

SDG3: Good Health and Well-being SDGwatch Status Report Tamil Nadu 2020 (People with disabilities during the pandemic) SDG3: Good Health and Well-being SDGwatch Status Report Tamil Nadu 2020 (People with disabilities during the pandemic)

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Prepared by:



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HRF

The Human Rights Advocacy and Research Foundation (HRF) works to protect and promote the human rights of socially excluded communities and vulnerable sections of society, mindful of intersectionality. The Foundation enables these communities to exercise their constitutional rights, amplifies their voice, and enhances their participation in decision making through demystifying laws and state mechanisms, building their capacity, and supporting them to deepen democracy and build inclusive, sustainable and resilient communities. We broaden space for civic engagement and support human rights defenders to promote a culture of human rights to secure a life with dignity for all at all times.

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Introduction —

Health is wealth' is an adage that elbowed its way into the forefront of global consciousness and endeavour in 2020. Whether it is - is not was, because the pandemic is not yet behind us - a black swan, a grey rhino, or an arbinger of worse to come is a debate for the ages. What is not in doubt is that the underspending on social welfare and building strong democratic institutions enabled the virus to become a raging pandemic that has wiped off a major part of the world's economy, resulted in hundreds of thousands of painful and lonely deaths, scarred a whole generation of children and you, unleashed the threshold of social violence - and this is just the start. The true cost will be borne by generations yet to be born, and, for the first time in living memory - and perhaps human history - children inherit a world of less opportunities than their parents.

The global consensus is that the pandemic has pushed back the sustainable development goals, and the 'decade of action' that the 2020s was to be, is now a decade of trying to defend the gains, slowdown the reverses, and mitigate the effects of worst forms of poverty. It is too early to pass a verdict on the doomsday predictions - human beings and social systems are remarkably resilient - but the importance of public health, and therefore public investment in it has been underscored like never before, in a stinging rebuttal of neo-liberal economics. Even conservative mouthpieces across the world were forced to concede that many of the ideas that were dismissed as extremist - such as universal basic income and health for all - were a necessity if society as we know it, is to survive.

The 17 sustainable development goals (SDG) are interrelated and integrated, just like human rights. Though the focus could be on one



goal, or one among the socially excluded communities or a sub-set of them, to ensure that 'no one is left behind' the interconnectedness and indivisibility soon becomes apparent. A study on the status of health and well-being (SDG 3) during the pandemic brought out the interconnectedness in all its stark, undeniable simplicity, much as Orcam's razor strips away all the non-essentials. There was no place to hide when entire systems collapsed - not least due to a 100 day lockdown with a four hour notice. If ever there needed to be a demonstration of the cost of not investing in public health and public health infrastructure was needed, the 24% collapse of the Indian economy in the first quarter of financial year 2020-21 was it.

The study was initiated to explore the impact of the pandemic on socially excluded communities, with a focus on the indigenous and tribal communities. Gender and disabilities were to be cross-cutting. However, the impact on them was so much, and they lived in such remote areas, that the only feasible option was to have case studies and not a survey per se. The batton was taken up by disabled people's organisations, and the study was completed with its original orientation, but with a different demographic. It was to provide insights into the health and health systems, whether they could fulfil the basic purpose for which they were put in place - and whether they were in place at all.

The findings are sobering, more so considering that Tamil Nadu is one of the better administered states of the union. Despite formulating myriad schemes for the health and well-being of the citizens, the state seems to have failed to even make known the schemes to the eligible citizens, with civil society organisations (CSO) having to step in to fill the gap by providing the last mile contact and information dissemination. Even so, utilisation is low among those surveyed.



The lead researcher for the study was Ms Adya Siddarth. She was supported by Ms Smitha Sadasivam, Ms. Meenakshi Balasbramanian, Mr. Gnana Bharathi, Ms. Mercy Annapoorani, Mr. Alphonse Raj, Dr. S Venkatraman, and Mr Murugesh. Amar Seva Sangam, Ayikudi and Multiple Sclerosis Society of India (MSSI), Chennai extended organisational support. The study was anchored by HRF, and made possible by a generous grant from GIZ. We place on record our heartfelt appreciation to each for their contribution.

It is our hope that the findings of this study will strengthen evidence based engagement and policy intervention at all levels, and lead to more investment in public health and better impact. It is a prerequisite to ensure that no one is left behind - a commitment made by the Government of Tamil Nadu in 2012 in its Tamil Nadu Vision 2023, and the Government of India in 2015.

Edwin

Director (Programmes), HRF January 2021

GOOD HEALTH AND WELL-BEING -

ood health and well-being are key drivers for achieving sustainable development. The third goal of the UN Sustainable Development Goals (SDG) aspires to ensure healthy lives and promote well-being for all at all ages. Building on the Millenium Development Goals (MDGs)¹, SDG3 has a broader scope that adopts a multi-sectoral approach towards health and includes additional targets and indicators for addressing non-communicable diseases (NCDs), mental health, substance abuse, injuries and violence and most importantly achieving Universal Health Coverage (UHC).

Though SDG3 is focused on health, it finds linkages with other goals i.e. SDG2 (hunger, food security and improved nutrition), SDG5 (reproductive and sexual health), SDG6 (water and sanitation), SDG7 (affordable and reliable energy), and SDG11 (Safe and sustainable transport systems), apart from SDG16 and SDG17.

Universal health coverage

The World Health Organisation (WHO) defines Universal Health Coverage (UHC) as the access to affordable and quality health services, from health promotion to prevention, treatment, rehabilitation, and palliative care, for everyone. It calls for well-functioning health systems which are people and community-centered. The central theme of UHC is provision of primary health care for well-being and better quality of life for all, with a focus on equity and reaching the most vulnerable and disadvantaged populations.

¹ MDG 4: reduce child mortality, MDG 5: improve maternal health, MDG 6: combat HIV/AIDS, malaria and other diseases. Source: https://www.who.int/topics/millennium_development_goals/en/ Accessed on 2nd January 2021



The SDG target 3.8, talks about achieving UHC through including financial risk protection, access to quality essential health-care services and access to safe, effective, quality, and affordable essential medicines and vaccines for all.

This target is quoted² to be the linchpin of development in health care and an enabler for all other health targets.

Social determinants of health

Social Determinants of Health (SDH) are certain non-medical factors which influence inequities in health. According to the WHO, these play an important role, in addition to health-specific targets, in ensuring better health outcomes. SDH essentially are the conditions in which people are born, grow, work, live, and age. They include a wider set of social, political and economic forces and systems that shape the conditions of daily living. They bring to attention the social inequities that exist in many countries, where poor socio-economic conditions often imply poor status of health in such populations. A few examples³ of the SDH given by the WHO are income, social protection, education, unemployment and job security, working life conditions, food insecurity, housing, basic amenities and the environment, early childhood development, social support and inclusion, structural conflict, and access to affordable and quality health services. Taking action on the SDH is a necessary step towards ensuring better health for all.

³ https://www.who.int/health-topics/social-determinants-of-health#tab=tab 1 Accessed on 2 January 2021



² https://www.who.int/news/item/08-12-2015-from-mdgs-to-sdgs-who-launches-new-report Accessedon 2 Januaury 2021



India's approach to SDGs and health

The Government of India aligns its National Health Policy (NHP) 2017 with the SDG3. With a 'Health for All' objective, the policy seeks to promote research on SDH and pays attention to neglected issues such as disability and transgender health. It emphasises the role of health governance and local self-government Institutions as being instrumental for ensuring action on SDH. The NHP identifies seven priority areas outside the health sector which can prevent and promote health. These include air pollution, better solid waste management, water quality, occupational safety, road safety, housing, vector control, and reduction of violence and urban stress. The NHP also has a special focus on Gender Based Violence (GBV) through dignified, gendersensitive and women-friendly health services and infrastructure in addition to free healthcare for victims and survivors of GBV.

For UHC the policy aims at providing free and comprehensive primary healthcare for reproductive, maternal, child and adolescent health and also for prevalent communicable, non-communicable and occupational diseases. In 2017 the GoI launched a flagship scheme known as Ayushmaan Bharat or the Pradhan Mantri Jan Arogya Yojana (PMJAY) to help economically vulnerable Indians who are in need of healthcare facilities. It offers coverage of up to INR 500,000 per family per year for secondary and tertiary hospitalisation care. It also aims at setting up health and wellness centers by transforming existing PHCc and sub centres to bring healthcare closer to the people.

Tamil Nadu's approach to SDG3

As per the Niti Ayog's report on SDG performance in India, Tamil Nadu is one of the frontrunners in the index-wise scoring of different goals and targets.

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On SDG3, Tamil Nadu is said to have already achieved a few SDG targets such as reduction in maternal mortality to below 70 per 100,000 live births. SDG3 and health action is institutionalised through the National Health Mission Tamil Nadu by the Department of Health and Family Welfare Government of Tamil Nadu. The department has different programmes with distinct as well as overlapping focus areas for health.

- 1. The State National Rural Health Mission (NRHM) was set up to improve the health of people living in villages. The key objectives of this mission includes a) Reduction of infant mortality and maternal mortality b) UHC: women's health, child health, drinking water, sanitation and hygiene, nutrition and universal immunisation
 - c) Communicable and Non-Communicable Diseases (NCD)
 - d) Population stabilisation-Gender e) Integrated comprehensive primary health care f) Revitalising local health traditions and mainstreaming Indian systems of medicine (ISM).
- 2. Tamil Nadu Health System and Reform Programme (TNHSRP) is a World Bank funded programme that aims at achieving specific SDG3 targets such as 3.4, 3.6, 3.7, and 3.8 to improve the quality of care in public health facilities, NCDs and injuries, and Reproductive and Child Health (RCH). The RCH interventions have a special focus on nine priority districts: Dharmapuri, Thiruvannamalai, Nilgiris, Ariyalur, Ramanathapuram, Theni, Thoothukudi, Tirunelveli, and Virudhunagar. These districts have a relatively large tribal population and some are low performing on RCH indicators.
- **3. Tamil Nadu Urban Health Care Project (TNUHCP)** is a new project funded by the Japan International Cooperation Agency (JICA). The aim of the project is to improve health outcomes of the poor and disadvantaged accessing government medical





institutions in the urban areas. The project looks at strengthening the infrastructure and capacity of medical institutions and providing better primary health care for NCDs.

- 4. Tamil Nadu Health Systems Project (TNHSP) is a partnership between the Government of Tamil Nadu and the World Bank towards fulfilling the health policy drafted by the state in 2003 to improve the health status of people belonging to lower socioeconomic strata including tribal communities. The thematic areas under this project are child health, indigenous peoples, health system performance, population and reproductive health, and injuries and NCDs. Under tribal health care the project looks at implementing the Tribal Development Plan in 12 districts in Tamil Nadu.
- 5. The Chief Minister's Comprehensive Health Insurance Scheme provides cashless hospitalisation facilities for specific ailments/ procedures in certain empanelled government and private hospitals in the state. The scheme provides a coverage of upto INR 500,000⁴ per family per year and is eligible for families whose income is less than INR 72,000 per annum.
- 6. UHC in Tamil Nadu is termed as *Anaivarukkum Nalavazhvu Thittam*. This has been implemented on a pilot basis in select blocks of Perambalur, Krishnagiri and Pudukottai districts. The goal of the government is to create more than 4000 health and wellness centres in Tamil Nadu by 2020-21 which will be less than 50% of the target (around 9000 centres) set by the Government of India for the state. The primary focus of these centres will be maternal and

⁴ USD 1 = INR 73; Euro 1 = INR 85.





child health, communicable diseases management and NCD screening and management. The state claims to have begun the NDC screening process in many locations at the community level carried out by Women Health Volunteers (WHVs) from the Women Development Corporation.

Health-related achievements as claimed by the state are

- National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) is stated to have been implemented in all 32 districts of Tamil Nadu.⁵
- A total of 2682 health and wellness centres have been created under Ayushman Bharat.⁶
- According to a National Health Authority study, awareness of Ayushman Bharat is around 80% in Tamil Nadu.

⁶ PIB India https://pib.gov.in/PressReleasePage.aspx?PRID=1674243



⁵ NHM TN https://www.nhm.tn.gov.in/nhm-programs

RF conducted a household health survey in Tamil Nadu to understand the status of SDG3 due to, and during, the pandemic related lockdown. The survey included disability as a cross-cutting theme. Survey responses were received from around 27 districts in Tamil Nadu. Amar Seva Sangam, Ayikudi and Multiple Sclerosis Society of India (MSSI), Chennai are some of the organisations that supported in administering the survey. The current study is based on a sub-sample taken from the survey.

Objective

The objective of the study is to get a preliminary understanding of the status of health in the state in the backdrop of the global health goals. With Universal Health Coverage (UHC) being the mantra of the WHO and SDG3, it is important to understand how the government machinery is able to ensure policy and action are directed towards achievement of health and well-being for all, particularly marginalised and vulnerable communities.

Scope

The survey aimed to understand the health status of households, their levels of awareness, access and utilisation of health services, schemes and initiatives, and services available during the COVID-19 lockdown period. The maximum number of responses were received from the districts of Tirunelveli and Tenkasi. The number of responses from other districts were disproportionately lower. Hence this study presents findings from the analysis of responses from only these two districts.



The analysis has been done for a total of 660 household responses, that belong to lower socio-economic strata (monthly household income being less than INR 25,000).

Methodology

The survey was administered through a detailed questionnaire using Google Forms. The questionnaire had multiple sections which captured different aspects of health such as a) socio-economic profile of the household b) details about member with illness c) utilisation and effectiveness of health amenities and services d) nutrition and public hygiene, action taken by the government for disease prevention e) services available for households during the COVID-19 lockdown period and f) details on Persons with Disabilities (PwDs), if present.

The questions contained a mix of open-ended and closed questions to garner data for quantitative and qualitative analysis. The responses were filled by volunteers/respondents using Google Form and then analysed using Microsoft Excel and Google Sheets.



SUMMARY OF FINDINGS -

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Respondent profile

Most of the 660 survey respondents hail from small towns, villages, and hamlets. 60% belong to Tirunelveli district and 40% to Tenkasi district. The average age of respondents is 37 years with a minimum 18 and maximum of 70.55% of the respondents were female and the rest were male. 25% of the respondents are illiterate.

Most are employed as daily/weekly wage workers (62%) or seasonal wage workers (12%), mainly coolie work, beedi making, pottery making, textile work, masonry, agriculture labour, cattle herding, mill/factory work, store help. Less than 10% are self-employed persons. The remaining respondents are employed in some form of government (2%) or private service (6%). Less than 10% stated that they were unemployed.

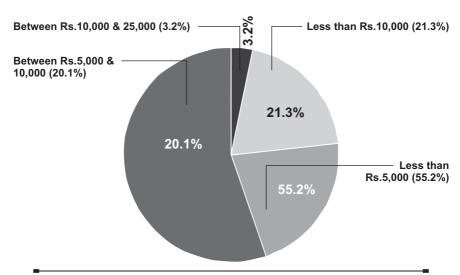


Figure 1: Percentage of respondents based on monthly household income





57% of the respondents have a family member in their household who has a disability. (The surveying organisation Amar Seva Sangam, Ayikudi, works in the disability sector and provides supportive services to PwDs).

The broad household monthly income categories are I) 21.3% less than INR 1000 II) 55.2% earn less than INR 5000 a month III) 20% earn between INR 5000 and INR 10,000 and IV) 3.2% between INR 10,000 and INR 25,000. Thus the majority of the surveyed population belong to economically weaker sections.

Access and utilisation of health facilities

The respondents were asked about the availability and utilisation of public health facilities such as the Primary Health Centre (PHC) and Government Hospital (GH). As mentioned above, the respondents hail mainly from rural locations in both districts. The location of a public health facility is one of the key factors of accessibility.

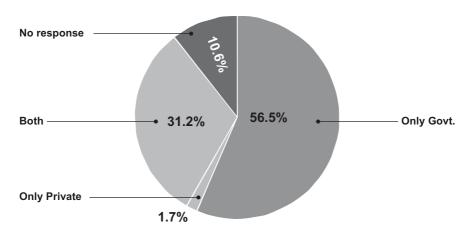


Figure 1: Type of health facilities accessed





The study showed that the average distance the household travelled for health care was 3 km for a PHC and 5 km for a GH.

56.5% of respondents indicated that they use only government health facilities (PHC, GH, etc) while less than 2% use only private health facilities. 31.2% indicated that they use both facilities and around 10% indicated use of neither government nor private facilities.

Most persons visit the PHC or GH on a monthly (35%) or quarterly (35%) basis. 12% stated that they have never visited a PHC or GH. Less than 5% said they had faced some form of discrimination while accessing a government health facility.

Disease awareness and action

SDG targets 3.4 and 3.5 relate to ending or reducing communicable diseases and NCDs. The study tried to capture the action taken by the government in this regard. More than 80% of households have received awareness on COVID-19.

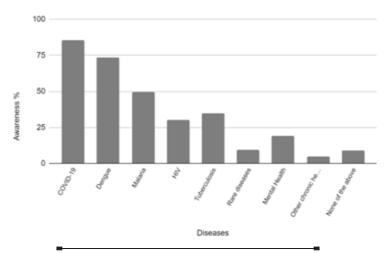


Figure 3: Disease-related awareness by government





Action taken by the government in some of these cases ranged from providing masks, sanitisers, health drinks and advice on precautionary measures such as hand-washing and physical distancing.

Less than 75% of households have received awareness on Dengue and around 50% on Malaria. 20% said there was some action taken by the government for Dengue and Malaria, such as cleaning the neighbourhood and applying bleaching powder. 30% seem to have received awareness of HIV, but less than 1% mentioned any action taken by the government.

Around 6% of households talked about distribution of medicines (blood pressure, sugar tablets). Around 19% of households have received awareness on mental health. However, less than 1% talked about action, such as counselling services, taken by the government. Overall 10% of households have not received any awareness and 68% expressed that no action has been taken by the government for any of the above diseases.

Awareness and utilisation of health schemes

Under the National Health Mission, the Government of India has many schemes covering specific aspects of health. For the current study certain key schemes were selected and included in the survey questionnaire.

Listed below are the schemes and details about them.

- 1. Ayushman Bharat Yojana (ABY) / Pradhan Mantri Jan Arogya Yojana (PMJAY) / National Health Protection Scheme.
- 2. Pradhan Mantri Bhartiya Janaushadhi Pariyojana (PMBJP) which provides quality medicines at affordable prices.
- 3. Chief Minister's Comprehensive Health Insurance Scheme (CMCHIS) or Amma Health Insurance for the state of Tamil Nadu.



- 4. Rashtriya Arogya Nidhi (RAN) to provide financial assistance to patients below the poverty line suffering from major life threatening diseases.
- 5. Niramaya Health Insurance Scheme (NHIS) under the National Trust for Persons with Disabilities (PwD).
- 6. District Mental Health programme (DMHP) which provide community mental health services and integration of mental health with general health services.
- 7. Integrated Child Development Services (ICDS) which provides food, preschool education, primary healthcare, immunisation, health check-up and referral services to young children and their mothers.
- 8. Reproductive, Maternal, Newborn, Child and Adolescent Health (RMNCH+A).
- 9. Janani Shishu Suraksha Karyakaram (JSSK) which benefits pregnant women delivering in public health institutions.
- 10. Chief Minister's Girl Child Protection Scheme of Tamil Nadu to benefit girl children and their rights through direct investment from the government.
- 11. Rashtriya Kishor Swasthya Karyakram (RKSK), a comprehensive adolescent health programme.
- 12. Mission Indradhanush and Intensified Mission Indradhanush (IMI) for intensified immunisation coverage in the country.
- 13. National AIDS Control Organisation (NACO) for prevention and control of HIV/AIDS.
- 14. National Tuberculosis Control Programme (Revised National Tuberculosis Control programme RNTCP).
- 15. National Tobacco Control Programme (NTCP).





The survey garnered responses on the respondents' awareness and utilisation of the above schemes. More than 60% are aware of the Chief Minister's Health Insurance Scheme - CMCHIS - yet only 10% have availed of the scheme.

The other scheme, which more people (44%) are aware of, is the Niramaya Health Insurance Scheme (NHIS) for PwDs. As mentioned earlier, 57% of households have a PwD present. A high level of awareness about this scheme among the households is probably indicative of the efforts taken by the NGO, Amar Seva Sangam in these districts. However only 7% have indicated that they have availed of this scheme.

Other schemes such as Ayushmaan Bharat and PMBJP have around 20% awareness levels but less than 5% of utilisation.

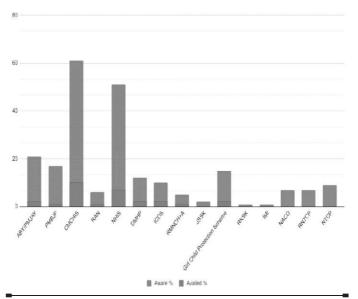


Figure 4: Percentage of Awareness and Utilisation of Health Schemes





There is only around 10% awareness for schemes such as DMHP, ICDS, and the Chief Minister's Girl Child Protection Scheme. The JSSK scheme for pregnant women has a low awareness rate of 2% and no indication of utilisation by households covered in this survey.

The analysis clearly shows a need for more awareness and understanding of different health schemes among the socio-economically excluded communities in particular.

There are a multitude of national and state schemes, which have different purposes, scope and eligibility. Information about all these need to be made easily available for common people and the underprivileged, in a way that they can make an informed choice and claim their right to better health. Further study and analysis is also required to understand the reason for the wide gap between awareness and utilisation of healthcare schemes.

Healthcare expenditure

The respondents were asked to mention their average monthly household spending on health. Based on the income categories (I, II, III and IV) a visual analysis of their expenditure on health is indicated in the graphs (Figure 5). The horizontal lines indicate the income range for the specific income category and the vertical line is a plot of their actual monthly health expenditure values for all respondents in that group.

The first two graphs, of the very low income households, clearly show the burden of health costs significantly closer to, or higher than, their monthly income. On further analysis it was found that 34% of the respondents who belong to income category I and II avail private health facilities. This brings to question the accessibility and utilisation of public health schemes and amenities for these extremely poor income





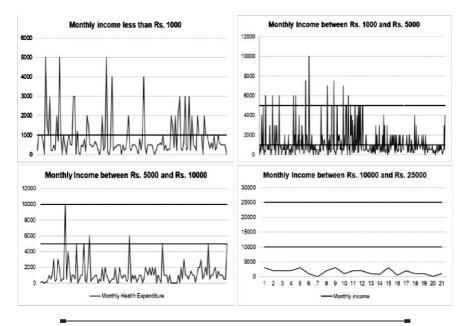


Figure 5: Comparison of health expenditure across income categories

Nutrition and hygiene

For nutrition, more than 75% indicated the presence of cereals, pulses, and vegetables in their diet. Around 25% said they consume fruits and 25% consume egg and meat in their diet. More than 95% of the respondents have three or more meals in a day. For buying their household provisions, 75% use local stores, 14% use local markets and 12% use supermarkets. 43% use the public distribution system (PDS). For water supply the respondents rely on government water supply (95%), Borewell (7%) and private tankers (3%) or natural water sources (5%). 88% said they had adequate water available to meet the needs of the household. 62% of respondents are satisfied with the quality of water that they use for their house, 10% were not satisfied

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and 28% were unsure about water quality levels.

With regard to neighbourhood hygiene, 62% are satisfied with the measures taken by the local self-government for sanitation and hygiene, 38% are not satisfied.

30% reported open defecation in their locality. The figures show the frequency of solid waste collection and sewage disposal. For solid waste 58% indicated daily collection or weekly collection (32%), while 10% report no or irregular collection. Similarly for sewage disposal 63% said they observe regular disposal of sewage by the local body, remaining indicated irregular or no disposal.

In the event of water stagnation in the neighborhood, respondents reported that the local self-government took the following measures a) applying bleaching powder (59%), b) cleaning up (65%) c) Dengue/Malaria control (14%). 10% said that water stagnation is not immediately addressed in their neighbourhood.

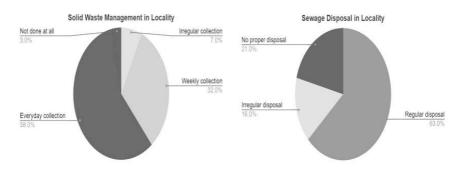


Figure 6: Frequency of solid waste collection and sewage disposal

Figure 6 shows that there is still a gap in the solid waste and sanitation measures at the local level. Action by the local self-government is a critical step towards maintaining environmental hygiene to ensure community well-being and prevention of communicable diseases.





Healthcare services during the COVID-19 period

The household survey tried to capture the healthcare services available to the respondents for specific vulnerable groups such as pregnant women, infants and children, adolescents, senior citizens, and patients needing palliative care.

54% said that they received antenatal and postnatal care at the doorstep during the lockdown period. 63% said that they did not receive any services for adolescent health care, while some did receive support in the form of iron supplements, deworming tablets and sanitary napkins. For infants and children, 59% said no services were available.

Around 12% said that the food from the anganwadi was delivered at home. Vaccination (2%), medicines (2%) and health check up (2%) were other services received by very few households. For senior citizens, 68% indicated no services, INR 1000 relief fund was received by 5%, pension was received by 2% and medicines (for blood pressure and sugar) by 3% of the households.

65% reported that they did not receive any services for nutrition, while 24% received dry rations such as rice, dal, and vegetables. 2% received medicines. COVID-19 specific relief material was received by 13% households. Households got one or more of the following: masks, hand sanitiser, and health drink.

Under the National Rural Health Mission, the role of community health workers such as Accredited Social Health Activists (ASHA) has gained importance, particularly for women's and children's health. They are the interface between the communities and the public health system.⁷

⁷ https://nhm.gov.in/index1.php?lang=1&level=1&sublinkid=150&lid=226





In the survey, the respondents were asked about the frequency of visits by community health workers such as ASHA or Village Health Nurses (VHNs). Given that more health workers were on duty during the COVID-19 lockdown, the respondents were asked about health worker visits before and during the lockdown.

Figure 7 shows that more health workers visited the homes on a daily or weekly basis during the lockdown. Around 11% have never had prior visits by health workers. 8% said that no health worker visited them during the period. Health workers play a key role in ensuring the right health awareness and services reach the most disadvantaged groups. Strengthening the role of this workforce is a necessary step for last mile delivery where no one is left behind.

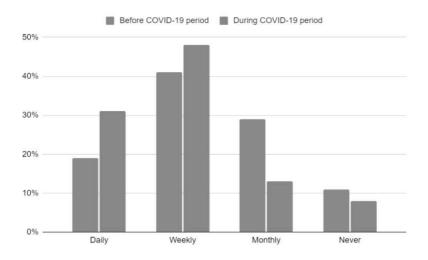


Figure 7: Frequency of health worker visits before and during COVID-19



SDG3 AND DISABILITY -

ttaining the SDGs is possible only with the inclusion of all in the path towards development. This includes all left behind (excluded or vulnerable) communities, of which Persons with Disabilities (PwDs) are amongst the most vulnerable. They continue to face significant challenges which include negative attitudes, stigma and discrimination, and lack of accessibility.

Leaving No One Behind (LNOB) and the commitment to human rights for PwD are guiding principles of the 2030 SDG Agenda which recognises disability as a cross-cutting issue particularly in achieving many of the goals and targets. PwDs are recognised as a primary disadvantaged group for ensuring healthy lives and well-being (WHO, 2019). The UN Convention on the Rights of Persons with Disabilities (CRPD) 2006 supports the full inclusion of the rights of PwDs in all aspects of development and implementation of the SDGs. The CRPD also emphasises their right to health, and presents a twin track approach where every development goal should include PwDs.

Disability-related findings

The Rights of Persons With Disabilities Act, 2016 (RPWD Act) in India recognises 21 types of disability: a) Blindness b) Low-vision c) Leprosy Cured Persons d) Hearing Impairment e) Locomotor Disability f) Dwarfism g) Intellectual Disability h) Mental Illness i) Autism Spectrum Disorder j) Cerebral Palsy k) Muscular Dystrophy l) Chronic Neurological Conditions m) Specific Learning Disabilities n) Multiple Sclerosis o) Speech and Language Disability p) Thalassemia q) Hemophilia r) Sickle Cell Disease s) Multiple Disabilities including deaf-blindness t) Acid Attack victims and u) Parkinson's disease.



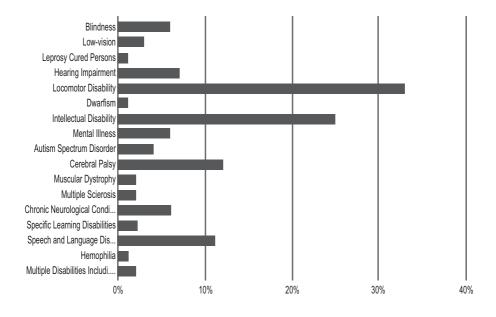


Figure 8: Categories of Persons with Disabilities covered under Survey

As mentioned earlier, 57% of the respondents (374 of 660) in the survey include a family member who is a PwD. The chart below is indicative of the number of one or more disabilities present in the surveyed households. The most common type of disability present is locomotor disability (33%) followed by intellectual disability (25%). More than 10% have cerebral palsy and speech and learning disabilities followed by (less than 10%) blindness, hearing impairment, mental illness and chronic neurological conditions.

For a PwD, the term 'accessibility' has more nuances in its meaning. The respondents were asked whether public amenities such as hospitals, clinics, PHCs, and other government health centres are accessible for the PwDs. They were asked specifically about the presence of ramps,



disabled friendly toilets, signages, sign language interpretation, braille, information in easy to understand language, disabled friendly equipment for diagnosis and treatment such as testing tables, x-ray machines, mammogram devices, and EEG mechanisms.

67% responded with a 'Yes' while around 30% responded with a 'No' (the remaining did not give a response). On being asked to elaborate on the specific challenge, most people cited physical access including travel, transport, and lack of ramps which make them dependent on another person. Some also mentioned a lack of confidence in these aspects.

Access and utilisation of information and policy

The chart below shows the levels of availability, awareness, coverage and utilisation of information, and policy and schemes applicable for PwDs. Regarding easy availability of public information on nutrition, health and rehabilitation for PwDs, more than 40% responded with 'Yes'. 20% were not aware about the availability of information.

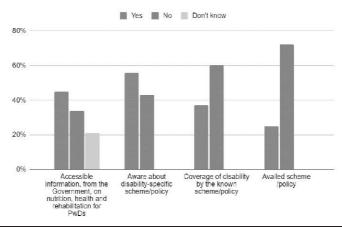


Figure 9: Accessibility of information, awareness, coverage and utilisation of scheme/policies for PwDs

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More than 50% are aware of disability specific schemes/policies, but only a little more than 20% have availed such schemes/policies. 60% feel that the scheme/policy known to them does not cover the specific type of disability faced by them.

COVID-19 and disability health

The Ministry of Social Justice and Empowerment had issued guidelines issued for persons with disabilities during COVID-19 period. 63% of the respondents said they were aware of these guidelines but 38% were not. The guidelines include provisions for

- 1. COVID Relief Fund (INR 1,000)
- 2. Toll free helpline with video call and sign language facility.
- 3. Free rations.

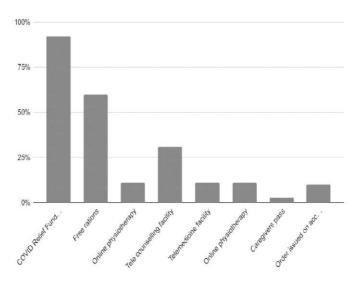


Figure 10: Percentage awareness on guidelines for PwDs issued by MSJE during COVID-19

⁸ http://disabilityaffairs.gov.in/content/page/whats-new.php





- 4. Tele counselling facility.
- 5. Telemedicine facility.
- 6. Online physiotherapy.
- 7. Caregivers pass.
- $8. \ \ Order is sued on accessing rations through a representative.$

Almost 92% of the respondents received the COVID relief fund for PwDs. Only 60% got free rations. Save for the tele-counselling facility accessed by 31%, others show low utilisation by the respondents. They faced challenges in accessing programmes ostensibly created for them, including lack of awareness and availability of the right information at their homes and community. Many have no source of income and found it challenging during COVID-19 period, in particular, as they were bound to their homes.



HEALTH ISSUES IN TRIBAL COMMUNITIES IN THE NILGIRIS



sland Trust is a non governmental organisation (NGO) working for the development of the tribal communities in the Nilgiris. Meenakshi⁹ is a counsellor and community health worker at Island Trust.

At the Primary Health Center (PHC) where she works, there are two female doctors and four nurses and five village health nurses. She works with 55 tribals living in the area to advise pregnant women and help them have a safe delivery.

The key health and welfare issues faced by tribal communities in the region are:

- 1. Anemia is a serious health issue in these communities. In general, most of them are malnourished. Pregnant women particularly are more prone to anemia. About 80-90 percent of the women who visit the PHC each month suffer from anemia. They have a hemoglobin level of 6 to 9 gm/dl, against the normal range between 12.1 to 15.1 gm/dl for women (National Health Portal of India). Childbirth takes place only after they have been given medicine and blood. Therefore most women need to visit the taluka or district hospitals for delivery.
- 2. Sickle cell anemia is a common disease among the tribals in Nilgiris. Children, women, and middle aged men are affected by this disease. The affected pregnant women have to be coaxed to visit hospitals in big cities like Coimbatore for treatment.

⁹ This case study summarises her experience.





- 3. Tribal people do not visit hospitals/health centres immediately when they become ill. This leads to more casualties when the disease progresses.
- 4. There is hesitancy and lack of confidence in the government health services. Most often they practice traditional methods of childbirth in the villages. When complications arise it may lead to death of mother and child.

Most of the tribal communities rely on the primary healthcare facilities in rural and remote areas. Studies (Malvankar, 2016; Kumar et al, 2020) have shown that these communities have distinctive health problems which are largely governed by their habitats, physical accessibility, and other socio-economic conditions. Their health problems need special attention through a deeper understanding of their social, environmental, and economic context and related health issues.

RECOMMENDATIONS — $\sqrt{}$

Based on the rapid survey and an overview of the state's response towards SDG3, health and well-being for all, following are some recommendations:

- 1. There are many schemes and policies at both national and state levels to cater to disadvantaged populations. However, there is little awareness on the existence of the different policies and related information. Disseminating these policies at the community level, in their languages, is an important step so that people can be made aware of what they can use based on their specific health requirements.
- 2. Strengthen the role of local government in ensuring community healthcare and well-being.
- 3. Increase the community health worker force, by equipping them with the right training and information to cater to specific health needs of the communities they work with.
- 4. Civil society groups working on specific health issues at the ground level can play an important role in information access and support to the community in availing the right health services and schemes.
- 5. Disadvantaged groups such as PwDs, tribal communities, senior citizens, patients needing palliative care, pregnant women and children from poor communities, are all vulnerable in terms of health. Specific attention needs to be paid to their health issues and their environmental conditions.
- 6. Universal Health Coverage and providing primary health care are extremely important for all. Ensuring the last mile reach of healthcare should be a priority for the government.



Tamil Nadu is one of the better performing states in terms of reaching specific health targets. However, it still has a long way to go to ensure that no one is left behind.

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