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LONG-TERM CARE FOR OLDER PERSONS IN ASIA AND THE PACIFIC

Long-term Care of Older Persons in India

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1 Introduction

Older persons, particularly the very old, are the fastest growing population segment in India, and with more than a hundred million people aged above 60 years, India is already facing some of the challenges of population ageing. While the Indian population was projected to increase by 40 per cent between 2000 and 2050, the number of persons aged 60+ will increase by 354 per cent. The number of older persons will rise to 354 million in 2050 accounting for almost 20 per cent of the population (United Nations, 2015). These proportions and numbers have important implications for societal institutions, namely the family, the community, the health system, the social welfare system, the labour market, and pension and financial services.

The need to formulate policies and programmes for older persons was acknowledged throughout the world in the 1980s after the United Nations First World Assembly on Ageing. At that time, developed countries were already experiencing and reacting to rapid population ageing, while developing countries, including India, were still battling with issues related to high population growth rates, such as infant and maternal mortality. Now, developing countries are beginning to deal with the challenges of population ageing and its impact on societal functioning.

The Government of India started addressing the challenges of a growing number of older persons in the 1990s and adopted the National Policy on Older Persons (NPOP) in 1999. Thereafter, the Maintenance and Welfare of Parents and Senior Citizens Act in 2007 defined the responsibilities of the family and the State in providing care for older persons. While policies and the law provided the framework, the most visible intervention in old age care was the launching of the National Programme for Health Care of the Elderly (NPHCE) in 2011. Prior to these interventions, an old age pension was available in different States though its provisions and the benefits were not uniform. Despite having a historical tradition of an old age pension, the long-felt need for a universal pension in India has yet to be accomplished.

Social Welfare is implemented by the States in India. The central (federal) Government depends on the state governments to implement policies and programmes, thus measures for the welfare of older persons are not uniform and implementation standards are seldom achieved. A growing number of civil society organizations and academic researchers, however, have begun to monitor and evaluate the implementation of policies and programmes for older persons. Such efforts have led to reviews and course corrections in policies and programmes.

Detailed analyses of demographic trends and policies and programmes for older people are readily available in Indian literature. Nevertheless, there is a dearth of research on issues related the very old population, the state of their health, systems of support and the availability of care. This report captures current research, demographic trends and projections, policies and programmes to support older persons in India and data on the health status of older persons. It also captures current health care and long-term care options for older persons and concludes with recommendations to improve long-term care for older persons in India.

2 Research

Research on health and long-term care in old age in India is not very extensive.

In 1985-1986, the Indian Council of Medical Research (ICMR) started funding research on ageing. A Task Force project was conducted in rural Tamil Nadu, to understand health and health care issues in old age (Rao, 1990). Since then several projects have been funded by the Division of Non- Communicable Diseases of ICMR on various aspects of geriatrics and gerontology. Research in ageing is carried out in several eminent Indian universities and institutions.

The ICMR conducted several workshops to identify areas of research in the field of geriatrics and gerontology in the Indian context, such as the “Indo-UK workshop on public health implications of ageing in India” in 1993, a WHO-ICMR workshop on research and health care priorities in geriatric medicine and ageing in 1999, a workshop on research in geriatrics and bio-gerontology in 2010, and an ICMR-FORTE joint workshop on ageing and health in 2014 are some of the examples of efforts to guide and fund research in the field of geriatrics and gerontology in India (Ramachandran and Shah, 1994; Shah and Singh, 1999). Subsequent development of policies and programmes has been heavily influenced by deliberations that took place during these activities.

Research output in the areas of the behavioural and social sciences have so far outweighed that of the biological and medical sciences. An annotated bibliography on research on older persons, composed from literature (both published and unpublished) was developed by the Tata Institute of Social Sciences, Mumbai in 1999-2000 in two volumes (Shah and Singh, 1999; Tata Institute of Social Sciences, 1999). The annotated bibliographies document studies from as early as 1972. In the first volume, 884 articles, 44 books and five theses were documented. The second volume documented 888 articles (including many unpublished presentations at conferences and workshops) and 115 theses, reports and books published by NGOs and research institutions.

Some of the areas covered under the studies included the following: problems of adjustment and coping; post-retirement life satisfaction; the elderly in the family; care-giving; social supports; attitudes; inter-generational interaction; leisure utilization roles; techno-social changes and the family; elder care across subcultures; impact of demographic changes; quality of life; and widowhood problems.

After the Second World Assembly on Ageing in 2002, the research in geriatrics and gerontology has been substantially influenced by the Madrid International Plan of Action on Ageing (MIPAA), which set the agenda for formulating and implementing public policies on ageing and will influence the direction and priorities for scientific gerontology research in the following decades. MIPAA emphasized the need to assess the ‘state of the art’ of existing knowledge across countries and regions and to identify priority gaps in information needed for policy

development. Accordingly, attempts have been made to review the body of knowledge in the field of ageing in India and to identify the priority areas for further research.

As part of its project on Building a Knowledge Base on Population Ageing in India (BKPAI), the United Nations Population Fund (UNFPA) published a compendium of research on ageing in India (Raju, 2011). In addition to outlining the status of research in India, the paper provided a situation analysis of the status of older persons in Indian society with reference to economic, social, psychological and health aspects, including the abuse of older persons. It also proposed models of care for older persons with diverse factors such as place of residence, social class and gender as determinants. The paper stressed protecting and strengthening the institution of the family through professional welfare services, financial support to low income families, and counselling services for family members. The paper, however, did not include the topics of home care and long-term care.

There is a need to adopt a multi-disciplinary and multi-activity approach to the issues of ageing, and to frame intervention models for the care of older persons in different institutions of society. Home care, long-term care, economics of care, quality assessment and quality assurance in institutions of care are some of the issues that need to be examined with for evidence for intervention.

3 Demographic trends in population ageing and their implications

In the beginning of the twentieth century, life expectancy at birth in India was very low at 23 years for both genders. In 1947, when India became independent from British rule, life expectancy at birth was around 32 years. Subsequent improvements in public health and medical services have led to substantial control of specific infectious diseases and some diseases were eradicated. Those improvements also led to a significant decrease in the mortality rates of all age groups. Government sponsored public health programmes on nutrition supplementation and sanitation, and maternal and child immunization programmes have improved maternal health and reduced infant mortality. Life expectancy at birth is now 67 years for males and 69 years for females – having more than doubled since the mid-twentieth century.

Census data from 2011 showed there were 98 million older persons in India, or 8.1 per cent of total population, up from 77 million in 2001 (table 1). The number of older persons in India is expected to increase three-fold to 298 million in 2051, accounting for a little over 17 per cent of the total population. The population aged 70+ increased from 9 million in 1961 to 29 million in 2001 and 43 million in 2011. The share of people aged 70+ in the total population increased from 2 per cent in 1961 to 4 per cent in 2011. The rapid growth in the proportion of older people within the total population will continue to grow from 2021 to 2051.

TABLE 1. DATA AND PROJECTIONS OF POPULATION, PROPORTION AND SEX RATIO OF OLDER PERSONS IN INDIA, 1961–2051

Population of older persons (millions)							
Age group	1961	2001	2011	2021	2031	2041	2051
60+	25	77	98	132	184	233	298
70+	9	29	43	52	75	104	131
80+	2	8	11	16	20	29	41
Proportion of older persons in the population							
Age group	1961	2001	2011	2021	2031	2041	2051
60+	5.6	7.5	8.1	9.7	12.1	14.0	16.6
70+	2.0	2.9	3.6	3.8	4.9	6.3	7.3
80+	0.6	0.8	0.9	1.2	1.3	1.7	2.3
Sex ratio of the older population							
Age group	2001	2011	2021	2031	2041	2051	
60+	103	100	97	102	105	102	
70+	99	108	103	100	108	111	
80+	105	104	114	106	104	115	

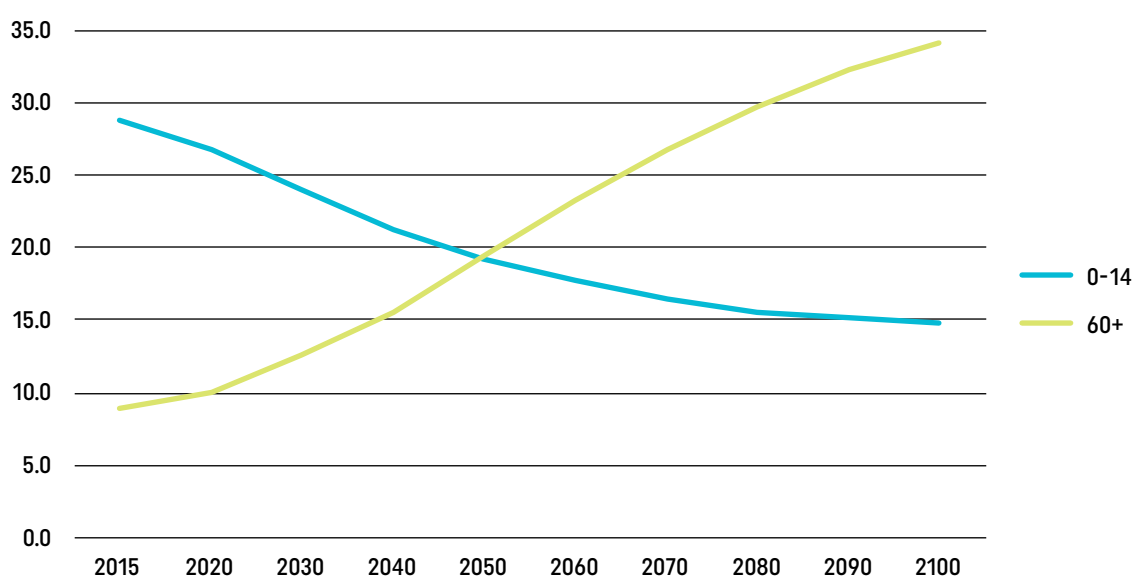
Source: Censuses of India (+projections), Government of India.

Between 1961 and 2011, the population aged 60+ nearly quadrupled. From 2011 to 2014, it is expected that the share of the population aged 60+ will increase by about 2 per cent every 10 years. The share of the population aged 70+ also increased from 2.0 to 3.6 per cent from 1961 to 2011, and the population share of persons 70+ is projected to increase by about 1 per cent by 2031, and then 1 per cent every 10 years up to 2051.

The sex ratio (number of females per 100 males) of the older population in India is in favour of females, just as in other parts of the world. Women comprise a majority of this population because female life expectancy is higher. The variation in the sex ratio is small for younger people, but among people aged 70+ and 80+ the sex ratio is expected to continue to increase between 2011 and 2051.

Based on the current rate of change, the 60+ age group is projected to outnumber the age group 0-14 soon after 2050 (figure 1) when the percentage of the child population and the population of older persons will be the same at about 19 per cent.

FIGURE 1. CROSSOVER OF THE PERCENTAGES OF THE CHILD POPULATION AND POPULATION OF OLDER PERSONS IN INDIA



Source: United Nations (2015).

The impact of population ageing is also evident in the dependency ratio (young age dependency: number of persons 0-14 years per 100 persons 15-59 years and old age dependency: number of persons 60+ years per 100 persons 15-59 years) and potential support ratio (number of persons aged 15 to 59 per every person aged 60+ (table 2).

The dependency ratio indicates the burden on workers to support dependent children and older persons. Projections of the demographic transition show a decline in the number of children and an increase in the number of older persons. During the period 2001 to 2051, child dependency is expected to fall by about 21.8 points whereas old age dependency would increase by 14.8 points from 13.1 in 2001 to 27.9 in 2051. Overall, the dependency burden is expected to show an increasing trend from 59.4 in 2011 to 68.2 in 2051.

TABLE 2. OLD AGE DEPENDENCY, POTENTIAL SUPPORT RATIO AND PARENT SUPPORT RATIO, 2001–2051

Population indicators	2001	2011	2021	2031	2041	2051
Median age	20.5	22.5	25.5	29.3	36.7	44.3
Young age dependency ratio	62.1	46.5	46.4	43.0	40.4	40.3
Old age dependency ratio	13.1	12.9	15.8	19.6	22.8	27.9
Potential support ratio	7.6	7.7	6.3	5.1	4.4	3.6
Parent support ratio	7.2	6.7	7.7	8.2	9.4	13.3

Source: Censuses of India (+projections), Government of India.

4 Policies and programmes

Several policies and programmes in India promote the welfare of older persons either by specifically targeting older persons or by providing support to populations that include older people. For example the National Policy on Older Persons targets old age while the National Policy for Persons with Disabilities targets persons (including older persons) with disabilities. Similarly there are specific and general programmes, particularly in the health sector. For example, NPHCE is an overarching programme for older persons, while the National Blindness Control Programme addresses cataracts, a common disability in old age.

4.1 National Policy on Older Persons

The framing of the National Policy on Older Persons (NPOP) was related to India's commitment to United Nations General Assembly resolutions 46/91 (1991) Principles for Older Persons and resolution 47/5 (1992) Proclamation on Ageing and the global targets on ageing for the year 2001, as well as various other resolutions.

As the initial policy document for senior citizens, NPOP was adopted in 1999 by the Ministry of Social Justice and Empowerment (MoSJE). Its mandate was derived from the Constitution of India. Article 41, the Directive Principles of State Policy, stresses "the State, within the limits of its economic capacity and development, shall make effective provision for securing the right of public assistance in cases of old age". There are other provisions, too, which direct the State to improve the quality of life of its citizens. The right to equality has been guaranteed by the Constitution as a fundamental right and these provisions apply equally to older persons.

The National Policy viewed the life cycle as a continuum, of which the phase of life after age 60 is integral part rather than the beginning of separate phase of dependency. Individuals aged 60+ should have choices and opportunities to lead an active, creative, productive and satisfying life. It also noted the need to prevent discrimination against older women on account of gender, widowhood and age. Section III of NPOP outlines principle areas of intervention and action strategies. The areas of intervention were as follows: financial security; health care and nutrition; education; welfare; protection of life and property; and other areas. Though all the areas of intervention are important for older persons requiring long-term care, the most important areas are financial security, health care and nutrition, and shelter. The action strategies included partnerships with non-governmental organizations; realization of potential of older persons; the family as a social institution; research; training of personnel; and media.

In response to the concern over financial security in old age, NPOP recommended an inflation-linked pension for all older persons living below the poverty line. The policy emphasized the need for protection against fraud and discrimination in entitlements. It recognized that

beyond the salaried class (who qualify for a pension from the employer) and older persons living below the poverty line who would receive a pension from the Government, large numbers of older persons without work and income would lack financial security. The policy aimed to establish a mechanism for universal financial security.

Older people are more likely to have chronic and multiple health problems that require constant attention and have the potential to result in disability and the loss of autonomy. They have a high risk of impaired functional capacity, and are likely to need long-term care and nursing care. Access to affordable health services was considered as the goal of NPOP. The cost of health care would be covered by a subsidy for the poor, a graded system of user charges for others and health insurance with participation of public and private health service providers.

Primary health care systems are the basic structure of public health care, and NPOP recommended strengthening and orienting the primary health care system to be able to meet the health care needs of older persons. It also noted the need for preventive, curative, restorative and rehabilitative services in primary health care. The National Policy recommended offering financial incentives in the form of tax relief and concessions to charitable societies, voluntary agencies and businesses providing services and health insurance. It recommended expanding private health systems in old age care, providing dedicated services in the form of geriatric wards and outpatient care and training medical and paramedical personnel in all levels of health care. Mobile health services and health camps can extend medical services to those who cannot reach the established health system. The National Policy also recommended expanding and strengthening mental health services. The health of older persons can also be promoted through health education for the general population on a life course approach and by empowering the family caregiver.

While NPOP emphasized the concept of healthy ageing, it also noted that some older people will be chronically ill, bed-bound, deprived of family support and terminally ill, who would need long-term care and hospice care with assistance from the State, public charities and voluntary organizations among others. The policy made public hospitals responsible for the care of abandoned and chronically ill patients.

Shelter is a basic human need and NPOP made several recommendations to ensure shelter for older persons. However it did not make any suggestion to meet the shelter needs of those who need long-term care and do not have a family, or those who are homeless.

The implementation of NPOP was left to individual ministries, departments and state governments, and the results were not fully satisfactory. In 2010, the Government of India, decided to review the NPOP and appointed a committee managed by MoSJE, to conduct a series of consultations with stakeholders from all sections of society. The committee submitted its recommendations in 2011, but the Government has not yet given its official sanction. The main recommendations for the new policy were to mainstream ageing issues and fully implement the Madrid International Plan of Action on Ageing (2002), the Maintenance and Welfare of Parents and Senior Citizens Act (2007) and NPHCE (2010-2011).

4.2 National Programme for Health Care for the Elderly (NPHCE)

The Ministry of Health and Family Welfare (MoHFW) launched NPHCE during the financial year 2010/11 as a part of the 11th Five-Year Plan initiative (MoHFW, 2011). The NPHCE was a fulfilment of the international and national commitments of the Government of India as envisaged under the United Nations Convention on the Rights of Persons with Disabilities, NPOP (adopted in 1999) and Section 20 of the Maintenance and Welfare of Parents and Senior Citizens Act, 2007, dealing with provisions for medical care of older persons.

The vision of the NPHCE is as follows: (1) to provide accessible, affordable, and high-quality long-term, comprehensive and dedicated care services to an ageing population; (2) to create a new “architecture” for ageing; (3) to build an enabling environment for “a society for all ages”; and (4) to promote the concept of active and healthy ageing in the health system of India. The specific objectives of NPHCE are to provide easy access to health services through community based primary health care; to identify health problems and manage them; to provide referral services to district hospitals and regional geriatric centres; to build the capacity of medical and paramedical professionals as well as caretakers within the family and to coordinate services with the National Health Mission, the Department of Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homoeopathy (AYUSH) and MoSJE.

The programme envisaged various government health facilities would provide promotional, preventive, curative and rehabilitative services in an integrated manner for older persons. The package of services would depend on the level of the health facility and the range of services would include health promotion, prevention, diagnosis and management of geriatric medical problems (out- and in-patient), day care, rehabilitation and home-based care as needed. Districts would be linked to regional geriatric centres for tertiary care. The services under the programme would be integrated below the district level and would be an integral part of the existing primary health care delivery system. More specialized care would be provided at the district level and above. The aim is to implement NPHCE in 100 out of 676 districts and eight medical schools. The number is expected to go up to 325 districts and 20 medical schools by the end of the 12th Five-Year Plan in 2017.

The NPHCE addresses most of the health problems in an institutional health-care system rather than home-based long-term care in a family setting, where most care of older persons takes place. It does not focus on issues specific to different regions within the country. The programme does not address the issue of creating incentives for families to care for older persons, which is important in India. The NPHCE is a new initiative aimed at addressing a fast ageing population, but requires more attention in implementation and coordination so that the programme can be a success (Verma and Khanna, 2013). In 2015, the Government of India added additional features to NPHCE for the very old (people aged 75+).

4.3 Social welfare system functioning in support of older persons

The Government of India enacted the Maintenance and Welfare of Parents and Senior Citizens Act 2007, under the auspices of MoSJE (Government of India, 2007). This legislation provided the legal basis to enforce the National Policy on Older Persons adopted in 1999. Under this legislation, older persons can claim maintenance from their legal heirs through a well-established quasi-judicial system. The Act attempts to define the role of family and the State in caring for older persons, moving beyond the issues of maintenance. Chapters I and II of the Act deal with issues related to maintenance and its administration, and Chapter III is related to establishment of homes for older persons. The Act mandated that each State would establish and maintain a sufficient number of homes for impoverished older persons. Chapter IV of the Act deals with health care issues and directed the State to ensure the availability of beds in hospitals owned or funded by the Government, for the treatment of chronic, degenerative and terminal diseases; and earmarked health facilities for older persons, managed by trained and experienced health professionals.

Implementation of the Act across the country has not been uniform. Although the law was enacted eight years ago, the tribunals for grievances are not yet in place in several states. The use of funds earmarked in the 11th Five-Year Plan was low and in the first three years of the 12th Five-Year Plan a similar trend persisted. With the disintegration of the joint family system, older persons need other sources of support. Thus, States should fulfil their constitutional duty to implement the act and provide for the welfare and extra protection of older persons, including palliative care.

The Integrated Programme for Older Persons, an initiative the MoSJE, provides care to older persons (MoSJE, 2015). It aims to provide stability for older persons amid rapidly unfolding societal changes and to improve their quality of life. The programme seeks to ensure basic amenities like shelter, food and medical care, and opportunities for personal enrichment. It encourages productive and active ageing through support for capacity building in institutions of civil society. Under this Integrated Programme, the Government of India proposes to provide financial support to do the followings: maintain homes for older persons, respite care homes and continuous care homes; run multi-service centres for older persons to provide day care, educational and entertainment opportunities, health care and companionship; maintain mobile medical units for older persons living in rural or isolated areas; provide specialized care by running day care centres for Alzheimer's disease and related disorders, multi-facility care centres for older widows, physiotherapy clinics and help lines and counselling centres for older persons. The Integrated Programme includes an education component to provide training in old age care and self-care, and conduct sensitization programmes for school/college students and awareness projects for the community. It also provides for the formation of volunteers' bureaus, and older person associations or self-help groups. The Integrated Programme recommended offering tax incentives to families caring for older persons in need of long-term care. Since adopting the Programme major income tax relief has been provided to older persons and their families.

The New Pension Scheme was rolled out in 2004 with universal eligibility. Pension schemes from non-banking financial institutions and mutual funds in the private sector are gaining popularity among urban Indians as a means to ensure financial security later in life.

In India, policies and programmes have targeted the needs of older persons for care and support. Each of the policies and programmes mentioned have created a role for civil society, which has had its most visible impact in the area of financial security. Various civil society groups such as the Workers and Peasants Strength Union, National Campaign for People's Right to Information, HelpAge India and others are now advocating for a universal pension for all older persons.

The sixtieth round of the National Sample Survey, conducted in 2004, focused on morbidity, health care and the conditions of older persons (NSSO, 2006). The survey was carried out between January and June 2004 covering 73,868 households from 4,755 villages and 2,668 urban frame survey blocks. Some of the important observations of the report are summarized below:

- Old age dependency increased steadily in the two decades prior to the survey, reflecting the ageing of the population.
- The sex ratio (number of females per 1,000 males) rose steadily.
- Some 5 per cent of older persons lived alone, though nearly 90 per cent lived in families with a spouse and children. In some parts of India affected by high migration, over 15 per cent of older women were living alone. Overall, 65 per cent of older persons were economically dependent on their spouse or children.
- Some 30 per cent of people aged 60+ reported an ailment during the previous 15 days, and 6.4 per cent had been hospitalized at least once in the previous year (compared to 2.5 per cent for all age groups).
- Some 8 per cent of older Indians were confined to their home or bed at the time of the survey. The proportion increased to 27 per cent among people age 80+ and women were more likely to be bed-bound than men.
- The perception of health, which is a determinant of health seeking behaviour, was an important observation of this study. Excellent to fair perception of health was reported by 83 per cent of older persons without illness and 56 to 66 per cent of those with an illness. This may indicate acceptance of illness as a part of the ageing process.
- There was an overall increasing trend of hospitalization in non-government sector hospitals compared to the forty-second and fifty-second rounds of the National Sample Survey.

In 2007, MoHFW and the World Health Organization (WHO) Country Office for India carried out a comparative analysis of select health parameters across the forty-second, fifty-second and sixtieth rounds of the National Sample Survey. It concluded that the problems of the aged may increase with the proportion of nuclear families, especially in urban areas, as nuclear families are less able to provide long-term care. Nevertheless, the proportion of older persons confined either to home or bed increases with age. Thus the care of older persons is a challenge to society, especially because access to pensions and social security in India is very limited (MoHFW and WHO Country Office for India, 2007).

Between 2008 and 2012, UNFPA conducted a research project in collaboration with the Institute for Social and Economic Change (ISEC), the Institute of Economic Growth, and the Tata Institute of Social Sciences, entitled Building a Knowledge Base on Population Ageing in India (BKPAI) (UNFPA and others, 2014). Primary surveys were carried out in seven States with larger populations of older persons than the national average; namely; Himachal Pradesh, Kerala, Maharashtra, Odisha, Punjab, Tamil Nadu and West Bengal. The study included 1,280 households with at least one person age 60+ from each of the seven States. A total 9,852 interviews with

older persons were conducted at 8,329 households between May and September 2011. The main objective was to strengthen the knowledge base on different aspects of ageing in India by facilitating/undertaking a series of thematic studies and disseminating the findings to different stakeholders. The studies made use of socioeconomic and demographic data and information, including work and income status; living arrangement and familial relations; subjective well-being, functionality and health care use; and awareness and use of social security schemes.

Health and well-being were investigated extensively. Some of the important observations related to the theme of this essay are summarized below.

- The majority (55 per cent) of older persons rated their health as poor. This was also reflected in their response to questionnaires on mental health, which were far from satisfactory. The self-assessments of older persons in this survey on physical and mental health were lower compared to previous reports and other societies. Both self-rated health and mental health may have a strong socio-economic gradient.
- Older persons had substantial disabilities in vision and locomotion. However, only 5 per cent of the study subjects had difficulty performing basic activities of daily living (ADL) (such as bathing, dressing and grooming) and required regular care and support.
- The study detected comparable levels of cognitive ability (measured by immediate recall of words) at par with many other societies. The study did not measure cognitive impairment.
- Indulgence in smoking, chewing tobacco or drinking alcohol especially among males was observed in 30 per cent of subjects.
- Some 13 per cent reported an ailment in the previous 15 days. Nearly 10 per cent were hospitalized in the year prior to the survey.
- Two thirds of subjects reported at least one chronic ailment such as arthritis, hypertension, diabetes, asthma and heart disease. The prevalence of chronic diseases was higher among women than men.
- Most patients with chronic diseases sought treatment and private health care was the preferred choice for treatment. Only a little over a quarter of patients sought care from public hospitals. Women were more likely to use unpaid or free health services from public health facilities compared to men who were more likely to rely on private health facilities.
- The economic burden of illness is substantial and was entirely borne by the family. Awareness of and access to health insurance schemes was negligible, including state-funded health insurance through Rashtriya Swasthya Bima Yojana (RSBY).

5.2 Other surveys

In addition to community-based surveys on the health and well-being of older persons, there have been several investigator-driven studies in hospital and community settings. These studies consider health issues that a patient presents with at a facility within the health system and

which have direct impact on clinical service development. Table 4 summarizes three studies in the public domain that considered data from a substantial number of patients.

TABLE 4. SUMMARY OF HEALTH PROBLEMS OF OLDER PERSONS IN PUBLISHED LITERATURE

Health care of the rural aged ^a		Evaluation of the health and functional status of older Indians ^b		Multicentre study to establish epidemiological data on health problems ^c	
Morbidity (n=1910)	%	Morbidity (n=1586)	%	Morbidity (n= 10035)	%
Visual handicap	88.0	Hypertension	39.5	Poor vision	45.4
Locomotion	40.0	Cataract	35.3	Hypertension (overall)	38.2
Central nervous system	18.7	Osteoarthritis	33.7	Arthritis	36.1
Cardio-vascular system	17.4	COPD ^d /Asthma	19.9	Bowel complaints	31.6
Respiratory disease	16.1	Ischemic Heart Disease	18.9	Depression	23.6
Skin	13.3	Benign prostatic hypertrophy	16.2	Hearing impairment	20.5
Abdomen/gastro-intestinal tract	09.9	Diabetes	15.2	Weight loss (last 6 months)	19.6
Hearing	08.8	Dyspepsia	11.0	Urinary problems	13.4
Urinary	03.5	Irritable bowel syndrome	09.2	Diabetes	13.3
Miscellaneous including cancer	07.5	Depression	08.5	Falls/fractures in 6 months	11.4
		Tuberculosis	02.8	Asthma/COPD1	11.4
		Anxiety disorder	02.8	Ischemic Heart Disease	07.7
		Cerebrovascular disorder	02.7	Tuberculosis	03.1
		Dementia	02.3	Paralytic attack	02.7
		Peripheral neuropathy	02.3	Parkinson's disease	01.4
		Obesity	02.3	Cancer	00.8
		Hernia	01.9	Tobacco consumption	23.4
		Parkinson's disease	01.7	Serum cholesterol >200mg/dl	32.5
		Miscellaneous	23.5	BMI >25	28.0
		Functional deficits (n=1268)		BMI <18.5	16.7
		Vision	48.5	Blood sugar>126mg/dl	14.9
		Hearing	31.6	Haemoglobin <11gm/dl	16.8
		Arm function	06.5		
		Leg function	04.8		
		ADL-instrumental ADL impairment	06.9		
		Cognitive impairment	05.1		
		Depression	20.0		
		Urinary incontinence	19.6		

Source: a: Rao (1990), b: Dey and others (2001), c: Srivastava (2007), d: chronic-obstructive pulmonary disease.

Enumeration of health problems in older persons has been a popular topic for post-graduate thesis research and small funded projects in different parts of the country. In most of these studies very old or homebound older persons are seldom recruited; in fact they are excluded as unstable patients who cannot sustain the long evaluation process. Furthermore, family

caregivers would not expose such a person to a visiting research team on the grounds of privacy. In a project of the Indian Council of Medical Research (ICMR) Task Force, “Determinants of functional status of older Indians” conducted in the National Capital Region of Delhi with a sample size of over 1,000, not a single person was encountered who had deficits in basic ADL (ICMR, 2007). As such, there is a need to overcome strong social norms that prevent researchers from collecting accurate data on older persons and thus prevent effective research on very old/bed-bound older persons that is essential to determine their health and social care requirements.

There is very little data derived from hospital as well as community setting on health issues of persons aged 80+. This is possible because there were not many octogenarians and nonagenarians in Indian society in the preceding decades. In the above-mentioned ICMR Task Force project less than 10 per cent of subjects were aged 80+ (ICMR, 2007). They were predominantly widowed (60.2 per cent), from lower socio-economic status (75.5 per cent), financially dependent (75.5 per cent) and either illiterate or little educated (79.6 per cent). For the most part, they did not undertake any health promoting activity (96.9 per cent) and had no access to free/subsidized health care (82.7 per cent). Some 40 per cent self-reported suffering from depression, and 28 per cent were found to be actually depressed assessed with a screening tool (Geriatric Depression Scale). Cognitive impairment on evaluation with the Mini Mental State Examination, after adjustment for education, was detected in 80 per cent of subjects. Functional assessment revealed impaired vision in 70 per cent, locomotion disability in 53 per cent, impaired hearing in 43 per cent and difficulty in chewing in 40 per cent of the study population. Physical and functional characteristics revealed that persons aged 80+ would have lower body weight (44.9 kg vs. 58.7 kg), lower body mass index (19.6 vs. 24.5), impaired basic ADL as assessed on the Barthel scale (17.9 vs. 19.5 on a scale of 20), cognitive impairment as assessed by the Mini Mental State Examination (13.6 vs. 18.2 on a scale of 30) and poorer quality of life on WHO quality of life scale (212 vs. 235) compared to older persons below 80 years of age.

In a study of 100 persons above 80 years of age, health and functionality issues were well reflected (Ambastha, 2014). These issues may indicate long-term care needs of an ageing population. The study found that 83 per cent of patients had two or more significant health problems and 43 per cent were unable to perform one or more ADL. Some 69 per cent were unable to perform instrumental ADL (such as housework, managing money and using a telephone). Mobility, transfer and climbing stairs were impaired in most of the subjects of the study. Dementia was detected in 13 per cent while cognitive impairment was extensively present. An attempt was made to detect any association between cognitive impairment, disability and multiple morbidity of advanced age with 37 biomarkers reported in the Newcastle 85+ study (Martin-Ruiz and others, 2011). While 15 biomarkers were associated with one of the three adverse clinical outcomes, six biomarkers (namely haemoglobin, haematocrit, albumin, grip strength, “timed up and go” score and Geriatric Depression Scale score) correlated with two adverse events while timed up and go score correlated with all the three adverse outcomes. The implications of these findings are that maintaining good nutritional status, improving physical functioning and inculcating a positive mental state would alleviate major adverse health conditions in the very old population.

6 Health care for older persons

Ageing has been most comprehensively defined by Miller (1999) as the process that converts fit adults into frailer adults with a progressively increased risk of illness, injury, and death. Health and wellbeing are integral to this definition. Older people are at far higher risk of a range of ailments: metabolic-vascular diseases; degenerative diseases of the brain, musculoskeletal system and sensory organs; cancer; chronic lung disease; and infectious diseases. These age-related conditions also lead to various disabilities and a decline in the overall functional capacity of older persons. Thus, older persons usually suffer from one or more non-communicable diseases. These include diabetes, hypertension and heart diseases, stroke, cancer and chronic lung diseases. Furthermore, mental health problems such as depression and dementia are extremely common in old age. Osteoarthritis and osteoporosis are significant causes of disability in old age. A composite description of the health status of older patients would be multi-morbidity and multi-disability. It would account for poor functionality and lack of resources to access health care.

To cope with these health challenges, older persons need easy and rapid access to quality primary and specialist health services, adequate financial resources, caregiver support and assistance in ADL. This section will address the health and long-term care issues of older persons with special reference to the very old.

Older people receive services from public and private sector health care providers, as do other age groups. The forty-second, fifty-second and sixtieth rounds of National Sample Survey showed an increasing number of older persons use private/non-governmental services over public sector health services both for hospitalized and non-hospitalized health care. High costs associated with health care increase the risk that an individual will fall below the poverty line after a hospitalization. This risk is even greater for the older population because of higher health costs related to multi-morbidity and the complexity of the health problems that are typical in old age.

The concept of a “dedicated geriatric service” was once considered a contradiction to the philosophy of integration of services, yet after much debate it has finally been accepted in view of the complexity of old age care. A busy primary care physician or specialist can rarely, if ever, carry out a detailed assessment and management planning given that time and training are limited. Demand for care is high and facilities are limited, thus older persons have to compete with the rest of the population for services. A recent ICMR research study at All India Institute of Medical Sciences gave an indication of the consequences of competition for health services. It showed that in its emergency department, only 16 per cent of older patients were hospitalized while older persons visiting the emergency with serious and unstable health conditions had a short term (one month) case fatality rate of 31 per cent (ICMR, 2012). This was possibly due to ageism and bias of choosing a younger patient over an older person with similar degree of seriousness and complexity.

In public sector health care, under NPHCE, dedicated old age care services have been proposed in district hospitals, community health centres, primary health centres and dispensaries – the most distant health outposts in the health system. During the 11th Five-Year Plan (2007-2012), 100 districts were included in the programme, and 200 more districts are planned to be included during the 12th Five-Year Plan period (2012-2017). In the tertiary health-care system, 20 medical schools are expected to establish state-of-the-art referral health facilities for older persons. In addition, two national centres of ageing are being established in New Delhi and in Chennai to develop the discipline in an Indian context with a mandate to expand post-graduate training, in-service training of health professionals, carry out research and guide government policies and programmes. A proposal for a standalone institute for research on ageing is also under consideration. These schemes have yet to be completed.

In private health care, dedicated services for older persons are rarely found. One reason could be the longer duration of hospital stay for older patients compared to younger patients. Due to increased costs in the private sector, older patients are generally discharged early before their full recovery. However, public or not-for-profit hospitals are usually under no such pressure to discharge patients quickly and thus older patients prefer such care if they can afford it.

Health care financing in India is low in terms of total public spending and as a proportion of the gross domestic product. Less than 10 per cent of the population has health security in terms of access to employer provided services or through private insurance. The private insurance industry excludes older persons from entry and restricts the upper limit of benefits to impractically low levels.

However, a health insurance policy is evolving in India. The Rashtriya Swasthya Bima Yojana (RSBY), funded by the Government of India, is a health insurance scheme for persons living below the poverty line. The Indian insurance sector has now been opened for foreign equity participation and it is expected that this will accelerate policy formulation in the health insurance sector.

1 SPECIAL INITIATIVES FOR THE 75+ POPULATION UNDER RASHTRIYA VARISHTA JAN SWASTHYA YOJANA (RVJSY)

The Government reviewed the existing NPHCE and decided to change the name of the programme officially to its Hindi version. In addition to the current activities, MoHFW adopted special initiatives to improve the quality of life of the population aged 75 years or older. Under the Rashtriya Varishta Jan Swasthya Yojana (RVJSY) the following interventions would be undertaken:

- Earmarking of 50 per cent of hospital beds created under the NPHCE (11th Plan)/ RVJSY (12th Plan) for older patients aged 75+ irrespective of the nature of illness.
- Developing a home care programme for the population aged 75+ by the regional geriatric centres for those who are physically unfit to visit a hospital or a health facility. The home care interventions would include: a visit by a team of paramedical health professionals

(one nurse and/or one physiotherapist) once in two weeks till recovery or death; provide clinical and therapeutic intervention as appropriate; provide service and train and supervise the family members in carrying out the same; provide education in health promotion and disease prevention; and facilitate referral to other professionals as and when required.

- Developing skilled labour and protocol for home care by regional geriatric centres
- Screening for early diagnosis of important non-communicable diseases at all levels of health care in this dedicated service.
- Developing a yoga therapy programme for the very old population by regional geriatric centres.
- Integrating AYUSH systems with adoption of AYUSH interventions/products.
- Vaccinating against influenza and pneumococcal pneumonia for high risk patients
- Developing a mobile telephony service to improve access to health care for those who cannot visit health facilities frequently.
- Producing health education material.
- Targeting research on health functionality issues of the very old population.

2 EDUCATION AND TRAINING OF CARE PROVIDERS

Geriatrics has a limited place in undergraduate medicine and nursing education. In undergraduate medicine curriculums one to two hours of theory classes (under medicine or community medicine) are available at some universities. It does not have the mandate from the Medical Council of India to be included in practical training or in internship training. The situation is similar for nursing education. During the 11th Five-Year Plan, under NPHCE, it was proposed to start post-graduate training for medical doctors in geriatric medicine in seven regional geriatric institutions and in-service training of health professionals including doctors in 100 district hospitals. However, it could only be started in one institution. In the period of the 12th Five-Year Plan, the scheme is expected to reach twelve additional medical schools and in-service training in many more districts and States all over India.

Currently there are four medical schools in the country with post-graduate programmes in geriatrics as follows: All India Institute of Medical Sciences, New Delhi; Madras Medical College, Chennai; Christian Medical College, Vellore; and Amrita Institute of Medical Sciences, Kochi. Each year nine post-graduates gain qualifications in Geriatric Medicine, which is too few to meet the needs of a population over older persons over 100 million strong in India.

There are several post-graduate diploma programmes in gerontology for non-health graduates, each with its own course content and emphasis. No evaluations have been carried out on the quality of these programmes. The Indira Gandhi Open University offers a post-graduate diploma through distance education for health professionals, but the Medical Council of In-

dia has not accepted this qualification because of the distance education mode of training and the acceptance of the programme has declined over the years. Various training institutions in the government, private sector and universities offer programmes for formal caregivers. While there is a need to standardize the content of these courses, they do provide a means for developing long-term care systems for older people in India.

3 HOME CARE AND LONG-TERM CARE

Older Indians prefer to live and age at home rather than in hospitals. A recent study from ICMR (2012) at the All India Institute of Medical Sciences revealed that 70 per cent of patients who died after receiving emergency care died in their home indicating the importance of developing home care services for older persons.

While health services are available in public and private health settings, the care of older persons remains a responsibility of the family. Families are resilient and can share the burden of providing for and caring for older family members. Over time, older people eventually lose the ability to survive independently due to increasingly restricted mobility, greater frailty, and a decline in physical health due to various acute or chronic disease or dementia. With the loss of independence, older persons must rely on others for basic ADL and may require assistance by some form of long-term care.

As per the sixtieth round of NSSO (2006), 8 per cent of persons aged 60+ and 27 per cent of persons aged 80+ years are homebound or bed-bound. Extrapolating these figures to the current population, some 8-10 million Indians are likely confined to their home or bed. There is a need to distinguish homebound persons from bed-bound persons. While homebound persons are likely to have restricted mobility or visual impairment, bed-bound persons are most likely to be completely or partially dependent on caregivers. The care requirement in each group differs substantially. Homebound persons require assistance in instrumental ADL while a bed-bound person requires assistance in basic ADL. However, in either case these individuals are in need of assistance and care from family members and formal caregivers.

Long-term care of bed-bound older persons is a challenging task in view of the variable length and quantity of such care. It is more so if the patient has dementia or a paralytic disease. Even a frail elderly with intact cognitive capacity may need intense care. Three issues are of great importance in long-term care: (1) assistance in ADL, especially personal hygiene; (2) treatment of chronic diseases and disabilities; and (3) acute health problems which are often unanticipated and disturb the stability of the care mechanism.

Institutional long-term care is virtually non-existent due to cultural and economic factors. In Indian society, inter-generational relationships, caring, ill health and so on are considered private issues and generally kept within the confines of the family. Thus, long-term care is mostly home-based. The family with or without paid help would provide the physical care whereas the local general practitioner is the main source of medical care at the community level. The sustainability of such a model has been a matter of debate as well as a concern in

view of rapidly changing societal norms. The economics and logistics of institutional long-term care are often unmanageable.

Therefore, the following issues related to long-term care need to be considered in the Indian context.

- The nature of care depends on whether the patient is cognitively intact or not. Dementia patients need more intensive care and are difficult to manage.
- Public and private hospitals with pressure on bed availability are ill-equipped to provide long-term care.
- Old age homes do a detailed health assessment before admitting older persons. In the event of the individual suffering from a major health problem and losing independence, many of these homes may ask the family member/ next of kin to withdraw the resident older person from their service.
- Hospices are available in India but mostly for cancer patients.
- There are few institutions that admit dependent persons requiring minimal medical care and maximal nursing care for unforeseen periods of time, except charitable organizations and nursing homes which also would prioritize those who are more critically ill and likely to face death in the foreseeable future.
- There are very few day care service providers.
- There is no financial mechanism to support long-term care in India.

Resources permitting, most families in this situation would employ a formal caregiver. Retaining such workers for long periods of time may not be feasible in view of the monotonous nature of the work. In recent years, providing caregivers who may be considered as contractual labour has turned into a commercial venture. There are institutions that train caregivers and organize their employment. The Social Defence policy of MoSJE has provided financial to institutions for the training of caregivers.

Some innovations by private sector and non-governmental operators in long-term care are worth examining. Illustrative examples are as follows: the Nightingale Medical Trust in Bengaluru offers day care, institutional care and medical assistance to homebound older persons (Nightingales Medical Trust, 2014). The Apollo Group of Hospitals offers to provide home medical care for older persons with life threatening illnesses (Apollo Hospitals, 2016). The Alzheimer's and Related Disorders Society of India (ARDSI) has four institutions for dementia patients in Kerala (ARDSI, 2015). The Max Group of Hospitals run a home health-care programme in Delhi (Max Health Care, 2016). Sama Nursing Home in Delhi also has a programme for patients requiring long-term medical and nursing interventions (Sama Hospital, 2015). These services come with a considerable cost, and with the exception of ARDSI, these services are medical-intervention oriented and in reality offer prolonged post-acute care rather than long-term care.

Home care and long-term care for the older population has attracted young entrepreneurs seeking business opportunities. Several startup companies with different business models have been launched in the last two years and many more are joining. One of the common models is to target older relatives (parents and grandparents) of non-resident Indians located in Western Europe, North America and Australia. The firm offers guaranteed round-the-clock services for all health and social problems for a fee. The emigrant family members would be assured that their relatives would be cared for. The other model, which is purely health-service oriented, provides all services available in a hospital (except invasive interventions) through their web site and “Android or Google Apps”. These services can be generic for all age groups or age specific. It is still too early to assess their impact on home care and long-term care, but the model makes sense from the long-term care point of view.

4 APPLICATION OF TECHNOLOGY IN HOME CARE/LONG-TERM CARE

All over the world information technology and electronic sensor-based technologies have made a great change in ease of home care and long-term care. The Ministry of Science and Technology has been funding innovative interventions for older persons and persons with disabilities through a scheme “Technology Initiative for Disabled and Elderly (TIDE)” for the last one decade or so. Under the scheme, information on all issues related to health and long-term care is provided through a website (www.olderagesolutions.org). In addition, the scheme has funded the development and commercialization for a variety of products to improve the quality of life of older persons.

5 ALTERNATIVE ACCOMMODATION

In India, care for older persons has always been provided mainly by the extended family while old-age homes have always been considered as alternative shelters for older persons in exceptional circumstances, nevertheless the concept has received support in most of the policies and programmes of the Government. Some old-age homes in India are supported by the Government, while others are private and not-for-profit. Older persons are also beginning to accept old age homes as an alternative if the situation requires. Although acceptance of old-age homes is increasing, significant gaps remain. For example, old-age homes are unregulated, and the Government has not set minimum standards or standard operating procedures for these facilities and services. No license is required to start an old-age home, thus it is difficult to estimate the exact number of old-age homes in the country. A report from HelpAge India (2009) placed the number of old age homes at 1,018 in 2009.

Old-age homes have generated substantial research interest among social gerontologists. In 2006-2007, the WHO India Office commissioned a study on the “evaluation of health status and health needs of old age home residents and establishment of minimum standards of health services in long stay institutions in India” which was conducted by All India Institute of Medical Sciences (WHO SEARO, 2006-2007). The study assessed the infrastructure of 22 old age homes within Delhi and the health status of 110 residents. The semi-qualitative study

made several conclusions and recommendations for improving the functioning of the old-age homes that focused on the physical space (such as ensuring the residents have adequate space and the environment is suited to the needs of older persons), management issues (such as admission criteria, scope of recreation and entertainment) and health care issues (such as access to emergency care, nutritious diet, physiotherapy, counselling and yoga).

After enacting the Maintenance and Welfare of Parents and Senior Citizens Act, 2007, and launching the Integrated Programme for Older Persons in 2015, old-age homes began to emerge as one of the key institutions of long-term care in India. This has intensified the need to establish a licensing and regulatory authority for old-age homes and similar institutions. Furthermore, minimum standards must be enforced and mechanisms for quality assurance must be put in place.

6 CIVIL SOCIETY ORGANIZATIONS

In rapidly changing Indian society, the family support system for old age care is under strain. Many older persons do not have any support system and live alone. In such a situation, support from civil society organizations and the community may be the only resource for these older persons.

Self-help groups and non-governmental organizations (NGOs) provide a large share of old age care in India. All the policies and programmes of MoSJE require the involvement of NGOs. The National Policy envisaged that there would be an apex association of older persons, which would be recognized as a legitimate partner in state interventions. The All India Senior Citizens' Confederation, and the Federation of Senior Citizens Organizations of Maharashtra are two such organizations. These organizations draw their membership from the urban middle class and articulate the viewpoints of older persons. Police and civic authorities in urban areas are now encouraging older persons to form associations and groups, in the same pattern as residents' welfare associations, for partnering in activities to promote welfare and prevent the abuse of older persons. There is now a general partnership between States and NGOs.

There are a large number of active NGOs both at the policy and planning level as well as at the grass roots implementation level working to improve the quality of life of older persons. The prominent NGOs in this regard are: HelpAge India; Age Care India; ARDSI; Dignity Foundation; Family Welfare Agency; Shree Manav Seva Sangh; Jeevan Adhar Seva Sanstha; Silver Inning Foundation; Age Well Foundation; Anugraha Foundation; and others.

HelpAge India is the most important NGO working in old age care in India. It plays a major role in advocacy and policy formulation through its presence in most parts of the country. In recent years, it has provided income generation activities and disaster rehabilitation for poorer communities. HelpAge India is also an important health-care provider to vulnerable and marginalized older persons. Some of the interventions of this organization are: mobile medical care to poor communities in rural areas and urban slums; blindness prevention by financial assistance for cataract surgery; rehabilitation services through physiotherapy units;

palliative care services in end of life situations; and help line services for all sorts of emergencies. HelpAge India provides financial assistance for building and maintaining old age homes and supports ARDSI to provide day care to patients with dementia.

ARDSI focuses on various aspects of dementia support and care. The organization was created by family members of patients with dementia and cognitive disorders as a support organization. Now it attracts volunteers and professionals from all walks of life. In recent years ARDSI has also contributed to advocacy, research, building of long-term care institutions, caregiver support, formal training of caregivers, training in continence care and support.

7 Recommendations to improve the focus on long-term care of older persons in India

1 LONG-TERM CARE AS A CENTRAL PART OF NPOP

Even though the proportion of older persons in the total population is only 8.9 per cent, this translates into more than 100 million older persons out of which more than 12 million are age 80+. Many older persons are in need of structured support for long-term care, a burden borne mainly by families. Thus, there is a need for stronger legislation, policies and programmes provided by the Government of India to expand the coverage of existing long-term care.

2 MULTI-MINISTERIAL COORDINATION

At present, the draft national health policy 2015 (para. 4.3.7.9) addresses long-term care in the following manner:

The elderly i.e. the population above 60 years comprise of 8.6 [per cent] of the population (103.8 million) and they are also a vulnerable section. Those above 75 years (20.52 million) are most vulnerable and almost 8 per cent of the elderly population is bed ridden or homebound (NSSO). India would need to develop its own cost effective and culturally appropriate approach . . . to addressing the health and care needs of the elderly. It would necessarily be a more community-centered approach where care is provided in synergy with family support, with a greater role for community level caregivers with good continuity of care with higher levels. A closely related concern is the growing need for palliative care where in life threatening illness or in end of life contexts there [are] active measures to relieve pain and suffering and provide support to the patient and the family. Increasing access to palliative care would be an important objective, and in this like for all geriatric illness, continuity of care across levels will play a major role.

While this is a very welcome inclusion, the draft policy acknowledges that long-term care also has a large community- and home-based component. There needs to be close coordination between MoHFW and MoSJE to establish effective development of an integrated system of care with attention to the public and private funded components.

Social welfare is a priority on the agendas of the States and the central Government. States with larger than average populations of older persons are advised to implement policies and programmes in line with NPOP.

3 INTEGRATING LONG-TERM CARE AS A COMPONENT OF UNIVERSAL HEALTH CARE

As India moves towards the goal of universal health coverage, which is a goal of national policies and the 2030 Agenda for Sustainable Development, there is an opportunity to integrate long-term care within it from the outset. A number of countries have addressed long-term care within universal health care systems, whether tax-funded or through social insurance. This could be replicated in India to the extent possible and allowed by resources.

4 HUMAN RESOURCES TO ADDRESS THE NEEDS OF OLDER PERSONS, PARTICULARLY LONG-TERM CARE

As long-term care needs grow with the ageing of the population, the care economy will also grow. This care economy will require more workers with specific human resource skills. In addition to an increased number of geriatricians and stronger geriatric components in medical and nursing curricula, the care economy will also require workers with skills in rehabilitation and physiotherapy, as well as social workers, counsellors, care workers and care coordinators. As the number of older persons grows, the care economy could be a significant sector of the labour force.

5 BUILDING INTERGENERATIONAL SOLIDARITY

A number of countries in the region have acknowledged the important role of intergenerational solidarity in providing long-term care and support for older persons, as reflected in the schemes and programmes they have implemented. Volunteers from youth clubs as well as “younger” older persons are engaged in providing volunteer care services at home for older persons. Intergenerational support is a key element of a viable community-based long-term care system.

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