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Health Systems Transformation Platform

POLICY BRIEF

Home Healthcare

A timely addition to fill a critical gap in India's healthcare system

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Acknowledgement

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About HSTP

The **Health Systems Transformation Platform (HSTP)** is a not-for-profit organization registered in the name of **Forum for Health Systems Design and Transformation**; a company licensed under section 8 of the Indian Companies Act 2013. An Indian homegrown organization, HSTP was set up to generate contextualised and evidence-backed recommendations and insights to strengthen Indian public health systems and policies that guide policymakers and health providers.

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Key Takeaways

The demographic, epidemiological and socio-cultural shift that India is undergoing has implications for the country's health system. Home healthcare could be a valuable and timely addition to fill a critical gap in meeting the changing needs of the population in transition. Care provided to people in their homes to maintain their health, quality of life and independence is referred to as home healthcare. Based on a study conducted by HSTP, the following measures are recommended to integrate home healthcare into India's healthcare system:

- **Develop a comprehensive policy on home healthcare.**
- **Recognise 'home' as a place for providing healthcare and as a 'place of work' for care providers.**
- **Develop standardised processes to deliver care at home.**
- **Ensure the availability of trained and adequate caregivers.**

Introduction

India is undergoing a demographic, epidemiological and socio-cultural transition. A decreasing total fertility rate implies fewer births and a smaller proportion of youth. The increasing life expectancy is contributing to a steady rise in the elderly population. India is projected to have 227 million people over the age of 60 years by 2036, equivalent to the combined current populations of Germany, United Kingdom, and France. The disease profile is changing in India with rising prevalence of non-communicable diseases (NCDs). Furthermore, NCDs are manifesting at an earlier age, around 45 years. People are thus living longer with chronic conditions necessitating the need for long term care. Approximately six million people are estimated to require palliative care annually.[1] The family structure and lifestyle have altered significantly over the last three decades, evident in the growing trend of smaller and nuclear families. These changes are making way for a shift in the traditional way of caring at home by family members. There is greater professionalisation and commercialisation of care at home. These shifts have broader implications for the country's health system.

Care provided to people in their homes to maintain their health, quality of life and independence is referred to as home healthcare. Also known as home-based care, it encompasses preventive, promotive, therapeutic, rehabilitative, long-term maintenance, and palliative care. The urgency of home healthcare has been highlighted by the COVID-19 pandemic, prompting private hospitals and state governments to offer home care packages. Key collaborations, such as those between the governments of Delhi and Karnataka with private home healthcare companies for managing COVID-19 at home, illustrate its potential. Home healthcare can replace up to 65 percent unnecessary hospital visits and reduce hospital costs by 20 percent.[2] Market estimates project the home healthcare industry to grow at a substantial rate of 15-19 percent annually, from nearly USD 6-7 billion in 2021 to USD 21 billion by 2027.[3]

Home healthcare is therefore a valuable and timely addition to India's healthcare system. It fills a critical gap in meeting the changing needs of a population in transition. Similar has been the experience in the United States of America, Europe, and neighbouring Asian nations like Thailand and Indonesia. This

policy brief reviews the evolving landscape of home healthcare in India and recommends measures to integrate it into the country's health system.

KEY INDICATORS

India's TFR reduced to 2.0 in 2019-21[4] from 3.4 in 1990-92[5].
The proportion of youth (15-29 years) will reduce to 22.7% (345 million) by 2036 compared to 27.5% (333 million) in 2011.[6]
Life expectancy increased to 67 years in 2021[7] from 60 years in 1991[8].
The proportion of population aged 60+ will increase to nearly 15% (227 million) by 2036 compared to 8.6% (101 million) in 2011.[9]
Old age dependency (population aged 60+ per 100 persons in the age group of 15-59 years) will increase to 23% in 2036 from 14% in 2011.[9]
The burden of NCDs (primarily cardiovascular disease, chronic respiratory disease, cancer, and diabetes) increased to 55.4% in 2016 from 30.5% in 1990.[10]
The average household size reduced to 4.4 in 2019-21[4] from 5.7 in 1990-92[5].

Methodology

The researchers at HSTP conducted a study to understand the need, scope, barriers, and opportunities in delivering healthcare services at home. The policy brief summarises the findings from the study that comprised literature review, in-depth interviews with 24 key informants, and consultations with 16 experts and key stakeholders. The interviews were conducted between February and May 2022. It incorporates the views and opinions of users and providers of home healthcare, representatives of organisations that deliver such services, conduct vocational training of providers, or accredit home healthcare companies, government representatives, non-government organisations, researchers, and academicians.

The home healthcare landscape in India

SERVICES, USERS, AND PROVIDERS OF HOME HEALTHCARE

The provision of healthcare services at home is an emerging phenomenon in India that has gained currency in the last decade. Restricted to assistance with activities of daily living (ADL) earlier, increasingly a combination of ADL and medical care is provided at home. Technological advancements and improved affordability, at least among a section of the population, have expanded the scope of healthcare services offered at home. These comprise both routine nursing care and specialised services. Home healthcare services may span short durations, ranging from a few minutes to a few hours, such as repetitive wound dressing or frequent injections. Additionally, they could be for longer duration, varying from a few weeks to months, or even extending over years.

Routine nursing care services at home: Monitoring of vitals, dressing of wounds and bedsores, intravenous or intramuscular injections, maintaining nutrition intake, among others.

Specialised services: Post-hospitalisation intensive care, monitoring and stabilisation services through a hospital-like environment at home, palliative care, dialysis, physiotherapy etc.

Older people comprise the majority users of home healthcare including those with conditions such as dementia, Alzheimer's, and Parkinson's disease. Other users are post-hospitalisation patients who need follow-up care, people with physical or intellectual disabilities, musculoskeletal conditions, chronic conditions such as diabetes, hypertension, and cancer, and those at end-of-life stage.

Home healthcare providers in India primarily fall into five categories – family members, community-based outreach workers, untrained aides, trained caregivers, and professionally qualified healthcare workers. This policy brief specifically focuses on the latter three categories whose role in home healthcare is least known and warrants policy intervention. Untrained aides mainly assist with activities of daily living but lack formal training in assisted living, relying on learning from experience. Trained caregivers comprise home health aides (HHA), general duty assistants (GDA), geriatric care assistants, nursing assistants, among others. They undergo vocational training to offer care such as ADL, monitoring vitals, dressing wounds and bedsores etc. The category of professionally qualified healthcare workers includes nurses, doctors, and allied healthcare professionals like physiotherapists, nutritionists, and counsellors, etc. Among these, nurses and physiotherapists are the most common providers of healthcare at home.

The providers work independently or through organisations such as private for-profit companies, non-profit organisations, hospitals, nursing bureaus, or old age homes. In the last decade, several corporate hospitals in India have established home healthcare departments. These departments provide post-discharge care to the hospitals' patients. The private, for-profit home healthcare companies too have gained prominence during this period.

LACK OF STANDARDS AND REGULATIONS IN HOME HEALTHCARE

Currently, there are no regulations or standardised processes to govern healthcare services at home in India. Organisations and individuals therefore follow practices at their discretion. Many organisations opt for cost-cutting measures, providing untrained and unverified staff, thereby compromising the quality of services. Biomedical waste generated at home is often disposed of with regular household waste. The households have no obligation to provide a safe and respectful working environment for care providers. There are no specific grievance redressal mechanisms for either the users or the providers of home healthcare. The users can seldom seek protection under the Consumer Protection Act 2019 due to the informal nature of most home healthcare services. Often there is no documentary proof of purchase of services. Even if there is a signed contract, the terms of agreement usually absolve the organisation of any legal liability. Thus, the rights and safety of both the users and providers remain inadequately protected making it critical to address these gaps to ensure their well-being.

The Maintenance and Welfare of Parents and Senior Citizens (Amendment) Bill, 2019, seeks to regulate home healthcare, though it is essentially limited to care for older people. It proposes the registration of institutions providing home care services for the elderly and prescribing minimum standards for them. However, it has not been passed more than four years since it was introduced in the Parliament. With no government oversight, some organisations have opted for voluntary accreditation.

PROVIDER AVAILABILITY AND THEIR CONCERNS

There is a growing demand for caregivers, particularly to care for older people. However, trained caregivers, especially those with mature and empathetic outlook are inadequate. These attributes are essential for caregivers who spend long hours with patients in their homes. The vocational training often does not prepare the caregivers well enough for their role. The Central Government, state governments and private institutions conduct vocational training albeit with different eligibility requirements and course duration. Three Central ministries-Health and Family Welfare (MoHFW), Skill Development and Entrepreneurship (MSDE) and Social Justice and Empowerment (MSJE), are involved in developing the course curricula and delivering vocational training. This leads to inconsistency and duplication in the training of caregivers.

Nurses, especially female nurses, are reluctant to work in homes because families do not treat them with respect and dignity. They are vulnerable to physical, verbal, and sexual abuse. *"There is no feeling of security in a patient's home..."* shared the head of a hospital's home care programme. Providers' other concerns are lack of time to rest when offering 12 or 24 hour services which can be extremely exhausting. Further, sometimes families expect them to run errands for the household and assist in cleaning, cooking etc. though they are meant to cater only to the client's needs. On occasions the resultant friction between the families and the caregivers leads to sudden discontinuation of service, inconveniencing both the parties.

There are no formal mechanisms for the providers to complain in case of a grievance. The Sexual Harassment of Women at Workplace (Prevention, Prohibition and Redressal) Act, 2013, allows women workers to complain against sexual harassment at workplace. While "workplace" includes "a dwelling place or a house" as per the Act, the definition of "domestic workers" is limited to women employed for household work. Its application to female home healthcare providers is a grey area. Moreover, the scope of the Act is limited to providing protection only to women and only against sexual harassment.

COST OF HOME HEALTHCARE AND COVERAGE UNDER INSURANCE

The study findings reveal that specialised services such as intensive care are cheaper at home than in hospital. However, the cost of hiring a provider at home for long term is substantial. A trained caregiver, such as a GDA, can cost monthly up to Rs. 40,000 and a nurse up to Rs. 1,00,000 for 24-hour service. Physiotherapy services usually cost 30 to 40 percent more at home than at physiotherapy clinics. The charges to take care of patients who are difficult to manage, such as those who are aggressive, have dementia or other mental health conditions, are higher. There are fewer skilled providers to attend to such patients. Currently, when the bulk of healthcare services at home are provided by the private, for-profit sector, their use is restricted due to high cost. The organisations reportedly retain a margin of 20 to 40 percent in their services. Some not-for-profit organisations offer services free or at a subsidised cost.

The Insurance Regulatory and Development Authority of India (IRDAI) recognises domiciliary hospitalisation in certain conditions. Based on the doctor's prescription services such as specialised nursing, medication, diagnostics, and physiotherapy are covered for 30 to 60 days post-hospitalisation. Some home healthcare companies have tie-ups with select insurers

to offer cashless homecare services. The feasibility of extending insurance coverage comprehensively to home healthcare and employing other financing mechanisms, needs to be deliberated upon amongst the stakeholders.

Integrating home healthcare into India's healthcare system

RECOMMENDATIONS

Both evidence and expert opinions allude to the increasing relevance of home healthcare in India. A compelling argument exists for integrating home healthcare as a formal mode of service delivery within the country's health system. The following measures are recommended towards that:

Develop a comprehensive policy on home healthcare

A policy document outlining the vision for home healthcare is vital to recognise it as a formal mode of healthcare delivery. The policy needs to incorporate aspects like creating a registry of organisations and providers of such services; ensuring transparency and accountability in the provision of services to safeguard the interests of users and providers; adopting standard human resource practices; transparency in the calculation of cost of services; permissible radiological investigations at home; managing emergencies; establishing grievance redressal mechanisms; biomedical waste management; insurance coverage, among others. Particular attention needs to be paid to the requirements of older women who are likely to outnumber older men in the coming years.

Recognise 'home' as a place for providing healthcare and as a 'place of work' for care providers

This is crucial to legitimise home healthcare as a formal mode of service delivery. It has implications for the rights and safety of users and providers. The fact that IRDAI and insurance companies acknowledge domiciliary care under certain conditions supports such a step. The MoHFW could call for stakeholder consultations and form an expert group for preparing a Model Bill to recognise and regulate home healthcare. The states could then adapt the Bill according to their context.

Develop standardised processes to deliver care at home

Caring for a person at home is a different proposition than caring in a hospital. Therefore, terms of engagement and treatment protocols must be tailored to the home environment to ensure safety and quality. Protocols specific to the type of care such as elder care, critical care, palliative care, dialysis, assistance with daily living activities, etc. need to be developed. The MoHFW could develop such protocols as an extension of the standard treatment guidelines it has already prepared.[11]

Ensure the availability of trained and adequate caregivers

To meet the growing demand of trained caregivers, especially for older people, streamlining their vocational training, nomenclature, roles, and career progression pathways is essential. For this, better coordination is required between the three ministries involved in vocational training. Permitting candidates as young as 14 years

to train and work as home health aide-trainee must be reconsidered.[12] Such young candidates are unlikely to have the desired attitude and aptitude for the role.

The shifting healthcare concerns of the Indian population ought to be addressed by extending access to services at home, while ensuring patient safety, care quality, and provider safety. Hence, it is imperative that a conducive policy environment be created for home healthcare to effectively complement the existing healthcare landscape of the country.

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