

**Minutes of Meeting of the NHRC Core Group on Disability
held on 15 February 2018**

A meeting of the Core Group on Disability was held in the Commission on 15 February 2018 which was **chaired by the Hon'ble Member, Shri S.C. Sinha, NHRC** and was attended by Senior officers/representatives of Ministry of Social Justice and Empowerment, Ministry of Health & Family Welfare, Ministry of Rural Development, All India Institute of Medical Sciences, Rehabilitation Council of India, domain experts and Civil Society Organizations/NGOs. The list of participants who attended the meeting is at **Annexure-I**.

2. At the outset, **Dr. Ranjit Singh, JS (P&A), NHRC**, welcomed all the participants. He apprised that the last meeting of the NHRC Core group on Disability was held in December 2016. Further, on the issue of Leprosy, a national Conference was organized in April 2015.

3. **Shri Ambuj Sharma Secretary General, NHRC**, in his welcome address, mentioned that unless the State Governments and the Government of India take affirmative actions following the provisions of the Act, the objective of the legislation will not be fulfilled and the whole purpose will be defeated. He further stressed upon the need for launching special campaigns throughout the country at the district level, not only for awareness generation about the issues relating to disability and leprosy, but also for simultaneously hearing of grievances of the persons with disability or affected by leprosy, and for taking remedial measures to resolve their grievances.

4. **Shri S.C. Sinha**, Hon'ble Member, NHRC while welcoming all the participants stated that each speaker would be given an opportunity to speak on both the issues namely, disability and leprosy. On the issue of leprosy, he requested the participants to elaborate on the ground situation as to how far we have been able to eradicate leprosy and the mental blocks associated with it. He further stated that the participants should also touch upon the various laws which are discriminatory in character and, therefore, need amendment. In this regard, he mentioned about the recommendations of the Law Commission for amending/ repealing laws which are discriminatory towards the persons affected by leprosy.

5. **Shri P.K. Pincha, Special Rapporteur, NHRC and ex-Commissioner for Persons with Disabilities**, initiated the discussion by pointing out the gaps between the United Convention on Rights of Persons with Disability (UNCRPD) and the Rights of Persons with Disabilities (RPD) Act, 2016. He stated that by and large the RPD Act, 2016 is basically in harmony with the UNCRPD but still there are certain glaring gaps between the two. Shri Pincha raised concern about the proviso of Section 3(3) of the RPD Act 2016 which states that 'no person with disability shall be discriminated on the ground of disability, unless it is shown that the impugned act or omission is a proportionate means of achieving a legitimate aim'. He stated that this proviso gives unfettered power in the hands of the executives to discriminate on the ground of disability which could lead to exclusions. Shri Sinha while agreeing with Shri Pincha apprised that a recommendation in this regard has already been sent earlier by the Commission to the Ministry of Social Justice and Empowerment.

6. Shri Pincha further apprised the participants that the clause (1) of Article 15 of the Indian Constitution bars the State from discriminating citizens on grounds of religion, race, sex, caste, and place of birth or any of them while clause (3) of Article 15 provides that nothing in the article shall bar the state from making any special provision for women and children. He suggested that there is a need to add disability in both clause 1 and clause 3 of Article 15 of the Indian Constitution. The Core Group members agreed with the suggestion.

7. On the **UNCRPD**, Shri Pincha stated that clause (3) of Article 4 of UNCRPD entrusts the State party to closely consult with and actively involve persons with disabilities including children with disabilities through their representative organisations, for the development and implementation of legislation and policies concerning issues relating to the persons with disabilities. He suggested that as India is a State party, the government should ensure that the persons with disabilities are actively consulted in respect of the matters which affect their rights. He further stated that RPD Act, 2016 makes good effort to give representation to the persons with disabilities in the bodies which are required to be created under the Act. However, when it comes to the composition of the Office of the Chief Commissioner under Section 74 of the RPD Act, it provides that only one out of three persons (1 Chief Commissioner and 2 Commissioners) shall be a person with disability. He stressed upon the fact that the existing Commissions on Women, SC, ST, Child Rights, etc., comprise of the members

belonging to the group for whom these Commissions are meant. On the similar lines, therefore, there should be provision for atleast two persons, i.e. either '*one Chief Commissioner and one Commissioner*' or '*two Commissioners*' belonging to the category of persons with disabilities under Section 74 of the Act. He further suggested that under section 98 of the RPD Act on 'Power to remove difficulties', the government can issue notification in this regard. Shri P.K. Pincha was requested by the Chair to provide a note on 'issuance of notification by the government under Section 74 of the Act for the appointment of 2 persons, i.e. either '*one Chief Commissioner and one Commissioner*' or '*two Commissioners*' with persons with disabilities and along with the rationale for the same.

8. Shri Pincha raised another concern pertaining to **Section 2 under the RPD Act, 2016**. He stated that sub sections 2(r), 2(s) and 2(t) of Section 2 provides definitions for 'persons with benchmark disabilities', person with disability and 'person with disability having high support needs' respectively. Further, subsection 2(s) provides a generic definition of persons with disabilities which has been literally copy pasted from para (2) of Article 1 of the UNCRPD. Shri Pincha further pointed out that Chapter 10 in the RPD Act, 2016 provides for certification of specified disability only which are mentioned in the Schedule of the Act, therefore the purpose of inserting 2(s) in the act is not clear. Shri Picha suggested that under section 98 of the Act, the government should issue a notification for removing this difficulty and accordingly, government may issue notification clarifying that sub section 2(s) of the Act does not create any stand alone category of persons with disabilities and rather enumerates certain common traits which are shared by all persons with disabilities, regardless of the category of disability they belong. Shri Sinha, however, differed and stated that since the RPD Act talks about the benchmark disabilities, then section 2(s) intrinsically becomes redundant.

9. The Chair (**Shri Sinha**) requested Shri Pincha to suggest some more actionable points that could go in the form of recommendations to the Government on the issue of implementation of the RPD Act, 2016. Shri P. K Pincha suggested the following **roadmap** including some points of action for consideration of the government for ensuring the implementation of the RPD Act.

- A. Finalization of rules under section 101 of RPD Act: The State Governments may constitute a committee for drafting the said rules. This Committee

should include government officials and representatives of organisations of persons with disabilities. Further, as the Central Government has come up with model rules, the same may be followed by the State Govts.

B. Institutionalizing monitoring regulatory and enforcement mechanisms/authorities as envisaged in the RPD Act:

- i. There is a need to regularize the Institution of State Commissioner for Persons with Disabilities so as to bring it in consonance with the provisions of this Act. Also, a five-member Committee need to be constituted as provided for in the Act to assist the State Commissioner.
- ii. There is a need to put in place the State Advisory Board on disability as stipulated in section 66 of the Act.
- iii. A district level committee should be set up in all districts as per the stipulation of the act.
- iv. Designate special courts and special public prosecutors for trying offences committed against the person with disabilities.

C. Issuance of Government orders/office memorandum: It is imperative that the government issues orders/office memorandums/instructions, etc. pursuant to various provisions of the Act.

D. Public education and awareness raising among stakeholders: There is a need to draw up a comprehensive plan for public education, sensitization and awareness raising amongst the stakeholders which has to be an ongoing activity.

10. **Shri Sudhir Kumar, Special Rapporteur, NHRC** stated that for the purpose of implementation of the Act, the disabilities defined under sub section 2(r) of the RPD Act, 2016, i.e., the benchmark disabilities, have been considered. Some of the disabilities which have been included were not there in the earlier Act. He pointed out that there are certain disabilities for which the assessment of the degree of disability is difficult and, therefore, gives scope to claim for disability certificate. Shri Sudhir Kumar suggested that there is a need to tighten the guidelines for the assessment of the physical disability. The Chair (Shri Sinha) **requested** Shri Sudhir Kumar to provide a note as to how physical disability

assessment guidelines can be improved upon for making it easier for issuance of the disability certificate.

11. Shri Sudhir Kumar further apprised that the Ministry of Social Justice and Empowerment, in pursuance of the provisions of Section 32 of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 {1 of 1996}, had constituted an Expert Committee for identification of posts for persons with disabilities. He suggested that the Committee should be reconvened for identifying the posts for Persons with Disabilities at Central level and if any State Government desires to take this task independently, it should form its own Committee. Further, the Committee should also review the distribution of posts after every three or six months.

12. **Dr. Manjari Tripathi, Professor, AIIMS**, suggested that the disabilities need to be mentioned in a more scientifically proper arrangement into categories. She proposed the list of 'Specified Disability' mentioned in the Schedule of the RPD Act, 2016 to be as follows:

1. Disabilities accruing from chronic/ highly recurring Neurological disorders:
 - a) Autism spectrum disorder/Cerebral Palsy/ Specific Learning Disability/ Intellectual Disability
 - b) Drug Refractory Epilepsy/ Epilepsy with any of 1(a) or 3
 - c) Muscular Dystrophy, Multiple Sclerosis, Motor Neuron Disease, Stroke, Neuropathy, dementia all causing either 1(a) or 3
2. Disabilities accruing from Vision Impairment
3. Disabilities accruing from Locomotor/Orthopaedic Impairment
4. Disabilities accruing from Speech and Hearing Impairment
 - a) Deafness
 - b) Speech and Language Disability
5. Multiple Disabilities
 - a) Deaf, Blind, it involves 2 and 4 above
 - b) Spinal Cord Injuries (traumatic and non traumatic); it involves 1 and 3 above*

6. Disorders of Blood

- a) Haemophilia
- b) Thalassemia

7. Mental Illness/ Mental Retardation/ Psychiatric Disorder

8. Leprosy with sequelae causing 2,3,4,5.

13. Dr. Manjari Tripathi spoke at length on the procedure to be followed for issuing of the disability certificate. She stated that presently, a disability certificate gets issued by a Medical Board consisting of at least three members duly constituted by the Central/State Government. If any of the member is not available the person with disability is not issued the certificate. This becomes problem for those who come from far areas. She stated that it should suffice if one doctor issues the disability certificate. In case the doctor is not confident then he/she could refer to another doctor. Dr. Tripathi further suggested that the disability certificate should be issued from the hospital treating the patient, instead from the district or area to which he/she belongs. Further, the disability certificate should be issued within a week of the request, and for the outstation patients it should be sooner. However, a recommendation in this regard has already been sent by the Commission to the Secretary, Department of Empowerment of Persons with Disabilities.

14. **Dr. Vineeta Shankar, Director, Sasakawa-India Leprosy Foundation**, made an observation on the Section 2(r), 2(s) and 2(t) of the RPD Act, 2016. She stated that confusion has occurred because of the order of placement of subsections 2(r), 2(s) and 2(t), and if sub section 2(s) had been placed first and then sub section 2(r), there would have been no confusion. However, she stated that sub section 2 (r) of the Act provides a generic definition and does not take away or add any specificity to the overall definition of the persons with disabilities.

15. Dr. Shankar stated that Leprosy Affected Persons (LAP) are dissatisfied with the degree of disability defined for the LAP under the Act as they become disabled at a percentage of disability which is less than 40 per cent. She suggested that for a leprosy affected person the benchmark disability should be brought down to a percentage below 40. The Chair (**Shri Sinha**) requested her

to share her views on the efficacy of the leprosy eradication programme. On medical aspect, she stated that a lot has been done at the ground level in terms of outreach but there are still many PHCs, where doctors lack expertise to identify leprosy. Further, there is non-availability of medicines to treat leprosy. On the welfare aspect, Dr. Shankar stated that although there has been decline in the number of people affected by leprosy, but stigma continues to be rampant for those who are affected by leprosy. There is lack of awareness about leprosy. People still have assumption that leprosy is contagious and hereditary.

16. **Dr. Dharamshaktu, Principal Advisor on Public Health, Ministry of Health and Family Welfare** highlighted that leprosy eradication programme requires community involvement. He stated that as far as leprosy identification and treatment is concerned, inadequate attention is being paid to the training which needs to be restored. He suggested that in every village, 4 persons should be identified, preferably unemployed or 10th standard dropout as they will remain in the village. These four persons can be given different sets of responsibilities. The first person would deal with the preventive, promotive, supporting services in respect of housing, water, sanitation and environment which directly affect leprosy. The second person will do the work related to the communicable diseases. Third person would deal with the nutrition and life support items. The last person will deal with all types of disability and impairment issues. Dr. Dharamshaktu was requested by the Chair (**Shri S.C Sinha**) to provide note on this.

17. **Shri. K.V.S. Rao, Director(R), Department of Empowerment of Persons with Disabilities** stated that the first meeting of the Central Advisory Board was held yesterday i.e. on 14.02.2018. Only 3 States have framed the rules. Others are considering consultation with CSO for finalizing the rules. He mentioned about important features of the Act. Regarding leprosy, he stated that their department comes into picture only after leprosy is cured but still suffering from some sensory problem. He gave example that 'dwarfism' was mentioned in the Act but the definition is improved in the Rules, as dwarfism would mean difficulty in climbing stairs and not merely having height of 4'10".

He further apprised the members about the steps taken by the Government for implementation of the RPD Act:-

- Regarding the discriminatory laws, he stated that the concerned Ministries are directed to take necessary actions to repeal or amend the laws in order to make lives of the Leprosy affected people better.
- The RPD Act, 2016 has lots of rights and entitlements for the persons with disability and, therefore, their department had organized regional conferences to create awareness about the Act and its Rules.
- The Department of Personnel and Training has issued an Office Memorandum regarding 4% reservation for the Persons with Benchmark Disabilities as per Section 2(r) of the Act against the posts and services of the Central Government. Identification of posts in Central Govt. was proposed to the State Govts but they have choice to accept it or not. The Committee has been constituted for the same.

17. **Shri. S.C Sinha** recommended that Rule 18 (1) needs to be re-examined as it covers an issue of certificate of disability stating that on receipt of an application under Rule 17, the medical authority or any other notified competent authority shall, verify the information as provided by the applicant and shall assess the disability in terms of the relevant guidelines issued by the Central Government and after satisfying himself that the applicant is a person with disability, issue a certificate of disability in his favor in Form V, VI and VII, as the case may be. Shri Sinha suggested that a Board is necessary in the rules, however, for the cases of vision disabilities, only one member is sufficient. Shri Rao stated that form V of the Rules should be taken note of as the amendment of the same will impact the rights of disabled.

18. **Shri Sinha**, suggested that there is a need to take care of the accessibility aspect of the Act and, therefore, random inspection of public buildings must be done to ensure that each public building is properly accessible to the disable population.

19. **Dr. Subodh Kumar, Dy. Director, Rehabilitation Council of India (RCI)** stated that the RCI is primarily mandated to promote research. He informed that Rehabilitation Council of India Act, 1992 to be amended and the draft amendment required to be submitted is under process. A core committee has been formed to identify various courses required in the field of disability. As per the Section 47 (1), without prejudice to any function and power of Rehabilitation Council of India constituted under the Rehabilitation Council of

India Act, 1992, the appropriate Government shall endeavor to develop human resource for the purpose of this Act. Dr. Kumar stated that they are providing financial support to Universities to conduct research. As per Section 39 (1) the appropriate Government, in consultation with the Chief Commissioner or the State Commissioner, as the case may be, shall conduct, encourage, support or promote awareness campaigns and sensitization programmes to ensure that the rights of the persons with disabilities provided under this Act are protected. Therefore, in alignment with this section, RCI has taken up 59 courses to be conducted by the private/national/medical colleges. He mentioned that training aspect need to be strengthened considering the growing population affected by various disabilities. Also, there is a need for a special educator for every 10 disabled children; therefore, more manpower is required to manage persons with disabilities. RCI is responsible for development and standardization of training courses in the field of Disability, Rehabilitation & Special Education and to update and upgrade the knowledge & skills of professionals working in different areas of disability. The information regarding Continuing Rehabilitation Education (CRE) topics and programmes being conducted at selected RCI approved training institutions is given nationwide for the Rehabilitation professionals & personnel working in the disability areas, so that they can join the nearby centre to upgrade their skills.

20. Dr. Anil Kumar, Director General, Deputy Director General (Leprosy), NLEP stated that the leprosy was declared eliminated in 2005 but it was never eradicated. He mentioned that incubation period itself is of 5 to 7 years. Drew attention to the 2010 ICMR survey where lot of hidden cases were found, therefore, in 2015 an intensified leprosy case detection campaign was launched by the Union Ministry of Health and Family Welfare. Out of 36 crore population covered in 163 districts across 20 states at least 35,000 hidden cases were detected during a massive door-to-door campaign from September 14-October 4, 2016. Hidden cases are those that go unreported, mainly due to the fear and stigma associated with the disease. Over 2 lakh volunteers, including Accredited Social Health Activists (ASHA), were involved in the campaign. Dr. Kumar mentioned about the drug, Rifampicin chemoprophylaxis, used as a preventive measure to the people in contact with the leprosy patients. Dr. Kumar talked about key areas of leprosy which need attention such as preventing leprosy, discrimination and detection. NLEP used the Panchayati Raj system to conduct awareness campaign in 6000 villages with the help of the

heads of villages. He shared his concern that more resources are required to but they have Rs. 46 crore only, which is insufficient.

21. He mentioned that the leprosy cases have increased from 58% to 68% but that shows that there are less hidden cases now. The 'Made in India' treatment called Chemoprophylaxis tried in a few districts has worked well.

22. Dr. Kumar stated that they need more resources to cover the entire country for detection of cases and treatment. Smt. Vineeta Shankar prompted that leprosy should be made Mission Mode because health is a state subject.

23. **Dr. Mary Verghese, Executive Director, The Leprosy Mission Trust India** suggested that there should be dedicated beds for leprosy patients especially in endemic districts and it should not be isolated and therefore there should also be dedicated hospitals for leprosy patients in the endemic districts.

24. **Ms. Nikita Sarah, Head-Advocacy and Communication, The Leprosy Mission Trust India** touched upon the following documents briefly and stated that the same will be provided to the Commission for ready reference:

- i. Assessment of disability of people affected by leprosy.
- ii. Private member bill prepared by K. T. S. Tulsī, MP which looks at the prevention of discrimination and inclusion of social rights.
- iii. She mentioned about the document which covers all the 119 discriminatory laws against person affected by Leprosy.

Ms. Sarah concluded by recommending that chronic neurological disorders must be included in the RPD Act, 2016. Shri S.C Sinha suggested that all the above mentioned documents will be used by the Commission while drafting recommendations.

24. **Shri S.C. Sinha** in the end of the meeting constituted a **sub-committee** on disability to be chaired by Dr. Ranjit Singh, Joint Secretary (P&A) and consisting of Dr. Subodh Kumar, Ms. Nikita Sara and Dr. Manjari Tripathi as members. They would engage in making a list of the entitlements of the specially abled persons and also other key issues pertaining to disability.

After due deliberations, the following recommendations emanated from the meeting:

1. Section 3(3) of the Rights of Person with Disability Act, 2016 mentions that no person with disability shall be discriminated on the ground of disability, unless it is shown that the impugned act or omission is a proportionate means of achieving the legitimate aim. Since the Act is silent on what constitutes the 'legitimate aim', it would give unfettered power to the executives to discriminate on the ground of disability. It was suggested that this issue could be taken care of while framing Rules by the Government.
2. Clause (1) of Article 15 of the Indian Constitution bars the State from discriminating citizens on grounds of religion, race, sex, caste, and place of birth or any of them while clause (3) of Article 15 provides that nothing in the article shall bar the state from making any special provision for women and children. It is recommended that disability should be added to clause (1) and clause (3) of Article 15 of the Constitution of India.
3. The composition of the Office of the Chief Commissioner under Section 74 of the RPD Act, provides that only one out of three persons (1 Chief Commissioner and 2 Commissioners) shall be a persons with disabilities. It is suggested that there should be provision for two persons i.e. either '*one Chief Commissioner and one Commissioner*' or '*two Commissioners*' with persons with disabilities under Section 74 of the Act. Accordingly, government can issue notification in this regard under Section 98 of the RPD Act.
4. Ministry of Social Justice and Empowerment, in pursuance of the provisions of Section 32 of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 {1 of 1996}, had constituted an Expert Committee for identification of posts for persons with disabilities. It is recommended that the Committee should be reconvened for identifying posts for persons with disabilities at Central level and if any State Government desires to take this task independently, it should form its own Committee. The Committee should also review the distribution of posts every three months.
5. Rehabilitation Council of India Act, 1992 (as amended in 2000) and National Trust Act, 1999 need to be harmonized.
6. There should be dedicated beds in the hospital for leprosy patients especially in endemic districts and it should not be isolated. Further, there should be dedicated hospitals also for leprosy patients in the endemic districts.

List of Participants

NHRC

1. Shri. S. C. Sinha, Member
2. Shri Ambuj Sharma, Secretary General
3. Dr. Ranjit Singh, Joint Secretary (P & A)
4. Dr. M. D. S Tyagi, Joint Director (Research)
5. Shri Sudhir Kumar, Special Rapporteur, NHRC
6. Shri P.K. Pincha, Special Rapporteur, NHRC
7. Pritika Sejwal, JRC
8. Priyanka Tariyal, JRC
9. Devesh Saxena, JLRC

Core Group Members and Special Invitees

1. Dr. Manjari Tripathi, Professor Neurology, Department of Neurology, AIIMS
2. Dr. Vineeta Shankar, Director, Sasakawa-India Leprosy Foundation
3. Shri. K.V.S. Rao, Director(R), Department of Empowerment of Persons with Disabilities
4. Dr. Subodh Kumar, Dy. Director, Rehabilitation Council of India
5. Dr. Anil Kumar, Deputy Director General (NLEP)
6. Dr. Mary Verghese, Executive Director, the Leprosy Mission Trust India
7. Ms. Nikita Sarah, Head-Advocacy and Communication, the Leprosy Mission Trust India