

SUPREME COURT OF INDIA

Pankaj Sinha

Vs.

Union of India

WP(Civil)No.767 of 2014

(Dipak Misra,CJI., A.M.Khanwilkar and Dr.D.Y.Chandrachud,JJ.,)

14.09.2018

JUDGMENT

Dipak Misra,CJI.,

The instant writ petition preferred under Article 32 of the Constitution of India seeks issue of directions to the Union of India and the States, the respondent Nos. 1 to 30 herein, to conduct periodic national survey for determining new cases relating to detection rate of leprosy and to publish and bring in the public domain the reports of National Sample Survey on Leprosy conducted in 2010-2011 and further to conduct regular and sustainable massive awareness campaigns for the general public to dispel fear associated with leprosy and support and encourage the people afflicted by the said disease to lead a life of equality and dignity.

2. It is also prayed that the respondents should ensure that Multi-Drug Therapy (MDT) drugs and other drugs for management of leprosy and complications in leprosy are available free of cost and do not go out of stock at all Primary Health Centres (PHCs) in the country and also direct all hospitals and health care institutions throughout the country, whether private or Government, not to discriminate against women with leprosy and not to turn them away and deny them treatment. A relief is also sought to issue mandamus to all the schools in the country not to discriminate against children from leprosy affected families and to provide them free education. The petitioners also seek for providing hygienic conditions in leprosy colonies and to make MCR footwear available free of cost to the leprosy affected persons in the country. That apart, a prayer has been made to direct the Union of India to frame separate rules for evaluation of disabilities suffered by 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).

3. When the matter was listed on 1st September, 2014, the following order came to be passed:-

"In support of the petition preferred under Article 32 of the Constitution of India, it is submitted by Mr. Gonsalves that despite the human civilization has advanced in

advancement made in the field of medicine and in spite of civilisation having reached the pinnacle of scientific research, an effective cure, namely, Multi-Drug Therapy (MDT) which has been available since 1981 that can completely cure 99% of leprosy bacteria, due to apathy of the Government of India and the State Governments, people are still suffering from the said disease, which is treated as a social stigma.

It is urged by him, had people been made aware by the competent authorities of the Central Government and the State Governments, millions of people who are suffering from leprosy would have been cured and come to the mainstream of life and would not have been ostracized from the society. Learned senior counsel would contend that because of non-concern, the leprosy affects more than one lakhs twenty five thousand persons yearly throughout the country, which is completely avoidable. It is averred in the petition that they are not allowed to have education, sanitary benefits, community based rehabilitation as a result of which they are driven to streets and eventually turn to begging or compelled to live in so-called leprosy homes where they are treated as unpersons or aliens.

In the writ petition, number of prayers have been made which pertains to issuance of directions for availability of the drugs at primary health centres and proper administration of the same for treatment of the pregnant women suffering from leprosy in an apposite manner with dignity, and making provision in educational institutions whether government or private, so that discrimination against the children of the leprosy affected families due to some kind of inhibition which has no constitutional sanction, is stopped and for providing banking facilities and establishment of such colonies where they can live for temporary period till they are cured and come to the society, etc."

4. On 28th November, 2014, the Court passed the following order:-

"Mr. Maninder Singh, learned Additional Solicitor General appearing for Union of India prays for four weeks time to file the requisite data as directed by this Court vide order dated 1.9.2014. Mr Singh has assured this Court that he will not seek further adjournment. The respondent States shall file their respective replies within the said period. If, they are unable to collect the data throughout the State, whatever data they have collected during the time granted by us, shall be brought on record. We have granted four weeks time as we are inclined to think that this is a cause which can be taken on a priority basis by the States, for what has been agitated before us is that the leprosy, as on today, is curable. Yet, because of apathy shown by the concerned authorities, it still remains a stigmatic disease in the society. It is inconceivable as it affects the human dignity and the basic concept of humanness."

5. Be it noted, the Insurance Regulatory and Development Authority (IRDA) and the Reserve Bank of India (RBI) were arrayed as respondent Nos.31 and 32 in the writ petition and they had taken time to obtain instructions.

6. On 13th January, 2015, after taking note of the submissions made by the learned counsel for the parties, the Court had noted thus:-

"Needless to say, curability is admitted depending upon the degree. As advised at present, we are of the convinced view that more progressive steps are required to be taken by the Union of India and the States. It would be advisable, if the Union of India and the States can think of having Leprosy Cure Centres, where medication follow up and other treatment protocols are followed in proper prospective so that the stigmatic disease is eradicated or reduced to a significant percentage. Mr. Maninder Singh, learned Additional Solicitor General and other learned counsel appearing for various States pray for four weeks' time to obtain instructions in this regard."

7. Taking into consideration the affidavits filed and instructions obtained, the Court, on 23rd April, 2015, passed the following order:-

"It is submitted by Mr. Maninder Singh, learned Additional Solicitor General appearing for Union of India, that as far as prayers (A) and (B) are concerned, he will produce the data and the report as prayed for and also file a reply supported by an affidavit in that regard. As far as prayer (E) is concerned, we would like Mr. Maninder Singh, learned Additional Solicitor General to obtain instructions whether the concerned Ministry, i.e., Ministry of Health and Family Welfare, Government of India, has any team which is exclusively meant to look after the leprosy homes or leprosy colonies and eventually the patients suffering from leprosy. We would like the affidavit to contain what kind of treatment is administered when the initial symptoms get manifested. In essence, whether there is any machinery to that effect. We have so directed as there is no dispute that the leprosy is totally curable in 21st century. We accept the submission of Mr. Kamlesh Kumar Mishra, learned counsel for the petitioner, that the Union of India and all the State Governments have a duty to see that this century old stigmatic disease is eradicated. We also accept his submission that it can be done with a concerted effort by the Union of India and the States. Mr. Ranjit Rao, learned AAG for the State of U.P., has submitted that in the State of U.P. there is a rehabilitation programme of the leprosy patients and throughout the State, the patients are administered medicines and some of them have been cured. Be it noted, the Director General of Medical and Health, Government of U.P. has filed an affidavit in that regard. At this juncture, it is necessary to state that the affidavit reflects that there are 72 leprosy centres and in the 72 centres, approximately 5,000 persons, including the leprosy patients and their dependents, are residing. The said aspect is required to be verified and accordingly we constitute a Committee consisting of Mr. Ashok Gupta, learned senior counsel, Supreme Court of India, Mr. Om Subhash Tripathi, M-1, Govindpur, Allahabad and Mr. Chander Shekhar Singh, 58/14, Lai Bhadur Shastri Marg, Civil Lines, Allahabad.

The Committee shall initially visit the leprosy homes at Lucknow, Banaras and Agra. The Committee shall submit a report within eight weeks hence. The State Government shall pay the fees of the members of the Committee which is conceded to by Mr. Ranjit Rao, learned AAG. This concession is given in presence of Mr. Vijay Bahadur Singh, learned Advocate General for the State of U.P. We are not determining the quantum of fees. We hope that the State will fix the quantum, regard

being had to the experience of the 5 members of the Committee at the Bar. The visits of the Committee shall be coordinate by Mr. Rao after holding discussions with Mr. Ashok Gupta, learned senior counsel."

8. It is worthy to note here that during the pendency of this writ petition, another Writ Petition (Civil) No. 1151 of 2017 was filed seeking the relief that number of legislations be declared as unconstitutional being violative of Articles 14, 19(1)(d), 19(1) (g) and 21 of the Constitution of India. In the course of hearing of the said writ petition, our attention had been drawn to the 256th Report of the Law Commission. The said report had been submitted on the basis of the initiative taken by the Union of India titled "Legal Enactments Simplification and Streamlining". The Law Commission had referred to the provisions of the Leprosy Act and adverted to the Second Interim Report No.249 wherein it had been mentioned that India is a member of the U.N. General Assembly which unanimously passed a resolution on the elimination of discrimination against persons affected by leprosy and their family members. As per the Law Commission Report, the Leprosy Act was against the spirit of the Resolution and, therefore, required immediate repeal in consultation with the States. Paragraphs 2.2.1, 2.2.2 and 2.2.3 were reproduced by this Court when the said writ petition was taken up on 5th July, 2018. We think it appropriate to reproduce the said paragraphs and other paragraphs that had been adverted to for proper appreciation:-

"In paragraphs 2.2.1 to 2.2.3, there has been a reference to the facts and myths surrounding leprosy. We think it appropriate to reproduce the said paragraphs:

"2.2.1 There are several myths and distortions surrounding Leprosy that are sought to be clarified in this Chapter. Such myths consider Leprosy as a hereditary and infectious disease that is caused due to impure blood and poverty. Many also believe that the infection of Leprosy spreads through food and water and is difficult to detect. However, all such beliefs are not based on evidence and therefore without merit.

2.2.2 Leprosy is not a hereditary disease and is not caused due to impure blood or poverty, but due to the causative agent Mycobacterium Leprae as mentioned above. Further, even though Leprosy is a chronic infectious disease, it is neither difficult to diagnose nor hard to treat. The main consideration for an effective Leprosy treatment is early detection and regularity in treatment.

2.2.3 All persons are not susceptible to Leprosy, although insanitary conditions, malnutrition and lack of personal hygiene may increase the chances of getting infected by the Leprosy bacillus or a host of other diseases and infections caused on account of such conditions. Further, Leprosy is not a fatal disease, even though on account of the stigma and discrimination, it may cause permanent psychological and social damage to the victims."

In paragraph 2.4.2., it has been mentioned that leprosy is a completely curable disease. We think it relevant to reproduce paragraph 2.4.2. which is to the following effect:

"2.4.2 Although Leprosy is the cause of irreversible disabilities, with advances in science and technology in the field of Leprosy treatment during the last three decades, it is now a completely curable disease that can be rendered non-infectious in the initial stages of the treatment itself. The treatment that has made it possible to cure Leprosy is the process of Multi-Drug Therapy ("MDT"), which was first recommended by the WHO in early 1980s after over 40 years of research and testing. Under MDT, powerful drugs such as Rifampicin, Clofazimine and others in combination with Dapsone, are administered to the affected person to effectively fight the Leprosy bacillus. Over the past two decades, more than 15 million Persons affected by Leprosy are said to have been cured under MDT."

Eventually, after analysing various aspects, the Law Commission recommended as follows:

"7.13 This statute should be titled as the "Elimination of Discrimination against Persons affected by Leprosy Bill, 2015". This standalone law, apart from comprehensively covering the repeal/modification of the specified statutes, shall contain principles of nondiscrimination and equal protection before law. These principles shall specify that (1) No person, or public or private establishment shall discriminate against any person affected by Leprosy, or members of his family on any ground in relation to their affliction of Leprosy, or their disability, physical attributes or any other form of their association with Leprosy; and (2) All persons affected by Leprosy and members of their family shall be entitled to the recognition, enjoyment and exercise, on an equal basis, of all human rights including freedoms guaranteed by the Constitution of India. Further, the law shall also contain enabling provisions regarding affirmative action and repeal and amend discriminatory provisions listed above.

7.14 A model Bill is provided in the Annexure for the consideration of the Government of India. The Law Commission of India believes that the fact that India is home to the most number of Persons affected by Leprosy in the world is a matter of deep shame. Further, despite clear scientific evidence and pioneering social efforts, the stigma associated with leprosy still continues unabated. The proposed Bill is an important step in eliminating the social discrimination faced by such persons, a necessary precursor to their reintegration into society. As a humane society that believes in human rights for all, especially its poorest, the Law Commission believes that the Bill should be converted into a law as expeditiously as possible by the Government of India."

9. After referring to the same, the Court observed:-

"The annexure contains a draft Bill, namely, Eliminating Discrimination Against Persons Affected by Leprosy (EDPAL) Bill, 2015. The Law Commission recommended the repeal of the Lepers Act and other laws, which create any kind of stigma, disability or discrimination against persons suffering from leprosy. Despite the recommendations made by the Law Commission, it is submitted by Mr.Raju

Ramachandran, learned senior counsel for the petitioner, no steps have been taken to repeal those obsolete laws, except for the Lepers Act which has been repealed."

10. In the said order, a reference was made to a two-Judge Bench decision rendered in *Dhirendra Pandua vs. State of Orissa and Others*¹ wherein the learned Judges had taken note of the progress made in the field of science and technology and curability of leprosy. The said paragraphs read as follows:-

"29. It is true that now with aggressive medication a patient may be fully cured of the disease, yet the Legislature in its wisdom has thought it fit to retain such provisions in the statute in order to eliminate the danger of its being transmitted to other people from the person affected by the disease. Having regard to these circumstances, we are convinced that the said classification does bear a reasonable and just relation with the object sought to be achieved by the statute in question and cannot be said to be unreasonable or arbitrary. Accordingly, we hold that Sections 16(l)(iv) and 17 (l)(b) of the Act are not violative of Article 14 of the Constitution.

30. Before parting with this case, we deem it appropriate to point out that having regard to the changed concept and knowledge gained about the disease of leprosy, on the recommendation of the Working Group on Eradication of Leprosy, appointed by the Government of India, many State Governments and Union Territories have repealed the antiquated Lepers Act, 1898 and subsequent similar State Acts, providing for the segregation and medical treatment of pauper lepers suffering from infectious type of disease. Therefore, keeping in view the present thinking and researches carried on leprosy as also on tuberculosis, and with professional input, the Legislature may seriously consider whether it is still necessary to retain such provisions in the statutes."

11. In the said order, the Court emphasized on social awakening, the curability of the disease and lack of professional approach to the same and the social stigma that still remains attached to the said disease. The directions issued by the Court in the said case are to the following effect:-

"(i) The Union of India and the Department of Health and other concerned Departments shall carry out awareness campaigns at various levels so that people come to know about the curability of the disease and of its not being contagious.

(ii) Some responsible authorities, at least two, shall be exclusively nominated for the said duty.

(iii) There should be specific programmes on All India Radio and Doordarshan, both at the Central and the State level, as also on the regional channels, for educating people about the fact that leprosy is not a communicable disease and not to treat any person suffering from that disease with any kind of stigma or discrimination.

(iv) The programmes shall be shown on Doordarshan, both on the national and the regional channels, to the extent feasible on prime time so that the people can see them.

(v) Hospitals should not decline to treat such patients suffering from leprosy for administering the first dosage and thereafter provide treatment if they suffer from any other disease. It has to be remembered that a person has a right to avail the treatment in the government hospitals.

(vi) The awareness campaign must cover all areas from urban areas to the panchayat level so that there will be a concrete and holistic approach with regard to awareness.

(vii) The Union of India and the States shall take steps to rehabilitate persons suffering from leprosy to bring them in the main-stream. It should be the primary duty of the State to see that this category of persons does not suffer from any kind of stigma.

(viii) We would commend to the Union of India and the State Governments to apprise us about the steps taken with regard to the repeal of the provisions where leprosy has been treated as a stigmatic disability. A report of compliance shall be filed by the Union of India as well as all the States."

12. The said writ petition was adjourned to 20th August, 2018, seeking due compliance. On 20th August, 2018, after hearing the learned Attorney General for India and learned counsel for the parties, the Court passed the following order:-

"In the course of hearing of the petition, we sought the assistance of Mr. K.K. Venugopal, learned Attorney General for India. According to Mr. Venugopal, apart from positive law and repeal of statutes which relate to the stigma attached to leprosy patients, there has to be awareness campaign at various levels so that the people come to know that the disease is not incurable and further, after administration of the first dosage, it ceases to be contagious. Learned Attorney General would also submit that the patients suffering from leprosy, who have lost their limbs, can be brought to the mainstream of society if certain treatments are given by plastic surgery.

Mr. Raju Ramachandran, learned senior counsel for the petitioner submitted that pending repeal of the enactments, this Court should issue directions so that the patients suffering from leprosy live a life of dignity with decency. Regard being had to the non-adversarial submissions at the Bar, we would ask the learned Attorney General as well as Mr. Raju Ramachandran, learned senior counsel for the petitioner to give their suggestions in writing so that this Court will be in a position to issue appropriate directions. Let the matter be listed on 10.09.2018. In the meantime, learned Attorney General shall apprise us whether a recommendation can be made to the legislature to pass an affirmative law conferring certain rights and benefits on the

persons suffering from leprosy and any statute, rule, regulation or enactment, running counter to the affirmative law, shall be treated to have been repealed."

13. On 10th September, 2018, the following order came to be passed:-

"Mr. Raju Ramachandran, learned senior counsel has filed certain 'Suggestions' as part of his submissions. He has given 11 suggestions. Out of the 11 suggestions, suggestion nos.10 and 11 pertain to the legislative realm. Mr. Venugopal, learned Attorney General would pray for six weeks' time in respect of these two aspects. As far as the other 9 suggestions are concerned, prima facie we are of the view that they would fall within the executive sphere. The said suggestions are - (i) Awareness, Sensitisation and Dissemination of action taken; (ii) Nondiscrimination; (iii) Pensionary benefits for persons affected by leprosy; (iv) Healthcare and Rehabilitation; (v) Housing assistance; (vi) Education; (vii) Employment and livelihood; (viii) Welfare; and (ix) Language and Expression.

We would request Mr. Venugopal, learned Attorney General to assist with regard to the aforesaid 9 aspects by filing his suggestions within four weeks hence. All the States shall file their response with regard to the steps taken and to be taken, keeping in view the constitutional goal."

14. In the instant writ petition, the petitioner has drawn the attention of the Court to the fact that although leprosy as a disease has been scientifically and medically proven to be curable and manageable with MDT, yet the fact remains that millions of people and their family members still suffer from leprosy and the social, economic and cultural stigma attached to the said disease. This fact reveals the lack of awareness and the prevailing misguided notions in the society pertaining to leprosy. Further, the miserable plight of the persons afflicted with leprosy does not end here. It has been highlighted that due to the disability that entails as a result of the disease, the people affected by leprosy suffer additional discrimination in the form of denial of access to health services, education and livelihood options. At present, majority of the populace which is afflicted with leprosy live as a marginalized section in the society deprived of even basic human rights which manifestly results in violation of the fundamental right to equality and right to live with dignity.

15. It has been further brought to the attention of the Court that as per the requirements of the World Health Organization (WHO), all countries are required to achieve a prevalence of less than one leprosy case per 10,000 persons and although India had declared way back in 31.12.2005 that it has achieved the said goal of elimination of leprosy, yet the progress reports of NLEP which have been reporting prevalence rate in certain States of the Ministry of Health and Family Welfare exhibit an entirely different reality. As per the said reports, out of 642 districts in India, only 543 districts have achieved a prevalence rate of less than one case of leprosy for 10,000 persons. The underestimation of the cases of leprosy and the declaration of elimination of leprosy has resulted in the integration of leprosy in general health services thereby leading to diversion of funds which would have otherwise been dedicated to eliminating leprosy.

16. The petitioners have expressed deep concern over the fact that although a National Sample Survey of Leprosy was conducted by the respondent No. 1, Union of India, yet the said survey has never been brought out in the public domain. The desired results have not been achieved due to improper dispensation of the MDT drugs through the PHCs established for the said purpose. It is urged that the staff of PHCs display sheer lack of sensitivity while dealing with patients affected with leprosy as a consequence of which the level of stigma and isolation still prevails amongst the said patients. Several incidents have also been reported which have brought to light the discriminatory treatment meted out by the Government hospitals to leprosy affected pregnant women and cases wherein women have been refused treatment solely on account of being affected by leprosy. Another aspect, that is, the area of education has also been brought forth by the petitioners. It has been urged that lack of adequate education facilities would further magnify the sense of insecurity and stigma prevailing amongst the persons affected with leprosy. For any development to take place, the first step would be in the direction of ensuring quality education for the children who are the wards of people affected with leprosy.

17. It has been pointed out that several instances have come to fore highlighting that the persons affected with leprosy are being provided with APL cards and not BPL cards which prevented these people from claiming benefits under various schemes brought out by the Government, such as the Antyodaya Anna Yojana (AAY), which again deprives this section of the populace from claiming their right to food. Deprivation of housing and other basic civic amenities, adequate sanitary facilities and rehabilitation programmes are yet other serious concerns which, if not addressed, would lead to the entire reformatory process taking a huge setback.

18. Keeping in view the factual matrix in entirety and the submissions advanced, we think it appropriate to issue the following directions :-

(i) The Union and the States are to undertake periodical national surveys for determining the prevalence rate and new cases detection rate of leprosy and, at the same time, publish and bring the reports of the National Sample Survey of Leprosy conducted in 2010-11 and subsequent thereto into the public domain. That apart, the activities of the National Leprosy Eradication Programme (NLEP) must be given wide publicity;

(ii) On leprosy day which is internationally observed every year on the last Sunday of January, the Union of India along with all State Governments should organize massive awareness campaigns to increase public awareness about the signs and symptoms of leprosy and the fact that it is perfectly curable by the Multi Drug Therapy (MDT). Awareness should also be spread about the free availability of MDT at all government health care facilities in the country, the prescribed course for MDT treatment and all other relevant information related to MDT. The content and information contained in the awareness programmes should discontinue to use

frightening images of people disabled with leprosy and instead use positive images of cured persons sharing their experiences of being cured of leprosy;

(iii) The Union and the States are to ensure that drugs for management of leprosy and its complications including the MDT drugs are available free of cost and do not go out of stock at all Primary Health Centres (PHCs) or, as the case may be, public health facilities in the country;

(iv) All-year awareness campaigns should also be run, by the Union as well as the States, to inform the citizenry that under the National Leprosy Eradication Programme (NLEP), treatment is provided free of cost to all leprosy cases diagnosed through general health care system including NGOs;

(v) The Union and the States must organize seminars at all levels which serve as platforms to hear the views and experiences directly from the former patients and their families as well as doctors, social workers, experts, NGOs and Government officials;

(vi) The awareness campaigns must include information that a person affected by leprosy is not required to be sent to any special clinic or hospital or sanatorium and should not be isolated from the family members or the community. The awareness campaigns should also inform that a person affected with leprosy can lead a normal married life, can have children, can take part in social events and go to work or school as normal. Acceptability of leprosy patients in the society would go a long way in reducing the stigma attached to the disease;

(vii) Health care to leprosy patients, at both Government as well as private run medical institutions, must be such that medical officials and representatives desist from any discriminatory behaviour while examining and treating leprosy patients. Treatment of leprosy should be integrated into general health care which will usher in a no-isolation method in general wards and OPD services. In particular, it must be ensured that there is no discrimination against women suffering from leprosy and they are given equal and adequate opportunities for treatment in any hospital of their choice. To this effect, proactive measures must be taken for sensitization of hospital personnel;

(viii) Patients affected with leprosy, for whom partial deformity can be corrected by surgery, should be advised and provided adequate facility and opportunity to undergo such surgeries;

(ix) The possibility of including leprosy education in school curricula so as to give correct information about leprosy and leprosy patients and prevent discrimination against them should be explored;

(x) The Union and the State Governments must ensure that both private and public schools do not discriminate against children hailing from leprosy affected families. Such children should not be turned away and attempt should be made to provide them free education;

(xi) Due attention must be paid to ensure that the persons affected with leprosy are issued BPL cards so that they can avail the benefits under AAY scheme and other similar schemes which would enable them to secure their right to food;

(xii) The Union and the States should endeavour to provide MCR footwear free of cost to all leprosy affected persons in the country;

(xiii) The States together with the Union of India should consider formulating and implementing a scheme for providing at least a minimum assistance, preferably on a monthly basis, to all leprosy affected persons for rehabilitation;

(xiv) The Union and the State Governments must pro-actively plan and formulate 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.

(xv) 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).

19. The writ petition is, accordingly, disposed of. There shall be no order as to costs.

Judgment Referred.

¹(2008) 17 SCC 0311