

DRAFT

ARDSI's Dementia Country Strategy for India

**SUPPORTED BY ALZHIEMER'S AND RELATED DISORDERS SOCIETY
OF INDIA (ARDSI)**

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Abbreviations

ARDSI- Alzheimer's and Related Disorders Society of India

NHP-National health policy

NPOP- National Policy for Older Persons

NCOP-National Council for Older Persons

GOI-Government of India

NOAP-National Old Age Pension

IPOP-Integrated Programme for Older Persons

NOAP-National Old Age Pension

NPHCE-National Programme for Health Care of Elderly

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1 Introduction and Background

India is witnessing improved life expectancy and one of the important growing public health challenges is to ensure graceful ageing. However, India is rapidly seeing a surge in number of people affected on the old age related problems such as Alzheimer's and related disorders, including rise in cases of young early onset Dementia. In 2015, an estimated 4.41 million people living with dementia in India. This number is projected to double by 2030, to 7.6 million and 14.3 million by 2050 with a huge cost to the community (ARDSI, 2010b). Low and middle-income people are likely to be hardest hit as the dementia-related costs are growing enormously. Further, it has been estimated that the dementia care services will soar to 0.5% of GDP in India (ARDSI, 2010b).

In India, the elderly population comprises of 8.9 % (110 million) of the total population (ARDSI, 2010b) and a majority of them are vulnerable for dementia and other chronic conditions (GOI, 2015). A significant proportion of the elderly population is bedridden (National Sample Survey Office, 2016). Therefore, there is a need for India specific, culturally acceptable, cost-effective approaches to address the Alzheimer's and related disorders. This policy direction is to facilitate necessary of dementia friendly community centres that allow synergy of family and community support system with appropriate continuity of medical care services at all levels (GOI, 2015). Strengthening preventive measures; risk reduction, early detection; access to best medical care; improving social support services and; research in dementia would be an important overarching objective of this policy document. Furthermore, this document sets the clear direction to national dementia strategic plan as elucidated in Annexure-1.

2 Policy context

2.1 Why we need a national policy and strategic plan for India

There is a significant improvement in longevity of people of India since few decades. The growing longevity could be ascribed to improved immunization, healthcare services, nutrition and better housing. However, there is a simultaneous increase in age-related health problems and dementia happens one of the most serious conditions. Furthermore, dementia likely to have devastating effects on affected persons, family members in specific and community in general. Dementia comprises several related disorders such as; vascular dementia; Alzheimer's disease; frontotemporal dementia or mixed medical conditions dementia. Here onwards this document mentions the overarching term 'dementia' for ease of understanding and communication in this 'national dementia policy and strategic plan' document.

Dementia is a serious, chronic brain disease, usually progressive in nature with deterioration in memory, orientation, and comprehension. Dementia affects an average of around 4-5 per 100 people before the age of 65. The number doubles every five years after 65 and it is one of the common cause of disability among old age persons (ARDSI, 2010a). Recent estimates show that the number of dementia affected people in India is growing enormously as illustrated in *table 1*. However, the major challenge is to strengthen the overall quality of life of people with dementia.

Furthermore, several factors that determine the trajectory of quality of services towards dementia and old age requirement, this includes, attitude towards ageing people; ability to detect and treat dementia and related disorders; prevailing pessimism towards dementia affected people; lack of coherent plans to strengthen dementia services at national and state level. The dementia is serious brain disorders that continue to exist and grow in our society. Therefore, it is crucial to have significant efforts from a public health point of view by strengthening prevention, early detection and quality treatment services.

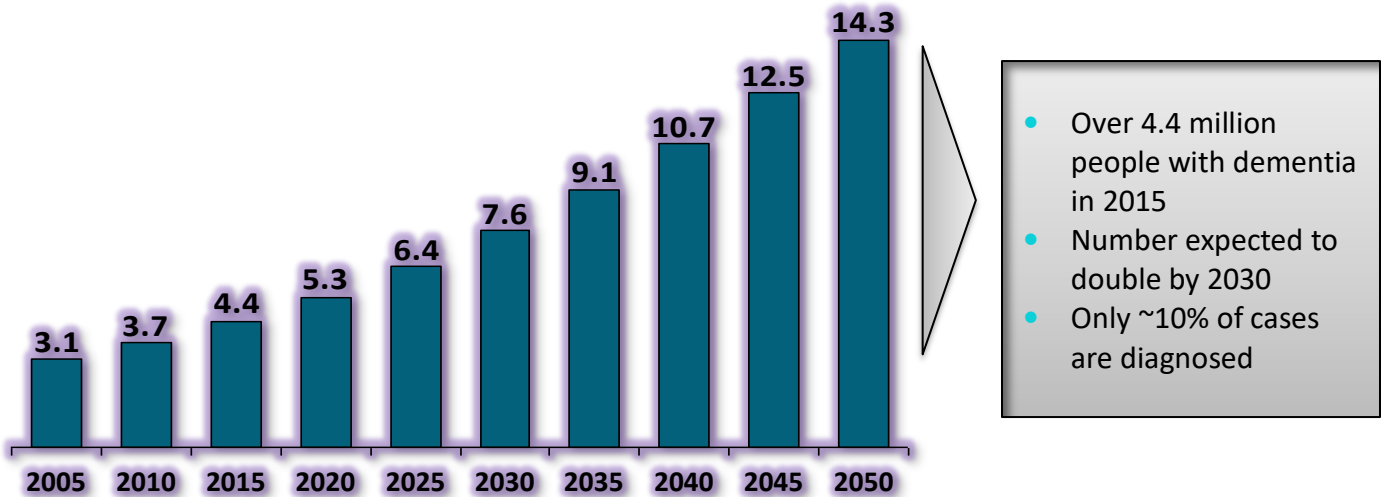
Thus, observing the growing numbers of dementia and estimated numbers increasing in the next few decades. This is further accentuated with significant implications for personal health, clinical outcomes, social and economic challenges (Connell, 2012). The government of India committed to strengthening dementia and old age-related problems through relevant policies and national strategic plan. Such comprehensive document could be guiding post to adequately fund and optimally resourced. Therefore, the national dementia policy and strategy should systemically address dementia at every level and all stages. This includes prevention/risk reduction, early detection, adequate support services, palliative care and research in dementia-related issues. This document sets a clear direction, from a policy maker's point of view, the policy context in connection with increasing burden of dementia and related disorders as well as to signpost the ways to strengthen national strategy plan.

Table 1 State wise estimated numbers with dementia 65-80years (Source: Dementia report India 2010)

States	Year	Estimated numbers with dementia 65-80years+	Percentage of change in dementia's compared to 2006
Jammu& Kashmir	2006	22000	
	2011	30000	35%
	2016	37000	68%
	2021	46000	108%
	2026	57000	158%
Himachal Prade	2006	21000	
	2011	26000	23%
	2016	31000	42%
	2021	36000	65%
	2026	42000	94%
Punjab	2006	86000	
	2011	107000	24%
	2016	124000	43%
	2021	143000	65%
	2026	167000	93%
Uttarnchal	2006	22000	
	2011	29000	31%
	2016	35000	61%
	2021	42000	93%
	2026	50000	130%
Haryana	2006	56000	
	2011	74000	31%
	2016	88000	56%
	2021	103000	83%
	2026	123000	118%
Delhi	2006	26000	
	2011	36000	39%
	2016	48000	84%
	2021	63000	144%
	2026	85000	226%
Rajasthan	2006	112000	
	2011	164000	46%
	2016	209000	86%
	2021	257000	128%
	2026	311000	176%
Uttar Pradesh	2006	310000	
	2011	456000	47%
	2016	580000	87%
	2021	711000	129%
	2026	861000	177%
Bihar	2006	134000	
	2011	205000	53%
	2016	277000	106%
	2021	350000	161%
	2026	431000	221%
Assam	2006	41000	
	2011	60000	40%
	2016	76000	78%
	2021	96000	124%
	2026	121000	183%

State	Year	Estimated numbers with dementia 65-80yrs+	Percentage of change in dementia compared to 2006
West Bengal	2006	182000	
	2011	244000	33%
	2016	303000	66%
	2021	374000	104%
	2026	464000	154%
Jharkhand	2006	38000	
	2011	59000	56%
	2016	83000	117%
	2021	109000	184%
	2026	139000	262%
Orissa	2006	95000	
	2011	123000	28%
	2016	148000	55%
	2021	178000	87%
	2026	215000	125%
Chhattisgarh	2006	40000	
	2011	57000	44%
	2016	73000	84%
	2021	91000	128%
	2026	111000	180%
Madhya Pradesh	2006	115000	
	2011	164000	42%
	2016	205000	78%
	2021	250000	116%
	2026	303000	163%
Gujrat	2006	123000	
	2011	163000	32%
	2016	204000	66%
	2021	256000	107%
	2026	320000	159%
Maharashtra	2006	277000	
	2011	360000	29%
	2016	429000	54%
	2021	501000	80%
	2026	591000	112%
Andhra Pradesh	2006	183000	
	2011	245000	34%
	2016	307000	68%
	2021	378000	106%
	2026	461000	151%
Karnataka	2006	139000	
	2011	183000	31%
	2016	225000	61%
	2021	276000	98%
	2026	338000	142%
Kerala	2006	134000	
	2011	158000	17%
	2016	182000	35%
	2021	212000	58%
	2026	251000	87%
Tamil Nadu	2006	209000	
	2011	255000	22%
	2016	305000	45%
	2021	366000	75%
	2026	439000	110%
North East states	2006	24000	
	2011	34000	37%
	2016	42000	73%
	2021	49000	97%
	2026	67000	173%

Figure 1 Number of People with Dementia in India (in millions) (Source: ARDSI 2018)



3 Dementia and economic cost and consequences

It is an established fact that there are huge human cost and their family carers living with dementia and it is crucial to recognize that PwD carers also to be accounted for economic cost and its consequences.

As shown in the above figure 1, in India there are 44 lakh people living with dementia. As the population of India ages, dementia will increasingly be a major public health and social problem as the dementia number rising to 76 lakhs by 2030 and around one crore forty-three lakh (14.3 million) by 2050. The cost to healthcare and cost to family-society is likely to rise dramatically. There is a necessity of consideration of the cost associated with dementia-related healthcare services and social services and this demands the potential systematic regular allocation of resources through an appropriate redesign. Additionally, there is need of serious attempt to prevent or delay of onset of dementia and is likely to have an impact on a number of people affected and services that are required. Furthermore, delay of onset of dementia could contribute to additional costs that could accrue with growing prevalence of the dementia condition.

The Cost of Dementia Care

The dementia care related costs likely to be substantial to public health and to those who are living with dementia. The estimated annual average cost of dementia care is illustrated in table-2.

Table 2 Dementia care cost estimation India-2010 (Source;(ARDSI, 2010a))

Dementia care costs	In INR	
1. Total cost estimated	147 billion	Estimated cost assuming 3.7 million PwD in India
2. Informal care/domiciliary costs	88.9 billion	Estimated cost assuming 3.7 million PwD in India
3. Medical costs	46.8 billion	Estimated cost assuming 3.7 million PwD in India
4. <u>Cost per person</u> with dementia/year	96850 INR	Assuming 1.6 hrs care per day
4.1 <u>Cost per person</u> with dementia/year	141386 INR	Assuming 3.7 hrs care per day
4.2 <u>Cost per person</u> with dementia/year	263,350 INR	Assuming 7.4 hrs care per day

The annual average cost of care for PwD range from 96850 INR to 263350 INR. The average cost of care depends on the severity of dementia. The cost includes formal and informal care and is likely to increase every year. The minimum average cost per year estimated is 42585 INR. With the reasonable estimate, India expected to spend at least 15000-16000 crores per year (ARDSI, 2010a). Since the number of PwD expected to double by 2030, the immediate concern is a consequence of cost of care that likely to multiply. Currently, the major burden of the cost of care is borne by family members of dementia affected persons. Observing the growing number of PwD and current growing awareness towards dementia care, there is a need to increase financial resources coupled with appropriate human resource development.

Dementia and health insurance

More than a quarter of PwD family carers undergo severe financial economic losses and find difficult to meet the requirement of the cost of care services. Often, an economically vulnerable section of the society is likely to spend more than their earning on healthcare and pushing them into poverty. Furthermore, in India, there is no provision to support caregivers as a welfare measure. Currently, the health insurance is not covering the dementia care services. The public sector health services are not offering specialised services to dementia living persons. The cost of dementia care continues to grow with the advancement of age and severity of the condition. Thus, economic vulnerability pushes family carers into poverty. Consequent to low family carer income and growing out of pocket expenditure exerts a major toll. Therefore, there is a need of the state or national government to take a proactive stance as a pre-emptive policy measure to build infrastructure, human resource capacity, dementia data information at different levels.

3.1 Dementia services gap in India

The dementia services in India are limited. Though The Alzheimer's and Related Disorders Society of India (ARDSI) established in 1992 and spearheaded the dementia advocacy in India, currently the ARDSI could establish 20 chapters across India. There are few more organizations also offering dementia care services either independently or in support of ARDSI. The services exclusively for people with dementia are approximately ; a): day care centres-15; b) Residential care facilities-12; c) Domiciliary care services-6; d) Memory clinics-100; e) Dementia help lines-10. Nevertheless, there are limited non-governmental organizations that are focused on dementia services. There is a significant inadequacy in establishing and running the dementia carer centres in India when compared to the proportion of dementia cases.

4 The term “POLICY” in the context of Alzheimer’s disease and related disorders and its relevance

Definitions are important and of practical value to use a consistent language which facilitates the comprehension of topics by the target audience. They help promote and guide exchange of ideas with and within the audience. The term “policy” is used to refer to ministerial statements and speeches, technical guidelines such as those contained in training materials, planning documents, decrees, directives and circulars, that influence public health activities in the health sector, at the health facility and community levels. The term may also be used simply to refer to established, prevailing practices in a specific domain. The term “policy” in the Alzheimer’s disease and related disorders policy initiative refers specifically to a written policy document which

- Sets long-term, outcome-oriented directions and priorities (‘what to do’) for Alzheimer’s disease and related disorder, in line with the resources that India and relevant states can mobilize, and identifies main strategies (‘how to do it’);
- Reflects system views concerning Alzheimer’s disease and related disorders, going beyond individuals. Ensures commitment and continuity over time and promotes standardization for Alzheimer’s disease and related disorders;
- Formalizes decisions already made, legitimizes existing guidelines, and institutionalizes strategies and interventions for Alzheimer’s disease and related disorders;
- Commits financial and human resources; Helps in strategic thinking and planning;
- Brings together all [Alzheimer’s disease and related disorders] elements in one document which ensures consistency and maximizes the use of available resources;
- Grants due importance to Alzheimer’s disease and related disorders and credibility, ensuring greater compliance, and reduces chances of misinterpretation;
- Clarifies the roles and responsibilities of staff define lines of communication and identifies coordination mechanisms and structures; Serves as a reference for all partners, and establishes directions for their involvement.

5 Vision

India's Dementia policy vision is to reduce the risk by ensuring life style modification, early detection, improved comprehensive care with supportive services and care givers training cum rehabilitation through sustainable strategic approaches.

6 Mission

The mission is to make dementia a national health priority and increase resources to strengthen, prevention/risk reduction, early detection and supportive services. Advance the research, capacity building and policy promotion for Alzheimer's disease and related disorders risk factors through improved brain health services.

7 Dementia policy enablers

Box 1 Constitutional provisions for elderly health problems and welfare issues

Article 41 of the Constitution: Article 41 of Directive Principles has particular relevance to *Old Age safety and security*. As per the Article 41 of the constitution of India, “the state shall, within the limits of its economic capacity and development, make effective provision for securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement and in other cases of undeserved want.”

Article 47 of the Constitution: Article 47 of the constitution of India provides that the state shall regard the raising of the level of nutrition and the standard of living of its people and improvement of public health as among its primary duties.

Other Constitutional Provisions: Entry 24 in list III of schedule VII of constitution of India deals with the welfare of labour, including conditions of work, and old age pension and maternity benefits. Furthermore, item 9 of the state list and item 20, 23 and 24 of concurrent list relates to old age pension, social security and social insurance, and economic and social planning. The right of parents, without any means, to be supported by their children having sufficient means has been recognized by section 125(1) (d) of the Code of Criminal Procedure 1973, and section 20 (1 & 3) of the Hindu Adoption and Maintenance Act, 1956.

Administrative arrangements: The Ministry of Social Justice and Empowerment focuses on policies and programmes for the elderly in close collaboration with State Governments, Non-governmental Organisations and Civil Society. The program for elderly people, by supporting old age homes, day care centres, mobile medical units.

Box 2 Legislations and relevant programs as key enablers for dementia supportive services

The Maintenance and Welfare of Parents and Senior Citizens Act, 2007

The act was enacted in December 2007, to ensure need based maintenance for senior citizens. The act suggests at least one old age home in every district with capacity of 150 persons in each centre. The main objectives of the act are: Revocation of transfer of property by senior citizens in case of negligence by relatives; Maintenance of Parents/senior citizens by children/ relatives made obligatory and justiciable through Tribunals; Pension provision for abandonment of senior citizens; adequate medical facilities and security for senior citizens; Establishment of Old Age Homes for indigent Senior Citizens.

National Policy for Older Persons (NPOP) 1999

The policy recognizes a person aged 60 years and above as elderly. The policy envisages state support in areas such as: financial; food security; healthcare; nutrition; shelter; education; welfare and protection of life and property.

National Council for Older Persons (NCOP) 1999

This is an apex body to advise the government in implementation of programs for elderly population issues. Its core functions are: represent collective issues related to elderly persons; provide feedback and suggest measures and act as nodal point to redress the grievances related elderly persons.

Central Sector Scheme of Integrated Programme for Older Persons (IPOP)1992

This program was initiated with the objective of strengthening the elderly people's quality of services such as: food, shelter, and medical care, encourage productive and active ageing. This program is expected to implement NGOs as well as Panchayat raj institutions.

Inter-Ministerial Committee on Older Persons

In order to strengthen NPOP, there is an inter-ministerial committee on older persons, chaired by ministry of social justice and empowerment. The committee is envisaged to implement and supervise the elderly programs.

National Old Age Pension (NOAP) Scheme 1994

The scheme is envisaged to improve economic status of senior citizens above age of 65 years who have no financial support.

National Programme for Health Care of Elderly (NPHCE)

In accordance with NPOP and section 20 of 'the maintenance and welfare of parents and senior citizens act, 2007', the ministry of health and family welfare-GOI, launched national program for health care of elderly in 11th five year plan. The key objectives are: identify problems in elderly people, access to preventive, promotive and rehabilitative services; build capacity of professionals; improve referrals; dedicated beds in district hospitals; develop 8 regional tertiary care centres for elderly persons and; reorient medical education.

National Policy on Senior Citizens 2011

The policy focuses to: promote healthy ageing in their place; sustain dignity of old age; mainstream senior citizens; improve institutional care; strengthen long term care savings and; set up homes with assisted living facilities.

National Program for Palliative Care

Palliative care is also known as supportive care which is required in the terminal cases of Cancer, AIDS etc. and can be provided relatively simply and inexpensively. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources. It can be provided in tertiary care facilities, in community health centres and even in patients' homes. It improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement.

The Goal of the scheme is to ensure availability and accessibility of rational, quality pain relief and palliative care to the needy, as an integral part of Health Care at all levels, in alignment with the community requirements.

http://dghs.gov.in/content/1351_3_NationalProgramforPalliativeCare.aspx

National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS)

India is experiencing a rapid health transition with a rising burden of Non-Communicable Diseases (NCD) Losses due to premature deaths due to these NCDs are also projected to increase over the years. Therefore, the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) was launched in 2010 in 100 districts across 21 States, in order to prevent and control the major NCDs. The main focus of the programme is on health promotion, early diagnosis, management and referral of cases, besides strengthening the infrastructure and capacity building

http://dghs.gov.in/content/1363_3_NationalProgrammePreventionControl.aspx

9 Guiding values

The following values will guide the national Alzheimer's and related dementia policy. Values guide our behaviours', judgments and how we accomplish our mission. Therefore, the following values are considered for national Alzheimer's disease and related dementia care services.

9.1 **CORE VALUES** are

9.1.1 **Respect**

- Treating all people affected by dementia with respect and ensuring their rights are protected

9.1.2 **Inclusiveness**

- Operate in a spirit of inclusiveness by providing opportunities for vulnerable in graceful ageing process of all

9.1.3 **Comprehensive care**

- Comprehensive care of vulnerable to Alzheimer's disease and other related dementia as the basic philosophy and strategy for overall national health development.

9.1.4 **Life course approach**

- A life-course approaches to old age; Alzheimer's disease and other related dementia survival that recognizes the continuum from preconception, pregnancy, the neonatal period through adolescence and ageing related issues such as dementia.

9.1.5 **Social-justice**

- Ensure the principle of social justice, equity, the ideals of freedom and opportunity as affirmed in the Constitution of India.

9.1.6 **Partnership**

- Effective partnership and collaboration between various health actors and sectors.

9.1.7 **Equity**

- Equity in health resource distribution and access to dementia-related services.

10 Core public health **PRINCIPLES** that govern the **NATIONAL STRATEGIC PLAN for Dementia**

The core principles that govern the National Strategic Plan draws inspiration from the Global Action Plan released by WHO in May 2017 with help of Alzheimer's Disease International-ADI and the regional consultations held by ARDSI in the cities of Bangalore, Kolkara, Mumbai and Delhi among various stakeholders comprising, carers, government

officials, health care professionals, service providers, policy makers, leading NGO representatives etc.

The Global Action Plan listed the following seven action areas which are reprioritized as under:-

The key principles that govern the national strategic plan for Alzheimer's and related disorders are reprioritized as under based out of the emerging trends and practical experiences which shall facilitate prevention/risk reduction, early detection and access to best medical care and social support system.

Identified global Action areas prioritized specific to Dementia in India

1. Dementia as a public health priority
2. Dementia Awareness and Friendliness
3. Dementia Risk Reduction
4. Dementia Diagnosis, treatment, care and support
5. Support for dementia carers
6. Dementia research and innovation
7. Information systems for dementia

Action Area:1 Make dementia a national health and social care priority

Dementia must be made and publicly stated as a national health and social care priority as this is affecting a large section of its society. This is expected to be reflected in the plans for service development, budgetary allocation and public spending.

Nearly 4.41 million people are affected directly or indirectly by dementia and related complexities, dementia requires a whole-of-government, broad, multi-stakeholder, public health approach. Such an approach will lead to a comprehensive response from the health and social care system (both public and private) and other government sectors, and which will engage people with dementia and their carers and other relevant stakeholders and partners.

Rationale. The development and coordination of policies, legislation, plans, frameworks and integrated programmes of care through a comprehensive, multisectoral approach will support the recognition, and address the complex needs, of people with dementia within the context of each country. This approach is in line with the principle of universal health coverage and the standards outlined in the Convention on the Rights of Persons with Disabilities.

National target 1: *At least 30% of the states will have developed their own state programmes, strategies, plans or frameworks for dementia, either on a stand-alone or integrated into other policies/plans, by 2025.*

Action Area-2 Dementia awareness and friendliness

There is common misbelief that dementia is a natural and inevitable part of ageing rather than a disease process, resulting in barriers to diagnosis and care. The lack of understanding also causes fear of developing dementia and leads to stigmatization and discrimination. Furthermore, people with dementia are frequently denied their human rights in both the community and care homes.

Dementia-awareness shall entail an accurate understanding of dementia and its various subtypes as clinical diseases, reduce stigmatization and discrimination associated with dementia, educate people about the human rights of people with dementia and the Convention on the Rights of Persons with Disabilities, enhance the general population's ability to recognize early symptoms and signs of dementia, and increase the public's knowledge of risk factors associated with dementia, thereby promoting healthy lifestyles and risk reduction behaviour in all.

A dementia-friendly society, in Indian context, possesses an inclusive and accessible community environment that optimizes opportunities for health, participation and security for all people, in order to ensure quality of life and dignity for people with dementia, their carers and families in a low resource setting. Shared key aspects of dementia friendly initiatives include sensitized stakeholders, who are the first to be approached by the patient and patient families. They include, local doctors, para medical staff, clinics, hospitals, shop keepers, community groups, transport operators etc. It is essential these stakeholders are sensitized adequately about the conditions of persons affected with Dementia with a view to promoting a greater involvement of common people with dementia in society and supporting families and carers of people with dementia. The concept of dementia friendliness is tightly linked to societies also being age-friendly. Both age- and dementia-friendly initiatives should take into account the fact that a significant number of older people are living alone and are sometimes very isolated.

Dementia-awareness campaigns and dementia-friendly programmes that are tailored to the cultural contexts and particular needs of a community can promote enhanced health and social outcomes that reflect the wishes and preferences of people with dementia, as well as improve the quality of life for people with dementia, their carers and the broader community.

Rationale. Increasing public awareness, acceptance and understanding of dementia and making the societal environment friendly to people affected with dementia to participate and mingle with community as ever, and continue their sense of autonomy through improved social participation.

National target 2.1: *80% of states where NGOs like ARDSI has chapters will have at least few functioning public-awareness campaign on dementia to foster a dementia-inclusive society by 2025.*

National target 2.2: *50% of states where NGOs like ARDSI has chapters will have at least few dementia-friendly initiative to foster a dementia-inclusive society by 2025.*

National target 2.3: 50% of states where NGOs like ARDSI is active shall have stakeholder specific sensitization guides.

Action area -3 Dementia risk reduction

The national dementia strategy shall incorporate the key principles of prevention/risk reduction of dementia. The preventive approach has immense potential because that reduces the risk of getting Dementia and could majorly reduce the care management costs both at the family levels and also at the societal levels;

There is an established inter-relationship between dementia and noncommunicable disease and lifestyle-related risk factors. These risk factors include physical inactivity, obesity, unbalanced diets, tobacco use, harmful use of alcohol, diabetes mellitus and mid-

life hypertension. In addition, other potentially-modifiable risk factors are more specific to dementia and include social isolation, low educational attainment, cognitive inactivity and mid-life depression. Reducing the level of exposure of individuals and populations to these potentially modifiable risk factors, beginning in childhood and extending throughout life, can strengthen the capacity of individuals and populations to make healthier choices and follow lifestyle patterns that foster good health.

The following measures are protective and can reduce the risk of cognitive decline and dementia: increase physical activity, prevent and reduce obesity, promotion of balanced and healthy diets, cessation of tobacco use and the harmful use of alcohol, social engagement, promotion of cognitive stimulating activities and learning as well as prevention and management of diabetes, hypertension especially in mid-life and depression.

Rationale. By improving the capacity of health and social care professionals to provide evidence-based, multisectoral, gender and culturally-appropriate interventions to the general population, educate about and proactively manage modifiable risk factors for dementia that are shared with other noncommunicable diseases, the risk of developing dementia can be reduced or its progression delayed.

National target 3.1: To achieve this action area, complementing the relevant national targets defined in the National action plan and Monitoring framework for prevention and control of noncommunicable diseases and any future revisions are achieved for risk reduction and reported.

Action Area -4 Dementia Diagnosis, treatment, care and support

Dementia identification, right diagnosis, access to treatment, availability of care within vicinity and support in terms of information, capacity building of care givers, effective therapies etc needs to be ensured at all levels. The three-tiered health care system in India needs to be strengthened appropriately with strategies for ensuring Diagnosis, treatment and care. There is a strong need to Develop an integrated, comprehensive range of care models for persons with dementia to bridge the gap between care at home and care in a care home.

Dementia is associated with complex needs and high levels of dependency and morbidity in its later stages, requiring a range of health and social care, including long-term-care services. People with dementia are also less likely to be diagnosed for comorbid health conditions, which, when left untreated, can cause faster decline, and to receive the care and support they need to manage them. The services that they require include case-finding, diagnosis, treatment (including pharmacological and psychosocial), rehabilitation, palliative/end-of-life care and other support such as home help, transport, food and the provision of a structured day with meaningful activities.

People with dementia should be empowered to live in the community and to receive care aligned with their wishes and preferences. To ensure that people with dementia can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity, they need integrated, person-centred, accessible, affordable health and social care, including long-term care. Long-term care covers all activities, whether these are provided by health, social or palliative care services or result from a dementia-friendly environment. Palliative care is a core component of the continuum of care for people living with dementia from the point of diagnosis

through to the end of life and into the bereavement stages for families and carers. It provides physical, psychosocial and spiritual support for people with dementia and their carers including support with advance care planning.

The draft action plan proposes some principles for organizing and developing health and social care, including long-term care systems for dementia by ensuring inter coordination between various ministries ensuring medical and social care. Providing sustainable care across the continuum from diagnosis to the end of life requires: timely diagnosis; the integration of dementia treatment and care into primary care; coordinated continuity of health and social care including long-term care between different providers and system levels, multidisciplinary collaboration and active cooperation between paid and unpaid carers. Planning responses to and recovery from humanitarian emergencies must ensure that individual support for people with dementia and community psychosocial support are widely available.

Adequately trained and qualified workforces are required to provide these interventions. The continuity of care between different care providers, multiple sectors and system levels and active collaboration between paid and unpaid carers are crucial, from the first symptoms of dementia until the end of life. Integrated, evidence-based, person-centered care is required in all settings where people with dementia live, ranging from their homes, the community, assisted-living facilities and nursing homes to hospitals and hospices. The skills and capacity of the workforce and services are often challenged by the complex needs of people with dementia.

Rationale. The needs and preferences of people with dementia can be met and their autonomy from diagnosis to the end of life respected through integrated, culturally-appropriate, person-centred, community-based health, psycho-social, long-term care and support and, where appropriate, the inputs of families and carers.

National target 4.1: *In at least 30% of the states, as a minimum, 40% of the estimated number of people with dementia are diagnosed by 2025 and is integral part of the Primary health care centers (wellness centers).*

National target 4.2: *In at least 30% of the states, Dementia day care for moderate and mediumly affected patients and Full time (24X7) care for advanced stage patients are created in collaboration social welfare departments in districts with 10 lakhs plus population.*

National target 4.3 *Capacities of 30% GPs and paramedical staff get built through regular yearly training by 2025.*

Suggested measures by MoHFW to realize about targets

Allocate and apportion resources from the following National Programmes

- A portion of NPHCE resource allocation to Dementia diagnosis, treatment wards, training and care
- A portion of NPCDCS resources to risk reduction measures by controlling and treating NCDs

- National Palliative care Program 10% of care setups are dedicated to terminal Dementia care
- National Mental Health Programme 15% allocation of its resources for Dementia care, counselling, setting up of memory clinics and training.
- NPOP resources apportioned for Dementia day care and full time care centres has to enabled access by MoHFW through certification and validation.

In addition to the above, MoHFW should create a National centre of Excellence on Dementia care and research and also engage in developing curriculum for ensuring training to General Physicians and para medical staff.

MoHFW to Offer technical support to State health departments for documenting and sharing best practices of evidence-based service delivery and care coordination, and provide support to Member States in developing dementia-care pathways in line with the principle of universal health coverage.

Develop and implement guidelines, tools and training materials, such as model training curricula covering core competencies relating to dementia for health and social care workers in the field. Provide support to state health departments in the formulation of human resource strategies for dementia, including the identification of gaps, specific needs and training requirements for health and social care workers as well as graduate and undergraduate education about integrated provision of long-term care that is person-centred from diagnosis to the end of life.

Provide guidance on strengthening the implementation of the dementia component by training existing staff, to provide quality care and evidence-based interventions through primary health care.

Action area- 5: Support for dementia carers

Carers can be defined by their relationship to the person with dementia and their care input. Many dementia carers are relatives or extended family members, but close friends, neighbours and paid lay persons or volunteers can also take on responsibilities for caring. Carers are involved in providing "hands-on" care and support for people with dementia or play a significant role in organizing the care delivered by others. Carers often know the person with dementia well, and therefore are likely to have knowledge of and information about the person with dementia that is crucial for developing effective personalized needs-based treatment and care plans. Carers should therefore be considered essential partners in the planning and provision of care in all settings according to the wishes and needs of the person with dementia.

It should be noted that being a carer for someone with dementia may affect the carer's physical and mental health and well-being and social relationships. Health systems must consider both the substantial need of people with dementia for help from others and its significant impact on carers and families including economic impact. Carers should have access to support and services tailored to their needs in order effectively to respond to and manage the physical, mental and social demands of their caring role.

Rationale. The creation and implementation of means to deliver multisectoral care, support and services for carers will help to meet the needs of carers, and prevent a decline in their physical and mental health and social well-being.

National target 5.1: *40% of states, where NGOs like ARDSI chapters are present, provide support and training programmes for carers and families of people with dementia by 2025.*

Action area-6: Dementia research and innovation

Research, care through innovative therapeutically effective practices including tested indigenous medicines/practices needs identified, consolidated, upscaled and mainstreamed for common practices to benefit people living with all forms of Dementia. This requires strong evidence creation through proven and internationally acceptable research methodologies engaging prominent academic institutions across the country. This will ensure variety of innovations for application and practice to benefit People with Dementias.

To reduce incidence of dementia and improve the lives of people with dementia, research and innovation are crucial as is their translation into daily practice. It is important not only that funding and appropriate infrastructures for dementia research and innovation are made available but also that mechanisms are in place that assist appropriate recruitment of people with dementia, their families and carers into research studies. Research and development costs are higher for dementia than other therapeutic areas, because of lower success rates, longer development times, and low recruitment rates into trials; this disproportion discourages investment in this area. Research is needed to find a cure for dementia, but research is equally needed into prevention, risk reduction, diagnosis, treatment and care, including the disciplines of social science, public health and implementation research.

State health departments and researchers need to come together to focus on strengthening dementia research agenda to ensure better prevention, diagnosis, treatment and care for people with dementia.

In vogue with time, use of innovative health technologies in prevention, risk reduction, early diagnosis, treatment, care and support relating to dementia has to be ensured with invention of modern technologies enabling these aspects. These innovations shall aim to improve knowledge, skills and coping mechanisms in order to facilitate and support the daily lives of people with dementia and their carers while meeting in particular identified needs in an evidence-based and age-, gender- and culturally-sensitive manner.

Rationale. The successful implementation of research into dementia aligned with identified research priorities and social and technological innovations can increase the likelihood of effective progress toward better prevention, diagnosis, treatment and care for people with dementia.

National target 6: *The national and regional researches are augmented, by 30% of current levels, on dementia patient centric care, to improve their living condition is sponsored by research organizations such as ICMR, DST, DBT and also funded by private stakeholders having interest on Dementia research.*

Action area7: Information systems for dementia

Dementia prevalence needs to be systematic by ensuring enumeration of cases. An exclusive MIS based helpline attached to an IVRS call center for benefitting people seeking information could be a viable solution. Similarly, Doctors/clinics could be encouraged to register confirmed

patients and advocacy to create a National dementia registry which can provide variety of information on age-wise prevalence, severity, types including other essential/relevant details.

Systematic, routine population-level monitoring of a core set of dementia indicators provides the data needed to guide evidence-based actions to improve services and to measure progress towards implementing national dementia policies. By building and/or strengthening information systems for dementia the functional trajectories of people with dementia, their carers and families can be improved. However, this will require significant changes, while respecting existing regulatory frameworks, to the routine collection, recording, linkage and disaggregation for sharing of health and administrative data of each encounter of a person with dementia with the health and social care system.

Rationale. Systematic monitoring and evaluation of the usage of health and social care systems can provide the best available evidence for policy development and service delivery, which can improve prevention and the accessibility and coordination of care for people with dementia across the continuum from risk reduction to the end of life.

National target 7: *30% of states routinely collect a core set of dementia indicators through a national registry incorporating health and social information every two years by 2025*

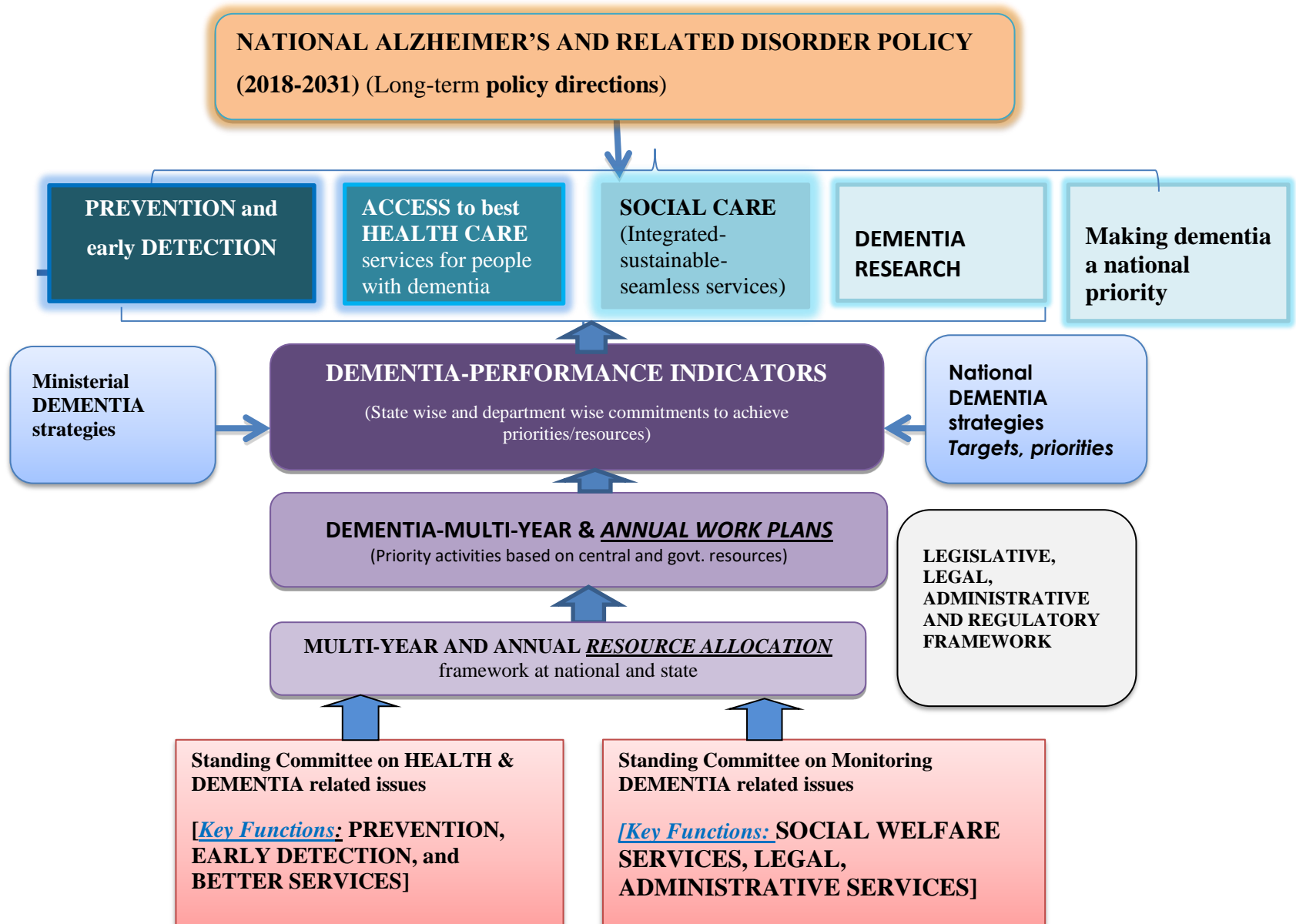
Dementia National Action Areas	Action area wise Targets
1. Dementia as a public health priority	1: <i>At least 30% of the states will have developed their own state programmes, strategies, plans or frameworks for dementia, either on a stand-alone or integrated into other policies/plans, by 2025.</i>
2. Dementia Awareness and Friendliness	<p>2.1: <i>80% of states where NGOs like ARDSI has chapters will have at least few functioning public-awareness campaign on dementia to foster a dementia-inclusive society by 2025.</i></p> <p>2.2: <i>50% of states where NGOs like ARDSI has chapters will have at least few dementia-friendly initiative to foster a dementia-inclusive society by 2025.</i></p> <p>2.3: <i>50% of states where NGOs like ARDSI is active shall have stakeholder specific sensitization guides/manuals</i></p>
3. Dementia Risk Reduction	3.: <i>To achieve this action area, complementing the relevant national targets defined in the National action plan and Monitoring framework for prevention and control of noncommunicable diseases and any future revisions are achieved for risk reduction and reported.</i>
4. Dementia Diagnosis, treatment, care and support	4.1: <i>In at least 30% of the states, as a minimum, 40% of the estimated number of people with dementia are</i>

	<p><i>diagnosed by 2025 and is integral part of the Primary health care centers (wellness centers).</i></p> <p>4.2: <i>In at least 30% of the states, Dementia day care for moderate and mediumly affected patients and Full time (24X7) care for advanced stage patients are created in collaboration social welfare departments in districts with 10 lakhs plus population.</i></p> <p>4.3 <i>Capacities of 30% GPs and paramedical staff get built through regular yearly training by2025.</i></p>
5. Support for dementia carers	5.1: <i>40% of states, where NGOs like ARDSI chapters are present, provide support and training programmes for carers and families of people with dementia by 2025.</i>
6. Dementia research and innovation	6: <i>The national and regional researches are augmented, by 30% of current levels, on dementia patient centric care, to improve their living condition is sponsored by research organizations such as ICMR, DST, DBT and also funded by private stakeholders having interest on Dementia research</i>
7. Information systems for dementia	7: <i>30% of states routinely collect a core set of dementia indicators through a national registry incorporating health and social information every two years by 2025</i>

11 Overarching Conceptual FRAMEWORK for Alzheimer’s and related disorder policy

The implementation of the policy aims at ensuring harmony, improving efficiency, clarifying the roles of relevant stakeholders and effective involvement of communities, Non-Governmental organizations and development partners through the proposed structures. The national Alzheimer’s and related disorder policy will be implemented through an integrated strategic plan with agreed goals/targets that respond to the needs of an Alzheimer’s and related disorder services.

Figure 2 Alzheimer's and related disorder THEORY OF CHANGE conceptual framework



There are a number of stakeholders whose policies and activities will directly or indirectly impact on the implementation of this Policy. To ensure effective implementation of the recommendations a standing committee on monitoring is to be constituted as suggested.

12 Strategic plans in Alzheimer's and related disorder policy Implementation

The Alzheimer's and related dementia society conducted a several stakeholders' consultation meeting in different parts of the country. It also reviewed the hurdles faced in implementation due to the vast inter-dependent and cross-functional organizational structure of the elderly population services. While the union health ministry provides leadership in policy initiation and implementation, there are several aspects (like legal support, old age pensions, health insurance, social welfare services etc.) that do not come under its purview of health department directly although they greatly affect the health status of Alzheimer's and related dementia affected population. For instance,

- The Labor Department to collect vital information related to dementia-disability and welfare services;
- The Education Department to ensure dementia-related health education and community empowerment;
- The Department of women and child development to oversee the welfare and development of women, children, elderly and dementia special needs, persons;
- The Agriculture Department for food safety and affording nutritious food especially to elderly/dementia vulnerable sections of the society
- The Public Distribution System which comes under the Food, Civil Supplies and Consumer Affairs Department to ensure accessible and balanced nutrition to dementia and elderly population;
- The Finance Department for funding on sector-wide approaches to special needs of people with dementia
- The Forest, Ecology and Environment Department to handle pollution and maintain the green cover to avoid environment-related health risk factors at least in dementia care centres
- The Department of Water Resources in providing safe drinking water to all, specifically in dementia healthcare centres
- The Department of Science & Technology and IT & BT in promoting research on priority areas related to Dementia. Explore research through traditional healing systems in dementia care practices. Enhance assistive information technologies to better care practices of people with disability.
- The Department of Commerce and Industries to develop State-relevant dementia specific medicines, pharmaceutical production, food price market monitoring and quality assessment
- The Department of Rural Development and Panchayat Raj to develop district and taluka level autonomous professional managed dementia and elderly care trusts to address the local health service requirement
- The Urban Development Department to manage, facilitate elderly and dementia care centres or facilitate private care centres in urban areas.

All of the above functions of different departments, directly and indirectly, affect the health status of *elderly population* who are likely to suffer from dementia but are separate from the Department of Health and are not addressed in general. Furthermore, the recommendations that follow related to palliative care have not addressed herein, as separate government bodies have not been established to examine them. Additionally, research in the field of Alzheimer's and related disorder forms the stepping stone to newer and innovative initiatives. Therefore, there is a need for advanced research in Alzheimer's and related dementia to encourage and promote research in health institutions and integrated coordinated approach to implement for Alzheimer's and related disorder policy.

Table 3: Illustration of inter-departmental coordinated approach for Alzheimer's and related disorder policy implementation

Depts./key policy actor/s	Role
Prime Minister/Chief Minister	<ul style="list-style-type: none"> ▪ Clarify and set a mandate to the department of health concerning <u>Alzheimer's</u> and related disorder policy. ▪ Ensure the implementation of <u>Alzheimer's and related disorder policy</u> through inter-sectoral coordination
The Cabinet	<ul style="list-style-type: none"> ▪ Ensure adequate legislative, legal and administrative support/framework. ▪ Review the performance through the legislative committee on <u>Alzheimer's</u> and related disorder policy.
I- Healthcare services interventions that promote prevention, early detection of Alzheimer's and related dementia	
Health Department	Oversee and <u>provide leadership in Alzheimer's</u> and related disorder policy implementation. The department shall also lead the process of agenda-setting on various issues identified with other related departments
Department of Finance	Support the department of health in developing the health sector-wide <u>comprehensive sustainable Alzheimer's and related dementia</u> research, preventive, promotive service relevant pool of funds and financing approaches.
II- Social policy interventions that improve comprehensive services to elderly & dementia friendly centres	

Department of Education	Ensure health education, communication for community empowerment related to dementia
Department of Agriculture	Ensure food safety, security, affordable nutritious food to <u>old age and dementia affected</u> persons.
Department of Public Distribution System	Ensure accessible, balanced food grains <u>to old age and dementia vulnerable populations</u> in each state. Establish monitoring and evaluation through e-portal to monitor the indicators.
Department of Labour	Ensure safe working conditions through proper regulations and the implementation of those <u>regulations in old age homes, dementia friendly centres</u> . Develop monitoring indicators and improve vital information related to labour health and welfare services
Department of Forest, Environment	Collaborate with the department of health and develop a health disease and environmental <u>risk factors surveillance systems related to dementia/NCDs</u> . Implement environmental improvement programs to reduce health risk factors.
Department of Transport	Priority could be given to developing old age homes, dementia friendly centres accessibility by expanding road networks.
Department of Water Resources	Provision of safe drinking water to all, more specifically to all old age homes, <u>dementia friendly centres/healthcare centres in each state</u> .
Department of Energy	Provision of sustainable <u>renewable energy for all old age homes, dementia friendly centres</u> .
Department of Youth Empowerment	Create an environment for <u>youth behavioural change communication to embrace old age homes, dementia friendly centres</u>
Central and state health commission	Oversee and advise the health sector on policy promotion, policy implementation monitoring and

	<i><u>possible legislation to old age homes, dementia friendly centres issues</u> wherever necessary.</i>
Department of Science, Technology and IT/BT	Promote state relevant old age, <i><u>dementia-related science research in collaboration</u></i> with the relevant public health institutes. Promote <i><u>research in AYUSH related to elderly problems and dementia-related issues</u></i> . Explore traditional medicine practices and <i><u>promote local health healing options for dementia prevention</u></i> , early detection and better care services.
Small and Medium Scale Pharma Industries	In collaboration with the department of health develop relevant pharmaceutical production and supply related to <i><u>old age, dementia relevant medicines at affordable prices</u></i> .
Department of Commerce and Industries	In collaboration with the department of health, develop food price market monitoring-surveillance systems that <i><u>subsidize food prices for elderly/dementia affected the population</u></i> . Conduct of Food quality assessment and use appraisal system.
Department of Rural Development and Panchayat Raj	In collaboration with the department of health, develop taluka and district level autonomous professionally managed <i><u>old age homes/dementia friendly centres/healthcare trusts</u></i> with adequate funding to monitor, manage, organize and address local health service requirements.
Department of Women and Child Development	In collaboration with the department of health, to oversee the welfare and development of the <i><u>elderly and dementia-disabled</u></i> of each state.
Department of Urban Development	In collaboration with the urban bodies, oversee the welfare and development of elderly and dementia affected persons in each state. <i><u>Develop in each urban area/ward/block level autonomous professional managed old age homes/dementia friendly centres/healthcare trusts</u></i> with adequate funding to

	monitor, manage, organize and address local health service requirements.
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12.1 Cabinet Sub-Committee

As ensuring effective implementations of the recommendations is an integral component of the Alzheimer’s and related disorder policy. There is a need for the creation of a committee at both central and state level comprising of a group of secretaries of the concerned departments and eminent personalities under the chairmanship of Prime Minister/Chief Minister/Chief Secretary to the government. These sub-committees is to be set up as part of the cabinet sub-committee to coordinate and oversee the implementation of the recommendations to the inter-connected ministries to achieve the goals.

13 Conclusion

This dementia policy document represents a commitment towards improving the overall health and social support services to people with dementia. The policy proposes a comprehensive and inclusive approach to addressing the dementia-related issues, which represents a radical departure from past approaches to addressing the dementia challenges in the country. The dementia policy was developed through an inclusive and participatory process involving all stakeholders at a different point in time and from different geographical sites. The policy identifies dementia relevant core values and guiding principles, orientations, and strategies aimed at achieving the highest standard of dementia care services in India. It also outlines a comprehensive dementia strategies implementation framework to achieve the stated policy vision and guiding public health principles such as prevention, early detection-diagnosis, access to best medical care, social support services and dementia research.

The document attempts to delineate the roles of the different stakeholders from different sector in delivering the dementia care services and details the institutional management arrangements under the devolved system of government, taking into account the specific roles of the various ministries. Finally, this dementia policy document provides a structure that harnesses and gives synergy to global WHO comprehensive dementia service delivery at all levels of government.

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