Minutes of the Meeting-

"Discuss with representatives of concerned Ministries/ Departments on the points mentioned by the Hon'ble Supreme Court of India while disposing off writ petition (Civil) No. 767/2014".

A meeting was held on 25nd march 2022 at 3.00 pm, under the Joint Chairmanship of Shri Rajiv Manjhi, Joint Secretary, and Dr. Anil Kumar, Deputy Director General (Leprosy) Dte.GHS, to "Discuss with representatives of concerned Ministries/ Departments on the points mentioned by the Hon'ble Supreme Court of India while disposing off writ petition (Civil) No. 767/2014".

List of Participants is at **Annexure-1**.

- 1. At the very outset, Shri Rajiv Manjhi, Joint Secretary, and Dr. Anil Kumar, Deputy Director General (Leprosy) welcomed participants and delved upon the key objectives of the meeting. Also explained the mandate of National Leprosy Eradication Programme in respect to rehabilitation programme is looking after medical rehabilitation. One of the objectives of the meeting was deliberation on action points emanating from the directions of Hon'ble Supreme Court which are spelled out as below along with inputs received from the representatives are as below:
 - A) The Union and the State Governments must pro-actively plan and formulated a comprehensive community based rehabilitation scheme which shall cater to all basic facilities and needs of the leprosy affected persons and their families. The scheme shall be aimed at eliminating the stigma that is associated with persons afflicted with leprosy.

Central Leprosy Division, Ministry of Health and Family Welfare:

Dr. Anil Kumar, DDG briefed about role of NLEP in Medical Rehabilitation for leprosy affected person. National Leprosy Eradication Programme is a centrally sponsored scheme under National Health Mission. This programme is being implemented in all the States/UTs. The major focus of the Programme is to detect the cases of leprosy at an early stage, and to provide complete treatment, free of cost, in order to prevent the occurrence of Grade II Disability (G2D) in the affected persons. NLEP is implementing DPMR (Disability Prevention and Medical Rehabilitation) i.e reaction management, provision of MCR footwear, Aids & Appliances, referral services for management of cases and Reconstructive surgery at District Hospitals and Medical Colleges/Central leprosy Institutes. Ultimately, it is the early case detection followed by complete treatment.

To address the issue of stigma and discrimination associated with leprosy and to increase the awareness, a nationwide campaign called "Sparsh Leprosy Awareness Campaigns" were introduced under National Leprosy Eradication Program on 'Anti-Leprosy Day', 2017 i.e. 30th January 2017. These are theme based campaigns, in which a different theme is introduced every year by Central Leprosy Division. Regular IEC and awareness is being given by the health workers throughout the year.

Dr. Bisworanjan Dash, DADG, Stated that Leprosy affected persons are those who are under treatment with MDT as well as leprosy cured but disabled person (LCDP). The schemes and benefits available for leprosy affected persons are to be publicized.

Shri. Rajiv Manjhi, JS, Dte.GHS agreed with DDG(L) and added that NLEP is taking care of medical rehabilitation of the leprosy affected persons, which may not be dubbed as comprehensive rehabilitation. He therefore asked representative of Department of Empowerment of Persons with Disability to explain the rehabilitations scheme, which are meant the leprosy affected persons and their families. Adding to this Dr. V. Santaram has mentioned the department may also brief about the comprehensive community based rehabilitation scheme for leprosy affected persons.

Department of Empowerment of Persons with Disability (DEPwD):

Shri.Shantanu Virendra stated that Leprosy cured is included as a specified disability under Rights of Persons with Disabilities Act, 2016, which came into force from 19.04.2017. The RPwD Act, 2016 provides various rights and entitlements for persons with disabilities which are equally applicable to leprosy cured. Unlike in the repealed PwD Act, 1995, leprosy cured has been clearly included as one of the beneficiary category of PwDs for getting reservation in government jobs.

He further stated that Relief to the disabled is a state subject by virtue of entry 9 of the State List. DEPwD implements the various schemes and programmes to supplement the efforts of the States in this direction which are equally applicable to all categories of PwDs covered under the RPwD Act, 2016. The Scholarship Schemes being implemented by the Department for students with disabilities are also applicable to leprosy cured students. However, the following schemes of the Department have separate element for leprosy cured persons:

Assistance to Disabled persons for purchasing / fitting of aids / appliances (ADIP) scheme:- Under this Scheme grant-in-aid is provided to assist the needy PwDs in procuring durable, sophisticated and scientifically manufactured,

modern, standard aids and appliances that can promote their physical, social and psychological rehabilitation, by reducing the effects of disabilities and enhance their economic potential. The aids and appliances supplied under the Scheme conform to BIS specifications to the extent possible. Under this programme for leprosy cured persons (LCPs), the following aids and appliances are provided:

- (i) ADL Kit consisting of Universal Cuff, Nail Cutting Device, Soap Holder, Button Hook, Zipper Pull, Writing Aid or Adapted Pen with positioning splint, Rubber Gloves, Insulated Scissors, Insulated Tumbler or Adapted Glass Holder, Wider Blim Plate, Long Handled Lever Tap, Cell Phone.
- (ii) Individual Devices (optional as per requirement) such as Adapted Spoon, Built up Spoon, Angled Spoon, Grip Aid, Latex Prosthesis, Gutter Splint, Extension outrigger- Short, Extension outrigger- Long, Thumb Spica, Volar/Dorsal cock-up, Finger Loops, Knuckle Bender, MCP Block, Opponens Strap, User Friendly Spoon, Build-up Screw Driver, Foot Drop Strap, Farming Gloves, Padded Sand Digger, Anti Claw Positioning Device/Knuckle Bender Splint, Fixed Ankle Brace, Patellar Tendon Bearing Brace(Conventional), Patellar Tendon Bearing Brace(Moulded), Foot Orthosis Moulded insole, Temporary below knee Prosthesis, Permanent below knee Prosthesis, Patellar Tendon Bearing Orthosis, Foot Drop Spring, Patellar tendon bearing Orthosis variant, Moulded Sandal, MCR Sandal, Custom made Symes Prosthesis, Ankle Foot Orthosis (AFO)/Fixed Ankle Brace (FAB), Accommodative foot Orthosis

In addition, Silicon liners, heel cup and finger foot cover have also been recently included for distribution to leprosy cured under the above scheme. Since 2014-15, 6329 leprosy cured persons have been benefited under this scheme.

Deendayal Disability Rehabilitation Scheme: Under this Scheme financial assistance is provided to voluntary organizations to make available the whole range of services necessary for rehabilitation of persons with disabilities including early intervention, development of daily living skills, education, training and awareness generation. One of the projects under the Scheme is 'Project for rehabilitation of leprosy cured persons'. Under this project, vocational training component is strongly encouraged project for shelter workshops are also covered for leprosy cured persons under this scheme. The objective of this project is to empower leprosy cured persons with skills that would enable self-employment or entrepreneurship either individually and/or collectively. Each vocational training center should cater to at least 25 or above

leprosy cured persons. The scheme also supports homes for severely disabled leprosy cured persons for 50-100 persons.

In the context of removing stigma and creating awareness towards rights and entitlements of LCPs are concerned, it is stated that the Department does not have disability-wise awareness generation programmes. However, the Department implements a Scheme for Awareness Generation and Publicity for creating awareness about schemes and programmes for PwDs covered under RPwD Act, 2016 including leprosy cured persons.

B) The Union Government may consider framing separate rules for assessing the disability quotient of the leprosy affected persons for the purpose of issuing disability certificate in exercise of the power granted under the Rights of Persons with Disabilities Act 2016 (No. 49 of 2016).

PwD Act (M.E Division) and Department of PMR VMMC & Safdarjung Hospital.

Dr. B Srinivas, and Dr. Diganta Borah have stated the already the rules for assessing the disability quotient of leprosy affected person is in place as per the Gazette of India, Ministry of Social Justice and Empowerment, Department of Empowerment of Person with Disabilities (Divyangian) has Notification dated 4th January 2018. In which Section I: para 16. Leprosy Cured Persons with disabilities. The same grading is being issued in issuing the disability certificate in the hospitals. As mentioned in the notification para 18.3 "The Medical Superintendent or Chief Medical Officer or Civil Surgeon or any other equivalent authority as notified by the State Government shall be the head of the certification board for the purpose of certification of locomotor disability including cerebral palsy, leprosy cured, dwarfism, acid attack victims and muscular dystrophy. The Board shall comprise of: (i) Medical Superintendent or Chief Medical Officer or Civil Surgeon (ii) Specialist in Physical Medicine and Rehabilitation or Specialist in Orthopedics (iii) One specialist as nominated by Chief Medical Officer as per the condition of the person with disability. This is being followed.

Central Leprosy Division, DteGHS, MoHFW

Dr. Anil Kumar, Dr. V Santaram and Dr. Bisworanjan Dash

Above mentioned points regarding disability certificate statement is agreed. However, Dr V Santaram, stated instead of grading of Eye as 0,1,2 mentioned in the Gazette, it should be Graded as 0 or 2 according to severity of disability in eye as per revised DPMR Guidelines of GOI 2011-12 Page no. 31 and 32. Asked the DEPwD to brief on the framing separate rules for assessing

the disability quotient of the leprosy affected persons for the purpose of issuing disability certificate.

Department of Empowerment of Persons with Disability:

The Department notified the guidelines for assessment of various specified disabilities on 04.01.2018. Under these guidelines, separate provision has been made for assessment of disability on account of leprosy under para 16. These guidelines are required to be followed by all competent medical authorities for assessment and certification.

- **2. Conclusion:** With the fruitful discussion it is clear that DteGHS, Ministry of Health and Family Welfare is looking after Medical Rehabilitation of the Leprosy affected persons. The Department of empowerment of Persons with Disability is having various rehabilitation schemes for leprosy affected persons and their family. The rehabilitation schemes and other benefits available for leprosy affected persons may be publicized.
- **3.** The Medical Superintendent or Chief Medical Officer or Civil Surgeon or any other equivalent authorities as notified by the State Government are the head of the certification board for the purpose of certification of leprosy cured and issuing the disability certificates as per the guidelines. However, as mentioned in the Gazette notification (Section I: para 16.6) there is provision of review after two years, if needed or desired by the affected person, in view of likely worsening of deformities in some persons.
- **4.** Meeting ended with a vote of thanks to the Chair.

Annexure I

Following officers attended the meeting:

- 1. Shri Rajiv Manjhi, Joint Secretary in Chair
- 2. Dr.Anil Kumar, Deputy Director General (Lep)
- 3. Dr. B Srinivas, Assistant Director General (ME)
- 4. Dr. V. Santaram, Director, RLTRI, Aska, Odisha
- 5. Dr. Bisworanjan Dash, DADG (Lep)
- 6. Dr. Diganta Borah, Prof. Dept of PMR VMMC & Safdarjung Hospital
- 7. Shri. Shantanu Virendra, Sr. Consultant Policy, Dept of Empowerment of PWDs
- 8. Mr. Z. A Khan, Deputy Director (Lep)
- 9. Dr. Vijay Dhange, Consultant Public Health (CLD)