

# Long-term care of older persons in India: Learning to deal with challenges

**Ilango Ponnuswami<sup>1</sup> and Rangasamy Rajasekaran<sup>2</sup>**

**Abstract.** It is estimated that the recent trends of an escalating older population in India will drastically increase in the next few decades. According to the United Nations Population Division and World Population Policies, persons above 60 years of age are projected to increase from eight per cent in 2010 to 19 per cent in 2050. This significant change in the older age population, along with the implications of socio-economic, cultural, financial and health issues will lead to challenges in long-term care of older persons from a gerontological social work perspective. Currently available elder care services in the country, mainly include residential care, both free and paid, day care centres, geriatric care in selected government and private hospitals and other services by non-governmental organisations. The availability and affordability of care, especially Long-Term Care, at primary, secondary and tertiary levels is an essential aspect to combat the health problems of older persons. Long-term care for the older persons which had remained primarily within the domain of families has started gaining recognition as an emerging vital area of service industry. However, there is a need to educate all stakeholders including older people themselves, caregivers and the entire society about how to deal with the enormous challenges of long-term care for the elderly. This paper supports the argument for a nationwide survey of existing care delivery systems, facilities, existing and required manpower, quality of eldercare services, regulatory and monitoring systems and legal measures. Greater awareness is required about the enormous need for long-term care, of growing professionalism of long-term care and of the innumerable socio-political and economic challenges associated with these developments.

*Keywords:* long-term care, quality of care, elder care, learning in later life.

## **Introduction**

India's population explosion has engendered alarming signs to be addressed by all relevant professionals. Areas of population pyramid shift show an increased percentage of the older age population and the epidemiological transition particularly characterized by Non-Communicable diseases. The census of India 2011, reports an Indian population of 1.21 billion

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<sup>1</sup> Department of Social Work, Bharathidasan University, Tiruchirappalli, India.  
(pon.ilango@bdu.ac.in)

<sup>2</sup> Department of Social Work, Bharathidasan University, Tiruchirappalli, India.

which comprises of nearly eight per cent of older people population who are 60 years plus making up approximately 104 million persons aged 60 years or above in India with 53 million females and 51 million males (Census of India, 2011). By 2050, the 60 years plus population is expected to increase approximately to 323 million which constitutes 19 per cent of the total population, a population larger than the entire population of USA. The 'Elderly in India 2016' report by Ministry of Statistics and Programme Implementation states that there were 103.8 million (8.6 per cent of the population) elderly persons in 2011 as compared to 76.6 million (5.6 per cent) in 2001. The report states that 71 per cent of the elderly population resides in villages while 29 per cent are in the cities. The gender ratio among elderly people was as high as 1028 women per 1,000 males in 1951; it subsequently dropped and again has reached 1033 in 2011 (Central Statistical Organisation, 2016).

**Table 1: Elderly Population (aged 60 years & above) in India (millions)**

Source	Total			Rural	Urban
	Persons	Female	Male		
Census 1961	24.7	12.4	12.4	21.0	3.7
Census 1971	32.7	15.8	16.9	27.3	5.4
Census 1981*	43.3	21.1	22.0	34.7	8.5
Census 1991**	56.7	27.3	29.4	44.3	12.4
Census 2001***	76.6	38.9	37.8	57.4	19.2
Census 2011***	103.8	52.8	51.1	73.3	30.6

\* The 1981 Census could not be held in Assam owing disturb conditions. The population figures for 1981 of Assam were worked out by 'interpolation'.

\*\* The 1991 Census was not held in Jammu & Kashmir. The population figures for 1991 of Jammu & Kashmir were worked out by interpolation.

\*\*\* The figures include the estimated population of Mao Maram, Paomata and Purul sub-divisions of Senapati district of Manipur

(Source: Ministry of Social Justice and Empowerment, Government of India, 2016).

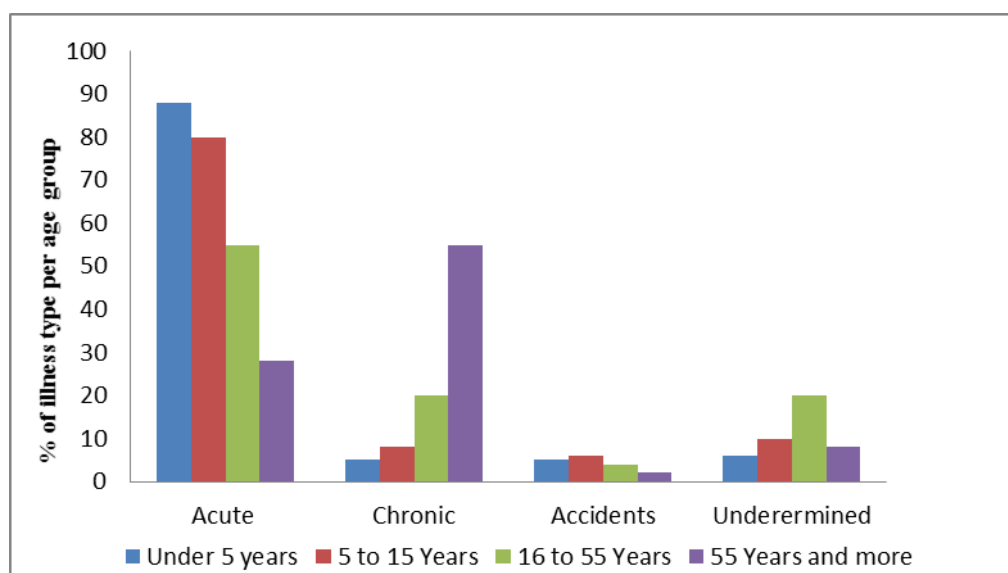
Among the older population in India, a key factor is that two thirds live in a rural setting. Half of the rural older population could be categorised as enduring poor socio-economic status; the majority of them, particularly elderly women are dependent on their families.

### Illness among older persons

The prevalence and morbidity patterns of disease among the older population show multiple ailments and a mixture of both communicable and non-communicable diseases. It also includes the impairment of sensory functions and degenerative diseases. Thus, the disease burden among our elderly population demands a review and reformation of our public health system with specific focus on long term care for an older population. Therefore, as shown in Figure 1, a basic structure of elder care needs to be strategically formulated to develop a holistic model to offer a complete package for comprehensive care for the elderly population. Integrated care should promote a proactive, preventive, curative and rehabilitative service.

An analysis made by the National Sample Survey Organisation (2006) clearly portrays the morbidity patterns of various age groups, in which the older population is subject to greater burdens of multiple ailments.

**Figure 1: Burden of illness type among Indians**



Source: Dror, Putten-Rademaker, & Koren, 2008

### Long-term care for older persons

India's changing age structure is characterized by an upward trend explained by an increased life expectancy achieved because of economic wellbeing, better medicines and medical facilities and reduction in fertility rates. The decadal growth in general population has shown a decreasing trend since 1961 and so is the growth in elderly population till 2001. This growing elderly population is becoming a major challenge for our health care delivery system. This draws attention to a wider gamut of implications both for the elderly persons and to society related to health issues, long-term care (LTC), social security measures, policy and legal initiatives, economic consequences and other areas of life. Peterson's (1980) three themes - education for older adults, public education about ageing, and the education of professionals and paraprofessionals in the field of ageing, is a useful framework to apply to the domain of LTC. Learning in later life is also considered to be one among the various emerging social innovations for better ways of living in the later life. This is evident from various cognitive learning research outputs. Most of the studies related to improving cognitive abilities affirm that learning improves brain function.

## **General understanding of the concept and definitions of long-term care**

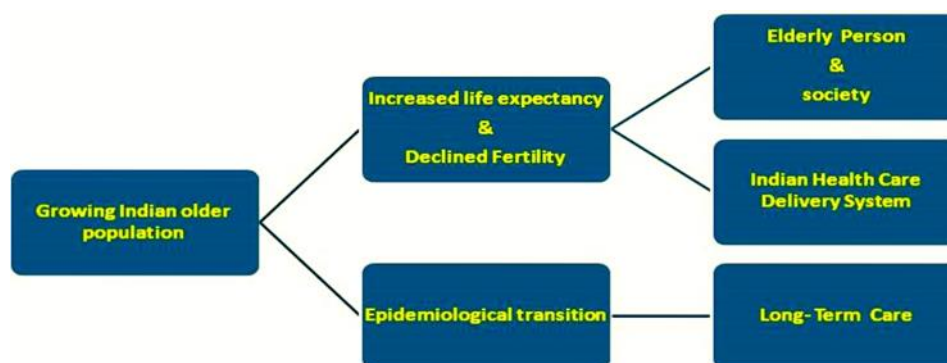
LTC service is a broad term used to describe a constellation of services, including a continuum of both medical and non-medical services designed to support the needs of older persons living with chronic health problems that affect their ability to perform everyday activities (McCall, 2001). Though the term appears to be self-explanatory, it is not very easy to arrive at a simple universal definition. The term LTC has moved its definitional framework into an operational concept. In this article we strive to incorporate all the dimensions, components and perspectives with reference to older persons only. Historically, the term “long-term care” has been used to refer to services and supports to help frail older adults and younger persons with disabilities to maintain their daily lives. Recently, alternative terms have gained wider use, including “long-term services and supports”. The needed support, depending on the degree of limitation, can be provided at home, in the community or in institutions. LTC is an integral part of health and social systems. It includes activities undertaken for people requiring care by informal caregivers (family, friends and neighbours), by formal caregivers, including professionals and auxiliaries (health, social and other workers), and by informal caregivers and volunteers. The need for LTC is influenced by changing physical, mental and/or cognitive functional capacities that are in turn, over the course of an individual’s life, influenced by the environment. Many people regain lost functional capacities, while others decline. The type of care needed and the duration of such care are thus often difficult to predict. The goals for LTC present obvious conflicts. Most apparent is the tension between safety versus choice, control, individuality and continuity of a meaningful personal life (Kane & Kane, 2001).

However, the goal of LTC is to ensure that an individual who is not fully capable of long-term self-care can maintain the best possible quality of life, with the greatest possible degree of independence, autonomy, participation, personal fulfilment and human dignity (World Health Organisation, 2000). Appropriate LTC includes respect for that individual’s values, preferences and needs; it may be home-based or institutional. People who require home-based LTC may also need other services, such as acute physical or mental health care and rehabilitation, together with financial, social and legal support. Informal caregivers should therefore have access to supportive services, including information on and assistance in securing help, training and respite (*ibid.*).

LTC services include assistance with activities of daily living [(ADLs) e.g., dressing, bathing, and toileting]; instrumental activities of daily living [(IADLs) e.g., medication management and housework]; and health maintenance tasks (Harris-Kojetin, Sengupta, Park-Lee & Valverde, 2013). LTC services assist people in maintaining or improving an optimal level of physical functioning and quality of life and can include help from other people and special equipment and assistive devices. However, to have a comprehensive understanding of LTC it is worth mentioning the definition by Pratt (2016). According to Pratt (*ibid.*), LTC can be defined as a variety of individualized and well-coordinated total care services that promote the maximum possible independence for people with functional limitation and that are provided over a period of extended time, using appropriate current technology and available

evidence-based practices, in accordance with holistic approach while maximizing both the quality of clinical care and individual's quality of life.

Figure 2: Significance of long-term care in the emerging context of India's population explosion.



### The current status, challenges and future of long-term care

In the Indian scenario, the elderly population is the fastest growing and will equal the population of United States of America by 2050. Families have been playing the major responsible role for providing necessary care. Most are able to support a continuum of basic care only. Yet, LTC for older persons in India has always been a family affair. At the policy level, the National Policy on Older Persons (Ministry of Health and Family Welfare) was adopted in the year 1999 by the Ministry of Social Justice and Empowerment (Ministry of Social Justice and Empowerment [MoSJE], 1999). Its mandate was derived from the Constitution of India. Article 41, the Directive Principles of State Policy, that stressed 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”. Hence, the National Policy on Older Persons directs 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. In spite of the policy measures, currently we do not have a sophisticated system to integrate the specialized multi-disciplinary psycho-geriatric/gerontological care. This needs to cut across or intersect with all the disciplines to incorporate all the necessary aspects of an old age home or senior citizen accommodation that provides not only shelter to older people with mental and physical disability but with required assistance in activities of daily living and intense nursing care with multi-disciplinary approach. Only a very few institutions such as the Tata Institute of Social Sciences (TISS) offer professional courses in gerontological social work in India. This lack of provision is testimony to its place as the least important and lowest priority among social work professionals in the field. It reminds us to take serious steps and measures to sort out the emerging LTC needs and the available professional human resource labour force to take up this challenge. Further, there has been limited research to address the hurdles from the gerontological social work perspective. But the majority of the older population prefers to receive informal care which is

bound by the traditional value of being looked after by their children, especially by sons rather than daughters. This caring exerts enormous amount of stress and burden on the family, relatives and caregivers. People who are primarily associated with elderly persons may experience economic constraints and burdens in their lives, irrespective of economic status. Older people living alone without any surviving caregivers also need long term care at some point of time or the other – this is currently problematic.

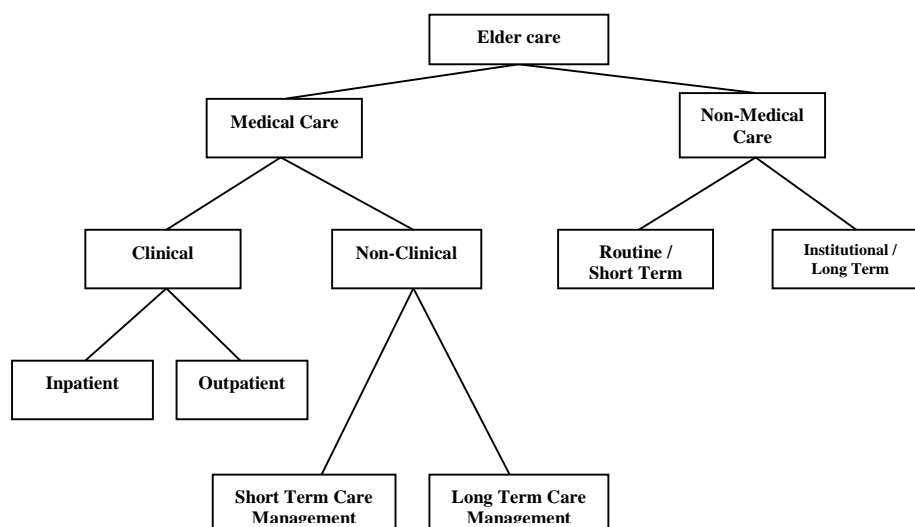
The status of a large majority of older persons is by and large ignored. So the time has come for serious thinking to create a provision of LTC funding in India. This should also include a creation of an autonomous body to pool together all the resources from diverse sources and utilise them for an older population who are desperately in need of LTC. Otherwise, they will have no other means to access and afford care by themselves. Recently, the central government launched the National Programme for Health Care of the Elderly (NPHCE) to address the health-related problems of elderly people (Government of India, 2011). This is intended to provide additional human resources and funding for home care, screening for early diagnosis, vaccinations for high-risk groups and health education for caregivers. The Vision of the NPHCE is to provide accessible, affordable and high-quality long-term, comprehensive and dedicated care services to an ageing population. It intends to create a new “architecture” for ageing; to build an enabling environment for “a society for all ages” and to promote the concept of active and healthy ageing in the health system of India (Ministry of Health and Family Welfare, 2011). The more 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.

Social welfare support provided to elderly persons includes old-age pensions, subsidized food and transport, lower income tax and higher savings interest rates. Benefits under certain schemes for the elderly, such as the old-age pension scheme and the public distribution system, are available to those below the poverty line. However, most elderly who live in rural areas are unaware of such services. Indian bureaucratic and administrative procedural systems make the elder population’s access to these benefits into a Herculean task. The system should be more transparent and made easier to access for the older population. However, in India we do not have a clear, transparent, proper and periodical monitoring of the implementation and the effectiveness of Government programmes such as the National Policy on Older Persons, NPHCE in accordance with older people’s needs and demands. Thus, the National Policy on Older Persons (MoSJE, 1999.) and National Programme for Health Care of the Elderly (2011) came into existence to address the health care of the elderly population. Their major theme exclusively focused on long term care with specific reference to older people.

Generally, home-based care is the acceptable norm in our country and it is remarkable that it meets the socio-cultural expectations of the people in line with our traditional value system.

Institutional care is neither affordable nor accessible to most of the elderly because of economic concerns and poor social security schemes or assistance for the elderly people in our country. Therefore, the home-based informal care is seen as the best choice and the easiest way to offer long term care for elderly people. Nevertheless, this over-dependence on familial care in this country has to go a long way to meet the demands for sufficient LTC services. The comprehensive policy framework that offers LTC as a fundamental right of older people has to be reframed carefully by considering the current political, socio-cultural and prevailing economic conditions. The priority for LTC services in India is still very low and continues to be the least governmental priority because most of the policy-makers think only in terms of investment and returns or equity shares of growth. Thus, the past contributions of the older population have been discounted and never thought of as an asset in terms of knowledge or expertise, wisdom and their ability to actively participate in the community as productive contributive members. However, an increasing life expectancy, an expanding middle class, technological sophistication, cultural fusions, the impact of globalization, free trade, the fast-growing workforce of women—all these factors have paved the way for greater demands for LTC. This is mainly because of the shrinking of the working population and the growing numbers in old age. So there is a mismatch in regard to the people in the work force. This is one of the major reasons why the private sector is providing more home care for the elderly. This trend of privatization is currently blooming in India, as a paid service, particularly noticed in states such as Kerala. Private home care has emerged as a timely service for those who are able to afford to hire such services. Then what about the rest of the elderly population? There are various stakeholders: the Government, NGOs, voluntary organisations, philanthropists, professionals, practice researchers and the whole society. It is urgent to develop an effective model to offer holistic and integrated approaches that include every aspect and dimension of LTC for an older population along with the considerations of availability, affordability and accessibility. It is important to maximize quality of care to emphasize elders' quality of life.

**Figure 3: Flow Chart Showing the Basic Structure of Elder Care.**



(Source: [www.deloitte.com/2014](http://www.deloitte.com/2014))

### Comprehensive long-term care: Links to later life learning in India.

Comprehensive LTC refers to the available, affordable, accessible and quality elder care which offers a constellation of medical, social and personal aspects of care including preventive, curative, restorative, legislative and rehabilitative measures. It aims to maximize the independence and dignity of older persons and to minimize the dysfunctionality; to encourage active healthy ageing by integrating appropriate and relevant application of technology; to incorporate all spheres of socio-economic, cultural-political and spiritual milieu of an Indian context, specifically to elders who need LTC. Effort is required to develop a common reserve funding structure, to merge with a suitable infrastructure to implement the social welfare programmes and policies to review the status of elderly persons on a regular periodical basis, preferably in a wider nationwide context. Equally, the demand and the challenge of LTC necessitates a strong data base and preparation of competent professional care givers along with education, training and research activities.

Figure 4: Comprehensive long-term care: Links to later life learning in India. (Authors)





According to Walter (2017), learning can improve overall mental health. While technology is becoming more sophisticated; there is technology, tailored specifically to seniors to make things easier especially for online learning. The Springfield College authorities confirms that Learning in Later Life Programme is a way to occupy the seniors to expand their knowledge on a variety of subjects while hopefully keeping their brain in good working order. Such programmes are helpful to reawaken seniors' passion for learning. It also gives them an opportunity to meet and make new friends providing a platform for older adults' socialization in such a way that their time is fruitfully occupied and their mind is reactivated. The establishment of the role of later life learning in the context of 'successful ageing' includes both sociological and educational perspectives, taking into consideration the complexity of older people's engagement in society and participation in education with regard to social use for the learning outcomes and personal growth. The positive impact of learning in later life linked to maintenance of cognitive function and the effective utilization of personal growth and self-efficacy of older adult learners have been supported by findings of many recent studies (Štatiénė, 2015). Education has been identified as one of the predictors of active engagement with life as an essential component of successful ageing; it can be helpful in terms of LTC of the older persons too (ibid.).

Regarding public education about ageing in the Indian context, it is very urgent. The main focus is to promote positive ageing and to raise the awareness of the general public to various ageing-related issues. Mass media tools including social, print and electronic media should be better utilized. The youth of the nation have to be targeted to prepare them for developing suitable knowledge of ageing to initiate innovations for better ways of living in their later years of life. From a gerontological social work perspective, knowledge building about ageing becomes essential to understand the ageing related issues of our nation. This in turn provides a rich scope for offering professional social work practice and service to LTC for older persons. Empirical research practice and academic exercises help to pave the way for innovation. Innovation can form the architecture to develop a comprehensive model that depicts a holistic and integrated approach towards learning in later life aligned with LTC of older persons. The following framework from the pioneer educational gerontologist, Peterson (1980), aims to connect LTC with learning in later life. His three foci were: Education for older adults, Public education about ageing and the Education of professionals and paraprofessionals in the field of ageing.

### **Education for older adults**

Health literacy is defined as the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways that promote and maintain good health. Being health literate involves a multitude of cognitive processes that are challenging for any one at any age. First of all, one needs an understanding of what kind of health issues he/she is struggling with, the kind of treatment given, the complexity of dealing with prescriptions and referrals, choosing appropriate health care service provider/s, dealing with costs, insurance and social security benefits, if at all there are any, while being exposed to a constant unstoppable inflow of conflicting information, ideas and suggestions from friends, relatives, magazines, internet etc. all these cognitive tasks

become increasingly difficult for older adults since they tend to process information at a slower pace, have less working memory (the ability to process multiple bits of information at a given moment), and experience difficulty in comprehending abstractions.

Age-appropriate teaching strategies for the older adult must be planned, purposeful and adapted to accommodate the special needs of the elderly person. Because of the high prevalence of inadequate health literacy in this population, all teaching should, at a minimum, include practices that have been demonstrated as effective with low literacy learners. However, specific strategies that adhere to the principles of geragogy should also be an integral part of every professional's teaching repertoire to promote health literacy in this special population. Geragogy is a model of teaching older adults that is based on the work of Knowles' Adult Learning Theory (Hayes, 2005). Teaching interventions within this framework are designed to compensate for the cognitive, sensory and physical effects of ageing, and to promote independence and achievement of the older learner's full potential. Age-appropriate teaching strategies that are based on the principles of geragogy include approaching the older adult in a way that communicates respect, acceptance and support, (Cornett, 2006). Creating a learning environment in which the older person can comfortably acknowledge what is and is not understood, scheduling several brief teaching sessions in mid-morning when energy levels are high, allowing additional time for the older adult to process new information by pausing after presenting each new concept or bit of information, helping the older adult focus, speaking slowly and clearly, providing written materials, using visuals and making repetitions wherever necessary.

### **Public education about ageing**

In India, probably like many other countries, there is a serious lack of understanding about ageing and its associated problems among the general public. There is also cultural stereotyping of ageing as an inevitable stage of life marked by sufferings. However, owing to the enormous diversity in the country, even public perceptions concerning old age and their ways of dealing with the older people and their problems are also quite diverse. Besides, the media have been promoting a very typical stereotypical image of ageing as a stage of life marked by illness, dependency and a lack of self-worth and respect from the society. On the other hand, of late, the rapid increase in the population of older people has triggered a sudden upsurge of commercial interest concerning LTC of the elderly who are seen as a potential growing market opportunity. Against this complex backdrop, we also have the widespread lack of awareness regarding ageing among the vast majority of rural people. The governments, both state and central, have undertaken enormous awareness campaigns concerning problems of children, women and even youth to some extent, but have not carried out any kind of public awareness campaigns regarding the situation, problems and rights of the older people. The NGOs working in the field of ageing in India have been involved in effective public awareness campaigns on ageing in isolated pockets of the country. However, their reach is very limited. The national level NGO HelpAge India has been doing exemplary work in this regard but even their reach is quite limited and restricted to their partner organizations.

When we understand the situation concerning public awareness of ageing in India, it is quite easy to understand how the specialized area of LTC of older people might be addressed in the country. The LTC of elderly predominantly remains as an area of expertise for a handful of corporate houses and some large NGOs. The vast majority of people in India feel that the responsibility of providing LTC to the elderly is primarily the responsibility of their families and fail to understand the responsibility of the government sector. Hence, there is a need to create awareness among the public concerning the need for LTC, its scientific aspects, the specific requirements and the responsibility of the state and other stakeholders in the matters relating to LTC of older people.

### **Education of professionals and para professionals**

Provision of formal LTC to the population requires an adequate, skilled and diverse workforce. Professionals-including physicians, social workers, therapists (physical, occupational, and speech), mental health providers, dietitians, pharmacists, podiatrists and dentists-provide many different kinds of essential services to at least a subset of those using LTC. Non-professionals, who provide the majority of personal care services, such as assistance with eating or bathing, have a major impact on both the health status and the quality of life of long-term care users. In addition to direct care providers (or caregivers), administrative, food service workers, housekeeping staff, and other personnel play essential roles.

The education and training requirements for formal LTC providers and informal care providers are clearly important for ensuring high quality of care. The training should be directed to all professionals, not only nurses but also therapists, social workers as well as other caregiving personnel. Providers themselves are principally responsible for ensuring adequate training and competency of their workforce. As a general principle, the workforce should have the education, training and commitment to provide care that is consistent with the needs of the individuals being served.

Emphasis in the future should be placed not only on the content of training programmes but more importantly on competency testing of skills for both formal and informal care providers. Training programmes should be tailored to provide appropriate care to special population groups such as individuals with developmental disabilities or AIDS, children and other groups. Providers also have to be trained and be competent in providing care that uses the most current clinical practice standards for different conditions such as dementia, diabetes, traumatic brain injury and others. Professionals have to be competent in care assessment and planning, supervision of care workers, coordination of care services, and client- and family-centered care. Increased attention to the education and training of the LTC workforce is needed to ensure that staff have both the knowledge and the skills to provide high quality of care, with particular attention to client-directed care and the needs of special population groups.

## Final comments

The present scenario of availability and utility of facilities for LTC of older persons is highly deplorable considering the rapidly growing older population in the context of declining family care. LTC should be considered as a priority by the government. The NPHCE should include a special infrastructure to deliver and monitor LTC. Systematic development of an exclusive funding structure that is proportionate with the growing older population becomes essential. It should include effective and active coordination and integration of multi-ministerial teams to carry out the policies and programmes for older persons as an urgent priority. However, effort should be made to see that such a formal structure does not weaken the intergenerational solidarity in the Indian society. Gerontological social work perspectives need to be integrated with training and development of skilled and competent manpower to effectively address the needs and demands of older population with a specific focus on LTC. Knowledge building process about ageing for the younger generation should be given prime importance. Government policies need to focus on legislative measures, social welfare programmes, non-governmental agencies' involvement, corporate and community initiatives to evolve a universal plan of action for learning in later life and LTC for older persons.

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