

Care homes have an important part to play in the long-term care system, and should not necessarily be seen as an option of last resort, to be avoided wherever possible. There is a clear danger that the cost containment policy agenda in high income countries, asserting the universal preference for care at home, and the better quality of life and care in the home setting may unfairly stigmatise users and providers of care home services.

The relevance of care homes is not limited to high income countries. Provision in low and middle income countries is currently very limited, but growing, particularly in urban settings in middle income countries. The alternative to family care (if this is not available) is charitable or state homes for the indigent where care is highly institutionalised.

In a survey of public hostels in Rio de Janeiro older people were over-represented among residents, and most had become homeless for the first time late in their lives, often having been referred to the hostel directly from hospital. The high prevalence of cognitive impairment among them suggests that the onset of dementia in those lacking family support may have been a contributory factor.

In China older people’s long-term care needs are mainly met by families. However, care homes, previously reserved for the ‘three nos’ (no children, no income, no relatives) are now less stigmatised, open to all, and proliferating in cities, particularly in the private sector.

### 4.3 Other important long-term care services in the continuum of dementia care

#### Respite care

Respite care is the temporary provision of care for a person with dementia at home or in a care home by people other than the primary informal caregiver. The rationale is to give the primary caregiver a break from their caregiving responsibilities (to rest, see friends and family, take holidays, catch up on other tasks), and thereby reduce strain. Respite can also be used to reassess the person with dementia, and provide rehabilitation.

Respite may last for anything from a few hours to weeks. It may be planned or unplanned for example in response to a crisis in home care arrangements.

Uptake is low among those offered the service. It may be that caregivers are coping well, or prefer to make private arrangements. Some may be concerned that they would be neglecting or abandoning the person with dementia, and that their condition might deteriorate in an unfamiliar care setting. When caregivers use respite services it tends to be in the advanced stages of the disease.

There is only limited evidence that respite care reduces caregiver strain, and no evidence that it delays transition into care homes. The main justification for respite services is the high level of caregiver satisfaction associated with their use, reported in many studies. Respite may not suit all families, but may be very helpful for some.

#### End-of-life care
Dementia is an incurable and life-limiting illness, and death with dementia is increasingly common. The World Health Organization states that ‘every person with a progressive illness has a right to palliative care’ which can be provided at home, in a care home setting, in hospital or in a specialist hospice unit. Palliative care regards dying as a normal process, and provides relief from pain and other distressing symptoms. It integrates psychological and spiritual aspects of care, supports patients’ quality of life, and helps families to cope during the illness and in bereavement.

Evidence suggests that palliative care is under-utilised for people with dementia at the end-of-life. Dementia is not often thought as a terminal illness, and the lack of specific dementia training for staff working in end-of-life facilities could also contribute.

For people with dementia the focus of palliative care should be:
- Detecting and attending to symptom burden (particularly pain, pressure sores, shortness of breath, eating and swallowing problems, infections, agitation and other psychological symptoms). At the same time, over-treatment with burdensome interventions, such as tube-feeding and antibiotics, should be avoided.
- Addressing legal issues, including advance care plans for their wishes
- Supporting caregivers and families, including clear information about potential complications of dementia and what to expect from the late stages of the illness. Studies suggest that caregivers often show resilience in bereavement, and that intervention and support services were needed most before the patient’s death.
- Professional staff training and development. Communication and shared decision-making are key factors in end-of-life care. Trust in professional staff is essential. However, many nurses and care home staff do not feel well prepared to deal with issues related to dying with dementia, and more training is needed in this area.

4.4 Future directions in long-term care

All components of the long-term care system for people with dementia; informal family caregivers, formal home care, respite care, residential care, nursing home care, dementia specialist care units, and end-of-life care could and should form part of a seamless continuum of provision across the journey of care.

Barriers to achieving this objective include; the late stage at which a diagnosis of dementia is made; the lack of continuity of care post-diagnosis; the lack of coordination and integration of services; the limited opportunities for people with dementia to express their preferences for care; and insufficiently person-centred packages of care.

European government policy developments over the last decade have involved progressive shifts; away from institutionalized care and towards home care; in favour of services that complement rather than replace informal care; away from public provisions and towards private or mixed services backed up by cash transfers. The shift towards cash transfers could provide greater diversity of choice, and place more control in the hands of people with dementia and their families in designing individual packages of care and support. It is also a promising innovation in terms of improving service integration.

Cost-containment will be a fundamental driver of long-term care policy at least in high income countries. Delivering improvements in the quality, comprehensiveness and coverage of long-term care services in this context will be a significant challenge, considered in detail in the last two chapters of this report.
QUALITY OF CARE, AND HOW IT CAN BE IMPROVED

In this chapter we consider the principles and actions that may need to be considered by all nations as they seek to develop a comprehensive and high quality system of care and support, focusing on the evidence-base that supports specific interventions and practices, highlighting four priority actions:

1. Measure and monitor the quality of care
2. Promote autonomy and choice
3. Coordinate and integrate care for people with dementia
4. Value and develop the dementia care workforce

5. 1 Measure and monitor the quality of care

- Measurements of the quality of care can be used to; inform policy making or strategy at a regional or national level; improve the quality of care within a system or at a facility; monitor the performance of a service funder or provider; identify poor performers to protect public safety; and provide consumer information to facilitate choice

- Indicators of the quality of care can comprise structures (resources available for delivering a service), processes (the delivery of care) and outcomes (the results of the care process). Outcome indicators (e.g. quality of life, or satisfaction) are intrinsically important, and capture the impact of all of the care processes, including those that are difficult to measure (for example, is the care ‘person-centred’?). Process indicators can often be ascertained from routine data, and reflect actual care delivered. However, they are only relevant to the extent to which they influence desired outcomes.

- For the quality of dementia care, the focus has been mainly upon structures and processes of care, particularly for regulators who seek to ensure safety and prevent harm and abuse, by enforcing compliance with minimum standards. Such indicators can detect deficiencies, but not excellence.

- In the USA, the Centres for Medicare and Medicaid Services care quality indicators (cms.gov) comprise five process and eight outcome indicators. They focus on biomedical care processes, and measure impairments affecting particular body parts or systems rather than the whole person in a more holistic way

- Commonly used process and outcome indicators may fail to capture the very essence of good quality care. The Alzheimer’s Society in the UK, for example, considers that there are three areas intimately connected with quality of life in care; environment, activities and relationships - enshrined in four abiding principles; know the person who is living with dementia; quality of life, not quality of care; everybody has a leadership role; and value focused care.

- Translating aspirations into measurable indicators is a challenge. However, there is a move away from indicators of structure and process, towards simple, valid holistic outcome measures, and a growing interest in service satisfaction measures, and quality of life as overarching indicators of care quality.

- In the UK, the Alzheimer’s Society conducted a survey of family members of people with dementia receiving care in care homes, and care home workers. Satisfaction ratings were high among family members; 74% of said they would recommend the care home to others, and 68% said that they thought that the quality of care was good. However, only 41% thought that the quality of life of the person with dementia was good. Only 26% of staff felt that people with dementia experienced a good quality of life. The Alzheimer’s Society commented on low expectations among family members and staff, who are perhaps too ready to be satisfied with quality of care, when not enough is being done to maintain quality of life.
In an initiative driven by the UK care home sector, Ipsos MORI designed and conducted an independent, confidential and standardised annual survey of residents living in UK care homes (yourcarerating.org). An overall performance rating (OPR) – ranging from 0 (worst) to 100 (best) - was derived from four themes covered in the questionnaire; Staff and Care; Facilities and Home; Choice and Control; Security and Procedures. The questionnaire also included happiness and overall satisfaction ratings.

- Findings from 14,000 respondents were generally positive; the average OPR was 83; 62% of residents were 'very satisfied', and 96% were satisfied or very satisfied with the care received, and 92% agreed that they were 'generally happy' with 55% agreeing strongly. However, there was some variation in these outcomes between providers, and much variation between individual care homes
- 'Your Care Rating’ demonstrates that it is possible to ask residents directly about satisfaction, and happiness (an aspect of quality of life). Variation in outcomes among providers and homes, suggests that this information could be valuable to consumers in selecting the best homes, and to providers in identifying problems and driving up standards.

These two surveys provide some reassurance regarding the quality of care in the UK residential and nursing home sectors, where 80% or more of residents have dementia or significant cognitive difficulties. A significant challenge will be rolling out surveys to cover the whole care home sector. Only a uniform national system would ensure consumer protection and informed choice.

Quality of life as an indicator of quality of care

- Quality of life (including emotional, physical, social and environmental domains) is a crucial outcome measure for health service research. Clinically orientated assessments are insufficiently patient-centred and holistic, and fail to capture all of the important ways in which health conditions impact on the person. For dementia, measures of overall clinical severity, cognition, functional ability and disturbed behaviour have traditionally been used to monitor the disease course and evaluate the effectiveness of interventions. Arguably, the maintenance and promotion of quality of life should be the primary and overarching objective in providing care for people with dementia.
- Tom Kitwood’s early work on personhood and wellbeing has been very influential in understanding quality of life in dementia. He proposed four global states of wellbeing: personal worth, agency, social confidence and hope; which were particularly apt to be compromised through adverse physical and social care environments experienced by people living with dementia.
- Several scales have been developed to assess quality of life (QoL) in dementia. Research suggests that subjective perceptions and experiences of those with mild to moderate dementia can be assessed, validly and reliably, by asking a person with dementia directly. For those with more advanced dementia, there are also proxy scales whereby a family or professional caregiver who knows the person with dementia well, gives their impression of their QoL.
- The self-reported QoL of people with dementia does not seem to change with the passage of time, or clinical progression of dementia. Maintenance of self-reported QoL is an encouraging sign that it is perfectly possible to ‘live well with dementia’. The challenge is to drive up QoL for all those with the condition, to the best that can be achieved.
- Self-reported QoL in dementia is not associated with sociodemographic or clinical factors, but there is a pronounced effect of mood; more depression and anxiety symptoms are linked to a lower QoL. In residential care there is some evidence that pain, falls, and the use of physical restraints may be associated with worse QoL.
- Characteristics of care homes may influence the QoL of individual residents. As with UK surveys, studies in the US suggest that a component of variation in resident QoL is between facilities rather than among residents within facilities, suggesting an important impact of the care environment or culture on QoL at facility level.

- In the 2007 Minnesota Nursing Home Resident Quality of Life and Consumer Satisfaction Survey, the QoL of residents was higher for homes where there was better provision of Certified Nursing Assistants and activity personnel. The conclusion was that greater availability of these staff for needs ranging from personal care to conversation increases residents’ feelings of well-being. Having controlled for cognitive impairment, residents of dementia specialist care units also had enhanced QoL. Such units address individualized resident needs, and have many design and care features that could contribute positively to QoL.

### 5.2 Promote autonomy and choice

- People with dementia and their caregivers should have more choice and control over decisions regarding the care and support that they receive throughout the journey of care, including care arrangements, place of residence, and what happens at the end of their lives. Applying this broad principle has important implications:
  - The ability (capacity) of the person with dementia to participate actively in important decisions tends to deteriorate as the condition advances. Therefore advance care planning may be advisable, and people with dementia may also wish to appoint a proxy to make decisions for them when capacity is lost.
  - Exercising consumer choice depends upon ready access to information about the availability of services, and their quality.
  - People differ in their values and preferences, and this in turn influences choices made regarding how care is to be planned and delivered. Better understanding of preferences should inform planning and allocation of services, and can be used to construct more person-centred packages of care and support, tailored to meet personal circumstances.

**Plan ahead (advance care planning)**

- Advanced care planning (ACP) is defined as ‘a process to make clear a person’s wishes and that will usually take place in anticipation of future deterioration of an individual’s condition, with loss of capacity, to make decisions and/or ability to communicate wishes to others’. ACP features in end-of-life care policies of many countries and it is a key feature of dementia care guidelines. ACP discussions can result in an oral or written statement of preferences or wishes, the appointment of a Lasting Power of Attorney, or an Advance Decision to Refuse Treatment in specific future circumstances. Lasting Power of Attorney is the nomination of a person to take decisions for a person with dementia on economic, health or personal matters, in case of loss of capacity.

- ACP has its origins in decision-making for end-of-life care, but it has a much broader application for people with dementia for whom many important decisions may need to be made after decision-making capacity has been lost, but some time before death.

- A population survey from Ireland suggests that conversations with family members regarding long term care preferences were, in general, unlikely to have occurred (only 24% of all those aged 65 and over), but this was more likely for better educated respondents, those who were older, and those who were already disabled.

- Use among people with dementia is more widespread. Surveys from the USA and Belgium suggest that more than half of people receiving dementia care had made some form of advance care planning, mostly prompted by a clinician, but with minimal involvement of legal representatives.
• These surveys were conducted in countries that have policies in place to encourage ACP, underpinned by legislation. Internationally, this is likely to be highly variable and much lower in those countries where awareness of dementia is limited, where ACP is not discussed, and where advanced directives may not carry legal force.

• Studies of ACP in dementia are in their infancy. Nevertheless, evidence suggests that
  - People with mild cognitive impairment and early dementia would rather that they, rather than their caregivers or physicians have the greatest say in decisions regarding their social care
  - People with dementia and their caregivers tend to concur as to end-of-life care decisions, increasing confidence in proxy decision-making
  - ACP can reduce unnecessary hospital admissions, and increase end-of-life hospice care.
  - Use of ACP is associated with an improvement in caregivers’ stress, anxiety and depression, and a decline in worries about the future for people with early dementia and their caregivers. More research is needed in this area.
  - There are many practical issues relating to implementing ACP in dementia, including: optimal timing of discussions; which professionals should initiate discussions; changes in preferences through the course of the illness; discrepant views of people with dementia and their caregivers; and the concern that ACP may offer ‘false promises’, as it is not always possible to follow someone’s advance directives.

Make information available to consumers (knowledge is power)

• In the USA (2001), Robert and Rosalie Kane noting that the US government spent $242 million annually on regulating care homes argued that money could be better spent on a ‘a market-based approach that emphasizes information... data on various types of care could be arrayed to show measures of quality (of care and of life), the nature of the services provided, staffing stability, and consumer satisfaction. The information could be disseminated through Web sites, but it could also be packaged to make it readily accessible to case managers.”

• Nursing Home Compare (http://www.medicare.gov/nursinghomecompare/search.html), run by the US government regulator, now provides detailed information on every Medicare and Medicaid certified nursing home in the country. Descriptions and ratings can be searched for particular nursing homes, and all nursing homes in and around a particular location can be identified and compared. The site uses information generated from certification inspections, and the minimum data set outcome indicators. Nursing homes can be compared against norms for the state and the US nationally, and each home is given an overall quality rating from one to five stars.

• Nevertheless, regulation persists, or has even been intensified. The costs of regulation in the US system have been recently estimated at 1.5% of total nursing home care costs. In most jurisdictions, these costs are passed on to the providers, and ultimately to the purchasers, whether this be individual consumers, or the state.

• Some providers argue that regulation is excessive, and of questionable benefit. In a perfectly performing free market, regulation might not be necessary. However, choice is restricted, because homes often need to be found at a time of crisis, within funding restrictions, and to meet specific care needs when places may be at a premium. Hence, regulation to maintain minimum standards remains necessary. The question is the cost-effectiveness of regulation and mandated data collection procedures. Research is limited, with some evidence of improvements in sub-standard providers, but also evidence that providers may ‘play the system’ to secure good ratings.

• In England, the Nuffield Trust recently recommended to government that a good quality national care quality ratings system would assess safety, effectiveness, and user experience, complementing inspection reports with routinely collected care quality process and outcome indicators. Effective surveillance would be needed to pick up problems quickly, and consumers would need data to be updated regularly. Choice of care quality indicators should be
transparent, and involve all relevant stakeholders, including service users. Finally, additional burden should be minimised, quantified, and subject to cost-benefit analysis

- Research conducted by the Alzheimer’s Society casts light on family caregivers’ use of information to locate a suitable care home for a relative with dementia
- One quarter of caregiver respondents reported difficulties in finding a suitable home. Information from care home providers and social work care managers, and visits to homes were most often cited as sources of information. Regulators, and the Alzheimer’s Society were less often consulted, although both provide useful guides and information.
- Leading factors influencing choice were the friendliness of staff, cleanliness of the home, and proximity to the family of the person with dementia, rather than those factors that might impact most on quality of life in care homes (e.g. design, access to open space, and activities)

Incorporate service users values and preferences into care

- Values are broad beliefs about aspects of life to which people attach importance, while preferences are more specific choices that flow from the values that people hold. Both are influenced by underlying enduring traits of personality and by attitudes. With respect to dementia care values and preferences might relate to the extent of involvement of family in their care; flexibility or structure in daily routines; needs for privacy; and whether to optimise freedom over safety and security.
- Research suggests that older users of long-term care services wished to express their values and preferences. Views varied between individuals but were generally quite strongly held. The implications seemed clear - the values assessment could help case managers become aware of their clients as individuals “with their own perspectives on quality of life and with idiosyncratic reactions to and opinions about their care”
- However, such assessments may be difficult to implement in practice unless staff have a genuine interest in eliciting and acting upon preferences, and unless the service does offer genuine person-centred choice.
- Some limited research has been carried out into older persons preferences for home care versus care in care homes, and for the extent of involvement of their family as caregivers. It is commonly stated that older people in general, and people with dementia in particular would prefer to be supported to remain in their own homes, for as long as possible, and this aspiration is enshrined in policies and plans relating to dementia care in many countries. Such evidence as there is calls into question the universal validity of these assumptions.
  - Findings from general population surveys of middle aged adults in the USA reveal that while most would prefer care at home, substantial minorities (16%-31%) would prefer care in a care home in the event that they developed long-term needs for care.
  - When presented with a specific scenario of complex needs for care arising from dementia, then care in a nursing home is often the preferred choice, particularly for those living alone.
  - Women seem more likely to opt for home care. Studies also reveal cultural influences with Black Americans more likely than other groups to opt for care provided by family and friends than for paid home care, and in the context of dementia, more likely to opt for paid home care than care in care homes.

Make care person-centred

- Person-centred care comprises: involving the service user; taking into account their individual needs, and their views as to how those should be met; and providing flexible and responsive services. The approach is applicable and relevant throughout the journey of care.
UK reviews of person-centred social care in the community concur that practice lags well behind policy rhetoric and ideology. Lack of prioritisation by management, lack of time for visits, and task-orientated approaches to care were all significant barriers. Service users were unfamiliar with the concept of person-centred care, but when it was described to them, they were clear that this was not what they were receiving. Frontline care workers were more knowledgeable, and some had attempted to apply their training.

In countries where the state has been the dominant provider of care services, the introduction of personal care budgets (or direct payments) should enable care recipients to have more control over their care, by contracting directly with community service providers, and even employing care assistants directly.

However, in the United Kingdom, a recent Alzheimer’s Society survey indicated low levels of uptake among people with dementia and their caregivers who might have been eligible for personal care budgets. The local market in community care services was often insufficiently developed to provide the diversity of options that would allow personal care budgets to be used to their maximum potential.

Survey respondents using direct payments were more satisfied with some aspects of their care, for example provision of information, and comprehensiveness of support. However, they did not feel that services were any more flexible.

Those who had refused the direct payment option (19%) did so mainly because they were satisfied with current arrangements, or perceived managing direct payments as complicated, difficult or stressful.

Recommendations were for additional support to be provided for people with dementia and their caregivers to participate in the direct payment system; more information, and special assistance for those with impaired decision-making capacity.

The ‘traditional’ approach to care in care homes has been characterised as originating from biomedical models, applied on a ‘one size fits all’ basis, and task-centred around physical nursing care and support with activities of daily living. Neglect of the physical and social environment in which the person receives care, and their unique psychosocial needs means that many people with dementia are left isolated, understimulated, frustrated and emotionally distressed.

Person-centred care (PCC) has been proposed as a more holistic alternative that can help to maintain personhood in the face of cognitive impairment and dementia. This comprises; a rich physical environment; attention to residents’ life histories, respectful communication and meaningful interaction with staff, and engagement in fulfilling activities.

Dementia Care Mapping (DCM) is a structured method of implementing person-centred care in institutional and day care settings, with an observational assessment tool that can be used both to aid implementation of PCC and evaluate its outcomes.

The evidence for PCC and DCM interventions in care homes is mixed. One large cluster-randomised controlled trial conducted in nursing homes in Sydney, Australia suggested important reductions in disturbed behaviour, particularly agitation and aggression, in the homes randomised to either DCM or PCC compared to homes receiving neither intervention. However, there were no effects on antipsychotic prescribing, and no improvements in quality of life. In a similar large trial of DCM in the Netherlands, there were no benefits noted in the homes randomised to receive DCM training. In both trials, there appeared to be some beneficial effects on burnout and mood of care home staff.

These trials suggest that while there can be clinical benefits of DCM this is most likely to be evident in homes that have not previously adopted person-centred care cultures, and when the implementation is conducted in a careful and controlled way (as was the case particularly in the Australian study). More research is needed, particularly since the effects on quality of life in those with less advanced dementia, and on satisfaction with care among residents and caregivers have yet to be tested.
5.3 Coordinate and integrate care for people with dementia

- People with dementia, and their caregivers often interact with a bewildering variety of health and social care providers. Professionals and agencies may not communicate directly, may not be aware of all of the issues involved in the person’s care, and may not assess, treat and support them in a holistic manner. Fragmentation of dementia care increases caregiver burden, adversely affects people with dementia, and is likely to increase costs.

- Case managers can coordinate care, providing continuity, advice and advocacy throughout the journey of care. They can provide information about services, and seek to make care more individualised and person-centred.

- There is moderately strong evidence that case management in dementia may improve quality of care, satisfaction with services, and quality of life. However, there is no evidence that case management increases the efficiency with which health services are used (reducing hospitalizations or emergency care), or reduces costs. Greater benefits are seen when case management is delivered a) with greater intensity, b) to those with complex health and social care needs, and c) in the context of a high degree of functional integration between agencies, particularly health and social care.

- The PRISMA model in Quebec, Canada, is a good example of successful integration. A Joint Governing Board is responsible for the governance, management and delivery of all health and social care services, and employs case managers with authority to work across all services and coordinate care. There is a single entry point for all PRISMA services. In a quasi-experimental trial, frail dependent clients of the PRISMA service used services more efficiently, had better health outcomes, fewer unmet needs, and greater satisfaction with care. This model is similar to the innovative MAIA system (Maisons pour l'autonomie et l'intégration des malades d'Alzheimer), a central feature of the Plan Alzheimer in France. This will give every patient access to a local ‘one stop-shop’, the MAIA, where a specifically dedicated case-manager designs an integrated health and social care plan.

- Case management can also support transitions from home to a care home. Transition to a care home is often inevitable due to a lack of co-resident caregivers, or the demands of care exceeding the capacity of caregivers even with support from community care services. The transition can have health and psychological consequences for the person with dementia. Guilt, sadness and emotional distress in caregivers are recurring themes. Trusted case managers can discuss and plan the transition with the person with dementia and their family, and provide stability and continuity of care across the transition. More research is needed to understand best practice strategies enabling people with dementia to live at home as long as possible and also identifying the right time and best approach for managing transfer to a care home.

5.4 Value and develop the dementia care workforce

- Dementia is everybody’s business. If people with dementia are to be enabled to live as full a life as possible, awareness, sensitivity and skills are needed in all sections of the workforce and wider society. Therefore workers in all of the health, welfare and social care agencies need to receive training about dementia as part of their basic curricula and continuing professional development. In a ‘dementia friendly’ community, shops and businesses, housing services, police, utility companies, banks and lawyers would all have a part to play. National ‘Dementia Friends’ programs have been rolled out in Japan (four million friends recruited and trained in the past eight years), and more recently in the United Kingdom where free coaching is being provided to one million people.
In high income countries, family caregivers are supported and complemented by a large and
growing cadre of paid care workers (nurse aides, home health aides and personal- and home-
care aides) operating in the home care and care home sectors, and responsible for delivering
much of the demanding and sensitive ‘hands on’ personal care to people with dementia. In the
UK there are 1.6 million frontline social care workers, and their numbers will need to double in
the next 20 years. 3.5 million additional direct care workers will be needed in the USA by 2030.
It is increasingly recognised that these workers are poorly paid, lack clear professional
structures, are too often not well trained or prepared for the demanding work in hand, and have
limited opportunities for career development.

A lack of knowledge and skills in the direct care workforce can lead to harmful, neglectful or
abusive care practices that add to rather than alleviate problems experienced by the person
with dementia and their family caregivers. However, training requirements are currently insufficient.
In the USA for example, the federal minimum of 75 hours of training for nurse aides had not
changed since it was mandated in 1987, with little focus on issues specific to dementia care.

The minimum mandated requirements for training for direct care workers need to be increased,
and core and more advanced competencies should be identified for direct care staff who are not
otherwise professionally qualified or registered. The responsibilities for ensuring that the social
care workforce has adequate knowledge and skills need to be clarified. Care provider
organisations, regulators and local and national government all have a part to play, including
enforcing minimum standards, designing, funding and providing training opportunities.

Increasing training, knowledge and skills may lead to a greater professionalization of the social
care workforce. This may be helpful in promoting retention, but may harm recruitment by driving
up entry requirements. However, Japan and Denmark that have both introduced greater
professionalization have succeeded in increasing their direct care workforces.

With remuneration close to minimum legal wage levels, pay is often not sufficient to support an
adequate standard of living (a living wage). If the employee is the only household breadwinner
this necessitates taking on another job, or living in poverty and/ or on social assistance. Union
representation tends to be low. Also, partly because of the low wages offered, these sectors
recruit selectively from marginalised population sub-groups with a lot of non-work social,
psychological and economic stresses in their lives. Workers who are recent migrants make up
an important part of the home care and care home workforce in parts of Europe, the Middle East
and South East Asia; they may be especially vulnerable to low pay, difficult working conditions
and abuse.

Undervaluation of social care has important adverse consequences for those working in the
sector, service providers, and their clients. The most direct consequence is a high turnover of
staff. In England, annual staff turnover for the sector is 19%, with a 3% vacancy rate, higher
than all other employment fields. In the USA, in a 2002 national survey, 37 of 43 states reported
serious shortages of direct care workers, and annual turnover rates range from 25% to 100%. In
the USA, lower staffing levels, a high turnover of direct care staff, and high levels of use of
agency staff are each independently associated with adverse resident outcomes in nursing
homes.

The costs of turnover are considerable, and often underestimated by providers. The direct costs
(separation payments and the costs of recruiting and training a replacement) are USD$1000 –
$6000 per direct care worker. Indirect costs of lost productivity, reduced quality of care,
deterioration in organisational culture and employee morale, and lost client revenue may amount
to much more than this. For 2004, sector-wide costs for the USA were estimated to be $4.1
billion annually.
Increased wages, improved benefits and working conditions for paid caregivers seem key to boosting retention. The introduction of more free market principles into the mixed economy that prevails in the long term care sector might help to establish pay levels that more accurately reflect the value of the labour provided. Governments’ wishes to control costs that they subsidise or reimburse are an important determinant of pay levels. Providers might still find it in their interests to improve pay and conditions, through ‘investing to save’. Put simply, the financial drain created by turnover can be diverted into programs and policies that encourage retention; paying more in salaries and benefits may save costs overall, as well as increasing productivity.

Chapter 6
FINANCING LONG-TERM CARE FOR DEMENTIA

6.1. The global costs of dementia

In the 2010 World Alzheimer Report, Alzheimer’s Disease International (ADI) estimated that the annual societal costs of dementia worldwide were US$604 billion. The costs of dementia included (and were sub-divided into) three components; the direct costs of medical care, the direct costs of social care (paid home care, and care in care homes), and the indirect costs of informal care provided by unpaid family caregivers.

Clearly, dementia has an enormous impact on socio-economic conditions worldwide. $US604 billion corresponds to 1.0% of the aggregated worldwide Gross Domestic Product (GDP). If dementia care were a country, it would be the world’s 21st largest economy, ranking between Poland and Saudi Arabia. If it was a company, it would be the world’s largest by annual revenue exceeding Wal-Mart (US$414 billion) and Exxon Mobil (US$311 billion).

The costs of dementia are very unevenly distributed. About 70% of the global societal costs of dementia are incurred in Western Europe and North America, and 89% of the total costs are incurred in high income countries. However, the minority (46%) of people with dementia live in high income countries, 39% of people with dementia live in middle income countries (where 10% of costs are incurred) and 14% in low income countries (accounting for less than 1% of the total costs).

In high income countries, the costs of informal care (accounting for 45% of the total) and the direct costs of social care (40%) contribute similar proportions to total costs, while the contribution of direct medical costs (15%) is much lower. However, in low and lower middle income countries direct social care costs are small and informal care costs predominate.

Costs appear much lower in less developed countries because the formal social care sector (accounting for the direct costs of care in the community by paid social care professionals, and from care provided in care homes) is practically non-existent. Therefore, responsibility falls largely on unpaid informal carers, and informal care costs predominate. Average wages (used to estimate informal care costs) are also much lower in these countries.

6.2 The attributable cost of dementia, and comparisons with costs of other major chronic diseases

In the USA nationally representative ADAMS study the societal cost attributable to dementia (controlling for the contribution of other health conditions) was US$ 41,689 per person. 68% of total costs arose from the direct costs of health and social care, and 32% from the costs of informal care. If the costs of hiring a replacement carer were used instead, then the contribution of informal care rose to 49% of total costs. Aggregated up to national level, the total attributable cost of dementia, was US$159 billion, of which US$109 billion arose from the direct costs of health and social care. The US$109 billion for dementia was similar to the US$102 billion for heart disease, and significantly higher than the US$77 billion for cancer.
In the UK, a report commissioned by the Alzheimer’s Research Trust sought to compare like-for-like chronic disease costs with national expenditure on research. The societal costs of dementia (£23 billion) almost matched those of cancer (£12 billion), heart disease (£8 billion) and stroke (£5 billion) combined. However, for every £1 million in costs arising from the disease, £129,269 was spent on cancer research, £73,153 on heart disease research and £4,882 on dementia research.

In Sweden, the annual costs of dementia (50 billion SEK) were higher than for depression (32.5 billion SEK), stroke (12.5 billion SEK), alcohol abuse (21-30 billion SEK) and osteoporosis (4.6 billion SEK).

6.3 What drives the cost of dementia?

Individual correlates of the cost of dementia

For people with dementia, total costs of illness are positively associated with the degree of cognitive impairment, behavioural and psychological symptoms, and with overall disease severity. Ultimately, these effects are mainly mediated through disability and hence through needs for care. This is not the case for other disorders, such as cancer and heart disease, where costs of medical interventions predominate over social care costs. For dementia, this is a function of the relative lack, and underprovision of effective healthcare interventions, particularly in the early stages of the disease.

The contribution of residence in a care home to the cost of dementia

It is often stated that the main cost-driver in high income countries is the cost of residence in care homes. This is true in part, but requires some qualification. The cost of residence and care in care homes is high, and escalates with the level of care required. Admission to these facilities would generally be restricted to people with dementia who have complex and advanced needs for care. The overall costs are comparable to those of employing a home care assistant for eight hours per day. In making cost comparisons, it is important to bear in mind that care home costs include ‘board and lodging’ costs as well as the specific costs of personal, nursing and medical care.

To clarify this issue, we carried out a fully systematic review, identifying and summarising the world literature on the relative costs of dementia care at home versus in care homes. We identified 20 relevant studies mostly carried out in Europe, Australasia and North America, with one study from Argentina, and were able to summarise data from 17 of them, reporting cost differences in International US$ using the 2010 price year.

With the exception of one study conducted in Taiwan, and one in Hungary, residential care was more expensive than community care. However, in four studies the differences in costs were not statistically significant. The excess annual cost of care in care homes ranged from minus US $16,284 to plus US $31,571 per year, with a median difference of plus US $8,288.

Where the hours of informal care inputs at home were valued at the market cost of a replacement professional caregiver, costs of care at home were similar to, or exceeded the cost of care in a care home. In three of the four studies in which ‘like for like’ comparisons of the cost of care among those with severe dementia were carried out, again the costs of care at home exceeded those of the cost of care in a care home.

In conclusion
- The difference in costs of dementia care, between those with dementia cared for at home and those cared for in a care home are negligible, seen from a societal perspective when the costs of unpaid informal care are properly valued.
- The main effect of moving into a care home is to shift the cost contribution from an indirect cost (income foregone by a family caregiver), into a direct cost of care provided by a care home worker.
- The cost of care in care homes relative to care at home is inflated by the inclusion of ‘board and lodging’ costs in the former, but not the latter set of cost estimates.
6.4 Future trends in the cost of dementia

- The commonest approach is to factor in projected increases in the numbers of people with dementia, assuming that age-specific prevalence, patterns of service utilization, and unit costs remain constant. Thus, ADI in its 2010 World Alzheimer Report predicted an 85% increase in worldwide societal costs from US$ 604 billion in 2010 to US$ 1,117 billion by 2030. In the USA ADAMS study estimates, the societal cost burden of dementia was projected to increase by 79% from 2010-2040.

- Assumptions regarding constant prevalence of dementia - Improvements in population health may mean that brain ageing is less pronounced in future generations of older people; realistic reductions in levels of exposure to cardiovascular and other risk factors for dementia could lead to a 3-9% reduction in the annual incidence of the disease. Some, but not all recent European studies have observed reductions in the last 20 years in the prevalence or incidence of dementia. Conversely, there is evidence from China that the age-specific prevalence of dementia may have increased.

- Assumptions regarding patterns of service utilization - In high income countries, due to demographic ageing, there will be a much larger relative increase in the numbers of ‘oldest old’ with dementia, who are much more likely to require care in a care home. In low and middle income countries, social and economic trends, including declining fertility, increased female labour force participation, increased workforce mobility, and a change in intergenerational attitudes towards and expectations of informal care are very likely to lead to a shift from informal care, provided unpaid by families, towards formal care by professional caregivers at home, or in a care home. This will have a fiscal impact, although the overall effect on costs from a societal perspective may be more neutral.

- Assumptions regarding unit costs for long term care - Governments seek to drive up quality while reducing costs (in particular public costs). However, most of the recommendations in our report for improving the quality of care for people with dementia seem likely to increase unit costs of care. There is some evidence that advance care planning can reduce unnecessary and unhelpful service utilisation, and a theoretical basis for hoping that making information available to consumers may drive costs down through the more efficient operation of a free market. Coordination and integration of care is also meant to increase efficiency and reduce costs, but with little evidence to support this as yet.

- The European Commission in its 2009 Ageing Report applied a complex model designed to assess the impact of variables that affect long-term care expenditure on the proportion of national gross domestic product (GDP) that is allocated as public funding for long-term care. The conclusions from these modelling exercises are that
  - The major driver for future increases in long term care spending in Europe is demographic ageing. Since those people who will be old in 2060 are already born, this is both nearly completely predictable, and inevitable.
  - Improvements in the health of future cohorts of older people, promoting informal care, restricting access to formal care, and limiting rises in unit costs would all tend to reduce projected cost increases, particularly for the wealthier EU 15 countries with their better established long term care systems. However, the effects would be marginal with respect to the sizeable budget increases anticipated as a result of demographic ageing.
The looming ‘crisis’ in long term care funding

• Standard & Poor’s (S&P) considers global aging to be the main threat to global economic stability, predicting that without changes to age-related public spending on health and social care, sovereign debt in developed economies will soon become unsustainable. For emerging economies, economic growth may give governments more time to consider policy options. However, with increasing demand for more effective social protection, S&P considers that the need to tackle demographically-driven budgetary challenges is hardly less pressing than that now faced by advanced economies.

• Standard and Poor’s clearly have a point. How affordable and sustainable are the current levels of provision for long-term care given the large projected increases in the numbers of older people with needs for care, coupled with a shrinking working age population?

The crisis explained

• In all societies, throughout history, children and older people consume (in goods and services) more than they produce, while the working age population produces more than it consumes. These lifecycle deficits and surpluses are sustainable because of the complex systems that have arisen informally or been implemented by governments to enable flows of economic resources from surplus to deficit ages.

• In traditional societies the arrangements are entirely informal but enshrined in cultural, philosophic and religious principles that value the nurturing of children by their parents, and the care and support of older parents by their children. The extended family, and the wider community provided a safety net. In what are now considered high income countries, the state began to take on an important role, initially to provide a safety net of last resort, and later to promote equity; universal access to education and health care; protection against unemployment and other economic shocks; and income security and social protection for older people through contributory and social pensions.

• These intergenerational transfers rely upon
  - a broad societal consensus for intergenerational reciprocity; that this is the right way in which society should be ordered, and
  - feasibility and sustainability; that is that there are adequate resources generated to be transferred to those that are less economically productive and need support or care, and that everything is in balance.

• These pillars of the traditional system of intergenerational reciprocity are threatened by rapid demographic ageing. In low income countries, pre-demographic transition, children predominate, while in mature post-demographic transition high income countries, the high consumption of the much greater relative number of older people predominates. Hence in the Philippines the child deficit is almost 15 times larger than the old-age deficit, while in Germany the old-age deficit is 50 per cent larger than the child deficit. When consumption across the economic life-cycle exceeds production, which tends to be the case when old-age deficits predominate, then a crisis of the kind averted to by Standard and Poor’s is in the offing.

• The United Nations has accurately described the challenge that population ageing poses for societies and governments worldwide - “to ensure that people everywhere can grow old with security and dignity and that they can continue to participate in social life as citizens with full rights”, while at the same time respecting the principle that “the rights of old people should not be incompatible with those of other groups, and reciprocal intergenerational relations should be encouraged.”
How can this challenge be met?

By bolstering social protection for all older people in low and middle income countries

- Some governments have sought to encourage or coerce families to shoulder their responsibility for the financial support and care for older parents. While such policies are understandable, they seem destined to fail in the longer-term due to the reduced availability and willingness of children to care.
- More sustainable strategies include universal non-contributory social pensions, targeted disability pensions and caregiver benefits. Social pensions provide insurance against risks that older people face, including uncertainty over how long they will live, how long they will remain healthy, whether they can count upon the support of others if they need it, and how long they can earn an income. They play a significant role in alleviating poverty. Most importantly they reinforce reciprocal family ties. Dependent older people are particularly likely to benefit, as informal care would be bolstered and paid care made more affordable.

By generating a ‘second demographic dividend’

- A ‘second demographic dividend’ can still be generated even in the context of global population ageing if resources generated by the first demographic dividend are wisely invested; in children’s health and education to increase the productivity of the next generation; in policies and programs to improve labour participation rates and labour income of young workers; and in incentivises for the working population to save and invest to provide for their own retirement costs.

By pooling risk

- In countries with very limited social and income protection for older people the risks of protracted and costly dependence in late life are still relatively modest, and it is unlikely that everyone, particularly the poorest in society will be able to make adequate provision. Equity, as well as motivation to save, is best promoted by some form of risk pooling, most commonly through a state organised or mandated insurance scheme. This provides a degree of social security, independent of ability to pay, and freedom from worries about the risk of becoming dependent.
- Most OECD (high income country) governments have collectively-financed schemes to support long term personal and nursing care costs. Just two countries, the UK and the USA have “safety-net” means-tested schemes for long-term care costs. Private long term care insurance has yet to find a foothold in financing systems of most OECD countries.

By ensuring that long-term care schemes are ‘fully-funded’

- A fully-funded scheme is one in which each generation collectively makes provision for their own future needs for pensions, health and long-term care. A ‘pay as you go’ (PAYGO) system is one in which the current working age population provides for the needs of the previous generation that is currently aged, usually through general taxation.
- PAYGO systems operate best when the relative number of contributors and beneficiaries under the system are fairly stable. This is clearly not the case in countries in which demographic ageing is advancing rapidly. Then, the growing numbers of people reaching retirement age are supported by shrinking numbers of active workers. PAYGO systems are widely recognised to be fiscally unsustainable, and pose a threat to intergenerational reciprocity. However, shifting from a PAYGO system to a fully-funded system is difficult, since the current generation of workers will be required to make increased contributions often for lesser benefits than are being enjoyed by their parents’ generation, and there may also have to be restrictions in the benefits available to the current older generation.
By rationing (targeting) of public spending on care

- In nearly all OECD countries with well-developed government funded social care systems, eligibility for home care services and admission to a care home has been tightened, so that only those with much more advanced needs for care are eligible to receive subsidised services. Demand for long-term care services, and their cost to the public purse, can also be controlled by requiring copayment for some or all services.

- Rationing could be seen as appropriate and efficient targeting of scarce public resources on those with the greatest need, and the greatest potential to benefit. However, for people with dementia, raising eligibility thresholds for community support for people with dementia may have resulted in earlier, crisis-driven and avoidable admissions to care homes. Rationing of care may open up a gap in services in the crucial early years when investment in advanced care planning, case management, caregiver education and support, may be most beneficial. In countries where access to long-term care benefits is means-tested enormous expenses can be incurred while assets are spent down. The financial burden affects most sectors of society, not only the richest.

- The OECD has recommended that governments use financial instruments to alleviate the pressure of out-of-pocket payments, while still generating copayments by mobilising cash from equity, for example reverse mortgages on property, or combined life and long term care insurance policies.

By supporting and incentivising informal care by family carers

- The OECD in its recent report ‘Help Wanted? Providing and Paying for Long-Term Care’ advocated increased investment in this area, calling it a ‘win-win-win’ situation, the three wins arising from; benefits to carers who, without support, are at increased risk of giving up or cutting back on paid work; benefits to care recipients, who generally prefer to be looked after by family and friends; and benefits to public finances, because it informal care involves less public expenditure than if this was provided in the public sector. Support and incentives can be provided by; by introducing cash benefits; making working arrangements more flexible; and offering support, education and training to caregivers.
  - Introducing cash benefits - Cash benefits may not be as generous as a proper wage, but nevertheless provide compensation and societal recognition of caregivers’ contributions. Direct payments can be made to the caregiver (a caregiver’s allowance) or to the care recipient (used to purchase respite or substitute home care, or to compensate for the loss of the caregiver’s paid employment). The danger of cash benefits is that they may lock family caregivers into a role that is still poorly remunerated, and provides few opportunities for participation in the paid labour force.
  - Making working arrangements more flexible - The chances of an informal caregiver having paid work outside of the home declines by 10% with every 1% increment in hours of personal care provided. This can be mitigated by flexible working schemes, which can include paid carer leave, flexible working hours, or working from home.
  - Offering support, training and education to caregivers - there is ample evidence that caregiver psychosocial interventions, particularly those that include multiple interactive components, can improve caregiver mood and quality of life, and delay transition into a care home. These interventions have typically targeted caregivers who are already engaged in substantial caregiving tasks, and experiencing strain. However, they may be especially effective in delaying transition into a care home when started relatively early. There is therefore a strong case to make psychoeducation and support available to all caregivers from the time of diagnosis, and then provide more focused multicomponent support as the condition progresses.
The World Health Organization policy document ‘Towards an International Consensus on Policy for Long-Term Care of the Ageing’ describes principles to inform policies for sustainable programs in long-term care that are consistent with the priorities of countries at different levels of development.

Having noted the huge variation in the nature and extent of resources available for long-term care, the cultural differences in the understanding and expression of chronic disease and disability, and hence the differing notions of ‘dependence’ and ‘needs for care’, the report’s authors stated as their first guiding principle: “With due attention to the appropriate balance of private and public responsibilities, each community should be able to determine objectively the level and kind of assistance required by an older person in need of care or by family members providing this care. The subsequent eligibility and payment for this assistance must also be addressed.”

The WHO considered it essential that fundamental basic standards be recognised; care should be of high quality; roles and responsibilities of individuals and families be clarified in relation to their government; and that differences between these groups be reconciled, stressing the focus on the individual and the family.

The World Health Organization was calling, in effect, for detailed, comprehensive and ongoing national dialogues involving government, policymakers, key stakeholders, and an informed public. This agenda is still relevant, since most countries have yet to reach a settled, sustainable and comfortable consensus on who needs care; who’s needs should be prioritised; how care should be delivered, and by whom; what cost would be reasonable and affordable; and (perhaps most importantly) how this should be financed.