

Comments of NHRC, India on the Questionnaire for the focus areas of the IX Session of the Open Ended Working Group on Ageing.

Long-term Care and palliative care

- 1) Long term care for older persons as such is not defined in the Indian laws and it has always been a family affair. The legal framework for the rights of the persons with disability includes provisions of constitution. The various Articles in Part - III and Part IV of the Indian Constitution, have direct or indirect bearing on social security measures and also on promoting welfare. Under Personal laws of Hindus and Muslims there is a strict provision for maintenance of the old age parents and grandparents. There is no personal law for Christians and Parsis for providing maintenance to the aged parents. If the parents want to seek maintenance from their children, they can apply through the Criminal Procedure Code to seek maintenance. Under Section 125 of Criminal Procedure Code, the elder parents can claim maintenance from their children. For the care and protection of the elderly Indian government enacted the Maintenance and Welfare of Parents Act, 2007. This act aims at providing maintenance to senior citizens in the country. It is an Act to provide for more effective provisions for the maintenance and welfare of parents and senior citizens guaranteed and recognized under the Constitution and for matters connected therewith or incidental thereto.
- 2) At the policy framework 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. National Program for Health Care of the Elderly came in the year 2011 and it covered various benefits to be claimed by the elderly.
- 3) The types of support and services covered under the policies and legal framework in India includes medical care, continuum of medical, Personal and social support services, day care services, health promotion, preventive services, diagnosis and management of geriatric medical problems, Rehabilitative services and home based care as needed.
- 4) **Specific Challenges faced by older persons in accessing long term care are:**
 - **Health issues:** 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. 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.

- **Poverty:** as it results in homelessness, malnutrition, unattended chronic diseases, lack of access to safe drinking water and sanitation, unaffordable medicines and treatments and income insecurity
- **Violence and abuse:** physical, emotional, mental, sexual and financial exploitation.
- **Lack of specific measures and services:** being old, they do not have enough resources and facilities to cope with the growing demand, particularly for specialized services such as residential centers, and long term home-care programmes or geriatric services, necessary to guarantee human rights of older persons.
- **Discrimination:** in all aspects of life including employment and access to housing, health care, and social services.
- There are very few day care service providers.
- There is no financial mechanism to support long-term care in India.

5) **Following measures can be taken to ensure high quality and sustainable long-term care systems for older persons:**

- Integrating long-term care as a component of universal health care.
- Human resources to address the needs of older persons, particularly long-term care.
- A UN Special Rapporteur on the Rights of Older Persons should be appointed to examine and report on the human rights situation of older persons throughout the world as well as to draw attention to the issue.
- The process of discussing the human rights situation of older people must take place on local, regional and international levels. It is essential that older persons themselves have a central role.
- 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 long term care of the older persons.
- 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 Long Term Care for older persons.

6) The NHRC–India has a **Core Group on Protection and Welfare of the Elderly Persons**. Based on the suggestions of the Core Group, Chairperson, NHRC India has sent letters to the Chief Ministers of all States and UTs and the concerned Union Ministry **recommending** the following:

- (i) The National Programme for Health Care for Elderly has been launched in 2010. Presently the plan covers only 418 districts or 60 per cent of the total districts in the country however even in these 418 districts the plan is yet not fully

implemented. It is suggested that the Ministry of Health and Family Welfare may ensure immediate implementation of the plan in all the 418 districts. Further, the programme may also be extended to all the districts of the country by the end of FY 2020-21.

- (ii) Government may also get a third party audit conducted of the implementation of National Programme for the Health Care of Elderly in order to assess the service delivery of the plan and also as to whether the funds for the Programme are being properly utilized.
- (iii) Since a very large number of elderly persons suffer from mental problems there is an urgent need for separate Centres/Institutes for Geriatric Mental Health care in various parts of the country. The M/o Health and Family Welfare may consider financing the setting up of one such Institute of Mental Health Care for Geriatrics in each Region of the country by the host State Government utilizing the funds received from the GOI under National Mental Health Programme (NMHP) or otherwise.
- (iv) It is recommended that the Ministry of Social Justice and Empowerment may also lay down detailed common minimum standards for the buildings of Old Age Homes and adherence to these common minimum standards may be made mandatory when old age homes are constructed. Similarly, the Ministry may also consider laying down common minimum standards for the services which should be available in an old age home.
- (v) The coverage of the old age pension is limited to Below Poverty Line (BPL) families and it is not reaching every elderly person. It is suggested that the Ministry of Social Justice and Empowerment may make Old age pension universal for all those who are non-tax payers and do not receive pension from any source. Further, the Ministry of Social Justice and Empowerment should enhance the old age pension making the pension amount reasonable. It is suggested that the old age pension may be raised to Rs. 2500 p.m.
- (vi) Construction of old age homes in all the districts of the country deserves to be taken up on top priority. GOI may consider part/fully financing the scheme for construction of old age homes in the districts of the country by the various state governments.
- (vii) Regular auditing and monitoring of the functioning of old age homes may be got done by third parties i.e. there should be an independent audit of the functioning of old age homes.
- (viii) Since a very large number of elderly persons suffer from mental problems, separate Centres/Institutes for Geriatric Mental Health care may be established in each Region of the country.

7) Rights essential for the enjoyment of the right to long term care for older persons:

- Right to social security
- Right to health
- Right to property and inheritance
- Right to freedom from discrimination
- Right to self-fulfillment
- Right to access to social and legal services

- 8) **The palliative care for older persons is not defined in legal and policy framework but mentioned in the National Policy on Senior Citizens 2011 as:**
- The policy will strive to create a tiered national level geriatric healthcare with focus on outpatient day care, palliative care, rehabilitation care and respite care.
 - Hospices and palliative care of the terminally ill would be provided in all district hospitals and the Indian protocol on palliative care will be disseminated to all doctors and medical professionals.
- 9) **Needs and challenges faced by older persons regarding end of life care:**
- Needs of the patient with dementia are under acknowledged and under treated.
 - Training and education in need in the staff training who are caring for older persons.
 - Pain Control: It will require training and awareness raising among health professionals and advocacy to change laws to make effective pain relief.
 - Development of national policy for the end of life care of the older persons.
 - Psychological and spiritual support to the older persons.
- 10) Studies done by Himanshu Sharma, Vankar Jagdish, Prabhakaran Anusha, and Sharma Bharti by the title End-of-life care: Indian perspective -1 and Guidelines for end-of-life and palliative care in Indian intensive care units: ISCCM consensus Ethical Position Statement- 2.

Note: 1 : <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3705699/>
National Center for Biotechnology Information

2 : <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3506078>

- 11) **There are policies specifically for the welfare and care of the older persons i.e. National Policy on Senior Citizens 2011**, The National Programme for the Health Care for the Elderly and other benefits are also given to the elderly as health insurance, tax benefits, pension schemes, travel allowances and opening of geriatric department in every state. Upto 70% of the work has been done by the Government of India by initiation of the policies, programmes and all benefits given to the elderly rest is depends upon the support of the family members and trained staff of the hospital.
- 12) **According to the National Policy on Senior Citizens 2011** other support services available to the older persons as twice in a year the PHC nurse or the ASHA will conduct a special screening of the 80+ population of villages and urban areas and public/private partnerships will be worked out for geriatric and palliative healthcare in rural areas recognizing the increase of non-communicable diseases (NCD) in the country and Hospices and palliative care of the terminally ill would be provided in all district hospitals and the Indian protocol on palliative care will be disseminated to all doctors and medical professionals.
- 13) **Following are the good practices available in terms long term care and palliative care:**

- Regional geriatric centers (RGC) in eight Regional Medical Institutions by setting up RGCs with a dedicated geriatric out-patient department (OPD) and 30-bedded geriatric ward for management of specific diseases of the elderly, training of health personnel in geriatric health-care and conducting research.
- Post-graduates in geriatric medicine (16) from the eight regional medical institutions
- Video Conferencing Units in the 8 Regional Medical Institutions to be utilized for capacity building and mentoring.
- District geriatric units with dedicated geriatric OPD and 10-bedded geriatric ward in 80-100 District Hospitals.
- Geriatric clinics/rehabilitation units set up for domiciliary visits in community/primary health centers in the selected districts
- Sub-centers provided with equipment for community outreach services
- Training of Human Resources in the Public Health-Care System in geriatric care.

14) As per the human rights perspective, 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 long term care of the elderly. 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 long term and palliative care for older persons.

Autonomy and Independence

1) Older people in India are the most heterogeneous group of all age groups and aging can take many forms: some older people may be healthy and live independently and independently, while others may be in need of care. assistance for several reasons, such as loss of mobility, or being dependent on care for example because of a chronic or degenerative disease, among others. Several mechanisms promote the autonomy of older people in India as mention below:

a) Maintenance and Welfare of Parents and Senior Citizens Act, 2007

Chapter III: Establishment of Old age

Section 19. Establishment of old age homes.-

1. The State Government may establish and maintain such number of old age homes at accessible places, as it may deem necessary, in a phased manner, beginning with at least one in each district to accommodate in such homes a minimum of one hundred fifty senior citizens who are indigent.
2. The State Government may, prescribe a scheme for management of old age homes, including the standards and various types of services to be provided by them which are necessary for medical care and means of entertainment to the inhabitants of such homes.

Explanation.- For the purposes of this section, “indigent” means any senior citizen who is not having sufficient means, as determined by the State Government, from time to time, to maintain himself.

b) Chapter II: Nature of Limited Liability Partnership

4. Maintenance of parents and senior citizens.-

1. A senior citizen including parent who is unable to maintain himself from his own earning or out of the property owned by him, shall be entitled to make an application under section 5 in case of—
 - i) parent or grand-parent, against one or more of his children not being a minor;
 - ii) a childless senior citizen, against such of his relative referred to in clause (g) of section 2.
2. The obligation of the children or relative, as the case may be, to maintain a senior citizen extends to the needs of such citizen so that senior citizen may lead a normal life.
3. The obligation of the children to maintain his or her parent extends to the needs of such parent either father or mother or both, as the case may be, so that such parent may lead a normal life.

4. Any person being a relative of a senior citizen and having sufficient means shall maintain such senior citizen provided he is in possession of the property of such senior citizen or he would inherit the property of such senior citizen:

Provided that where more than one relatives are entitled to inherit the property of a senior citizen, the maintenance shall be payable by such relative in the proportion in which they would inherit his property.

c) Chapter IV: Provisions for Medical Care of Senior Citizen

20. Medical support for senior citizen.-

The State Government shall ensure that, -

- i. the Government hospitals or hospitals funded fully or partially by the Government shall provide beds for all senior citizens as far as possible;
- ii. Separate queues be arranged for senior citizens;
- iii. facility for treatment of chronic, terminal and degenerative diseases is expanded for senior citizens;
- iv. Research activities for chronic elderly diseases and ageing is expanded;
- v. There are earmarked facilities for geriatric patients in every district hospital duly headed by a medical officer with experience in geriatric care.

2) The rights which are essential for the enjoyment of the right to autonomy and independence by older persons are –

- a) Right to Housing in Old Age.
- b) Right to Economic Security.
- c) Right to Sanitation and hygiene.
- d) Right to Food in Old Age
- e) Right of disabled Old persons.
- f) Right against Elder Abuse.
- g) Right to Vote.

3) The Key Issues and challenges faced by older persons regarding autonomy and independence –

- a) **Failing Health**- The aging process is synonymous with failing health. While death in young people India is mainly due to infectious diseases, older people are mostly vulnerable to non-communicable diseases.
- b) **Economic insecurity** - The problem of economic insecurity is faced by the elderly when they are unable to sustain themselves financially. Many older persons either lack the opportunity and/or the capacity to be as productive as they were. Increasing competition from younger people, individual, family and societal mind sets, chronic malnutrition and slowing physical and mental faculties, limited access to resources and lack of awareness of their rights

and entitlements play significant roles in reducing the ability of the elderly to remain financially productive, and thereby, independent.

- c) **Isolation**- Isolation, or a deep sense of loneliness, is a common complaint of many elderly is the feeling of being isolated. While there are a few who impose it on themselves, isolation is most often imposed purposefully or inadvertently by the families and/or communities where the elderly live. Isolation is a terrible feeling that, if not addressed, leads to tragic deterioration of the quality of life.
- d) **Neglect**- The elderly, especially those who are weak and/or dependent, require physical, mental and emotional care and support. When this is not provided, they suffer from neglect, a problem that occurs when a person is left uncared for and that is often linked with isolation.
- e) **Abuse**- The elderly are highly vulnerable to abuse, where a person is willfully or inadvertently harmed, usually by someone who is part of the family or otherwise close to the victim. It is very important that steps be taken, whenever and wherever possible, to protect people from abuse.
- f) **Lack of Preparedness for Old Age**- A large number of people enter 'old age' with little, or no, awareness of what this entails. While demographically, we acknowledge that a person is considered to be old when (s)he attains the age of 60 years, there is no such clear indicator available to the individual. For each person, there is a turning point after which (s)he feels physiologically or functionally 'old'. This event could take place at any age before or after the age of 60.

Studies on Older Persons

- a) **Elderly in India- Profile and Programmes 2016 by Ministry of Statistics and Programme Implementation** - For comprehensive development, planning and monitoring of various development programmes for the elderly in the country, the importance of having an up-to-date database can be found in the present study. The study is concerted efforts made by Central Statistics Office (CSO) to present all the relevant data for elderly at one place.
- b) **Situation Analysis Of The Elderly in India June 2011 by Ministry of Statistics and Programme Implementation** – The study addressed the various socio economic fronts including pension outlays, health care expenditures, fiscal discipline, savings levels etc. of elderly in India. The study also addressed the multiple medical and psychological problems faced by the elderly people in India.
- c) **Ageing Population in India: Select Economic Issues by IIM Bangalore, December 2013 by Charan Singh** - The study recommended a number of initiatives that can be undertaken in time for the care of the elderly by the government, so that addressing financial burden can be better planned and addressed. The paper, more importantly, suggests that financial literacy and a variety of financial instruments should be considered by the government to address the issues of ageing population in India.
- d) **Know Your Rights, Elderly People by The National Human Rights Commission, India, 2011**- In recent years, there have been significant advocacy efforts calling for enhanced action on the human rights of older

persons. The compilation by NHRC regarding the rights of elderly people is a step forward towards that direction.

4) Steps which have been taken to ensure older persons, enjoyment of their right to autonomy and independence –

a) Privileges and Benefits

(A) Economic Security

- (i) Indira Gandhi National Old Age Pension Scheme
- (ii) Social Pensions in Various States and Union Territories in India
- (iii) The Unorganized Worker's Social Security Act, 2008
- (iv) Post Retirement Benefits For Employees of Central Government
- (v) National Pension System
- (vi) Atal Pension Yojana Scheme
- (vii) Old Age Allowance in Punjab

b) Insurance Schemes: Health And Pension

- (i) Rashtriya Swasthya Bima Yojana
- (ii) Varishtha Medclaim for Senior Citizens
- (iii) Group Medical Insurance Scheme
- (iv) Jan Arogya Bima Policy
- (v) Senior Citizen Medclaim Policy
- (vi) LIC Jeevan Akshay
- (vii) ICICI Lombard Overseas Travel Insurance
- (viii) ING Golden Years Retirement Policy
- (ix) Smart Invest Pension Plan
- (x) Aviva New Pension Elite
- (xi) New Jeevan Dhara-I

c) Reverse Mortgage

- (i) Indusind Bank Ltd Senior Citizens Scheme
- (ii) Citibank Senior Citizen Account
- (iii) Allahabad Bank Personal Loan Scheme for Pensioners
- (iv) Senior Citizen Savings Scheme (SCSS) Account
- (v) ICICI Bank-Senior Citizen Savings Account
- (vi) PNB Personal Loan Scheme for Pensioners
- (vii) Life Plus Senior Citizens Account
- (viii) Senior Citizen Account- IDBI Bank Senior Citizen Accounts
- (ix) ICICI Bank Senior Citizens Savings Scheme

d) Health Security

- (i) Health Services to Central Government Employees
- (ii) E.S.I.
- (iii) Health Care Services in Various States
- (iv) National Programme for Health Care of the Elderly (NPHCE)

e) **Concessions in Travel**

- (i) By Road
- (ii) By Air

f) **Old Age Homes in India**

5) Mechanisms necessary for older persons to seek redress for the denial of autonomy and independence

- a) Organise large consultations on the situation of older persons' rights and how to better protect them, including the need or not for a comprehensive mechanism, inviting older persons' representatives and other civil society actors, such as equality bodies, NHRIs. Legal experts and so on.
- b) Create synergies with relevant initiatives at the national and regional levels and draft action plan for the protection and promotion of rights of elderly people.
- c) Adopt a human rights approach in all policies targeting older persons.
- d) Support and fund research on ageing, including the legal definition of old age, how soft law is implemented and taken into account in national case-law, the social and economic impact of a new instrument, etc., which can help deepen understanding and define substantively the rights of older persons.
- e) Acknowledge the human rights of older persons and the necessity to protect these at the UN level.
- f) The adoption of a convention on the Rights of Older People would significantly enhance the ability of our government and related helping organisations to address the needs of older adults.

6) The responsibilities of other, non-State, actors in respecting and protecting the right to autonomy and independence of older persons

The role of Civil society's functional contribution to respect and protect the right to autonomy and independence could be:

- a) Watchdog — against violation of human rights and governing deficiencies in protecting elderly rights in India.
 - b) Advocate — of the rights of older persons and provide them legal aid in order to protect the rights guaranteed under the Constitutions and Acts.
 - c) Agitator — on behalf of the older citizens pertaining to the medical, property and other rights.
 - d) Educator — of citizens on the rights, entitlements and responsibilities of older persons and the government about the pulse of the older people.
 - e) Service provider — to areas and people not reached by official efforts or as government's agent, the non-state actors shall step and provide service to old age persons.
 - f) Mobiliser — of public opinion for or against a programme or policy which is affecting the rights of the older persons in India.
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