

Annex 2: MSSSI Countrywide Advocacy Project Initial Framework

Delhi 9 – 10 June 2018

The Problem(s)

- Lack of affordable treatment. People affected with MS do not have access to affordable treatment (Disease Modified Drugs: Oral and injectable)
- There are no affordable medicines; and no insurance company is willing to cover MS
- MS Challenge for youth. It cause economic burden on individual, family and government.
- Lack of information (data)

The Vision

Across India, MS Persons have access to affordable MS treatments that improve their quality of life.

A vision is a source of inspiration which focuses on how we want the world to be in the future, even as that vision seems highly unlikely in the near future. This project is not meant to completely achieve this Vision; however, through the achieving the goals people with MS and MSSSI will move a step closer to the Vision.

Potential Goals

The following goals were identified by MSSSI. These goals will be further refined and prioritised.

1. Implementation of the disability Act 2016 (RPWD) by the state government (Ayushman Bharat – ESI hospitals – Government)
2. Include MS in the upcoming database of Rare diseases (or any other relevant database)
3. Reduce tax on import of Disease modified Drugs (DMD)
4. Promote generic drugs (DMD) prescriptions by medicos
5. Promote Research and development/manufacture of DMD with Indian Council of Medical Research (ICMR) make in India
6. All MS Persons are covered/reached out under insurance schemes/subsidies (2021)
7. State level implementation/adoption of existing policies/schemes for MS (2020)

8. Inclusion of MS as part of the government medical schemes and policies (2019)
9. Focusing on the first line of treatment

Goals are the victories we celebrate along the way to attaining our vision; they are the culmination of specific strategies and actions that help us move a step closer to our ultimate vision.

Tactics

The following are some examples of tactics that were discussed briefly during the workshop that MSSI could use as part of their advocacy work. More tailored and targeted tactics will be identified after the selection of the Goal(s) and the Target(s) to ensure they are relevant.

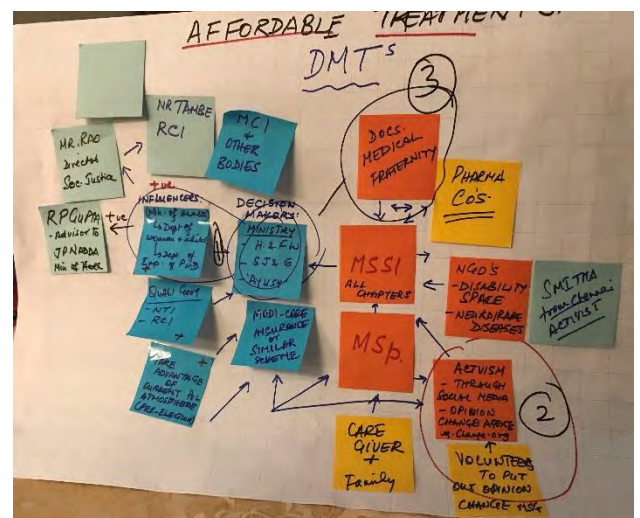
- Petition (e.g. change.org)
- Like minded NGOs (Rotary)
- Develop communication kit
- Media campaign (case studies – social media – print media – celebrity)
- Appointments with the government officials – memorandums of understanding
- Sensitising employers
- Research on economic impact of the disease

Stakeholders/targets mapping

a) **Tactical Mapping:** MSSI representatives worked into four groups to identifying people, individuals, groups, organisations, and institutions involved in the identified problem (lack of access to treatment). Potential Targets were marked by delegates. Final targets will be decided upon agreeing on the Goal(s).

Group 1:

- MSSI, Persons with MS - **medical fraternity** - pharma companies - NGO's (disability and/or neuro diseases) - **activism** through social media and change agents like change.org, caregivers – **volunteers** - Smitra activist from Chennai
- **Ministry of health - Ministry of social justice and employment - Ayusm, department of women and children at Ministry of Health - Department of people with disability at Ministry of health -** Quasi government (NTI, RCI) - Modi-care insurance or similar service - Mr Tambe from RCI - Mr Rao, Director of Social justice – RPGUPA, Advisor to JP NADDA, Minister of Health -

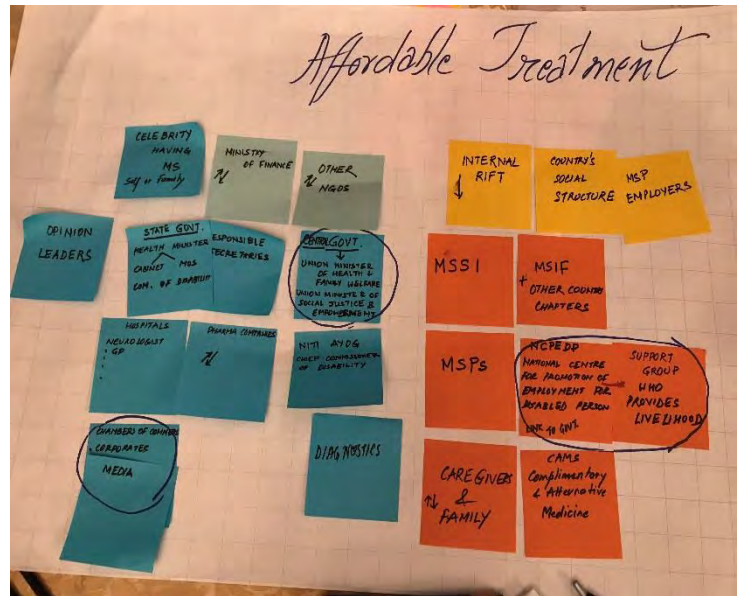


- **Things to consider:** Take advantage of the current political atmosphere (pre-election)

Group 2:

MSSI, Persons with MS – Caregivers and family - MSIF – **National Centre for Promotion of Employment for Disabled Person** (they have links to the government that can be used) – providers of complementary and alternative medicines

- **Central government** (Union Minister of Health & Family Welfare, Union Minister of Social Justice & Employment) – Chief Commissioner of Disability – State government (Health Minister, cabinet, MoS, Com. Of disability) – Opinion leaders – celebrity having MS or family, hospitals (neurologists & GPs) – Pharma companies – **Chambers of commerce – Corporates – Media**
- **Things to consider:** Internal rift – country’s social structure – MS Persons employers



Group 3:

- MSSI – MS Persons – Paramedicals – Donors and supporters – Corporate CSR – Fundraisers – Caregivers
- **Ministry of Health, Disability** (contacts in the ministry to be explored) – Pharmas - **medical fraternity** – centre for rare diseases – like minded NGOs – chief secretary of health – hospitals – insurance companies
- **Things to consider:** (the need to..) Prescribe generic drugs -Tax exemption on DMD – Making DMD in India – DMD reimbursement



Group 4:

- MSSI – local government – MS Persons – family of MS persons – friends and colleagues – caregivers – volunteers/activists – other NGOs – Society at large

- **Ministry of Health – Ministry of social Justice and Empowerment** – Disability division – Department of persons with disabilities – Department of Health and Family Welfare – Auysh – Government insurance companies – Central drugs control organisation – Medical councils – **Insurance companies – pharma companies** – State government Ministry of Health – NGOs (Rotary, Lions round table etc.) – CSR (Corporate foundations) – Department of Health Research

- **Things to consider:** Work doesn't only happens on the central movement level (See diagram)

b) The Spectrum of Allies:

In most social and economic change situations there is a struggle between those who want the change being proposed and those who don't. The below tool was used to define to what extend each of the identified stakeholders/targets are in support/opposing the change.

