Bill No. 130 of 2017

THE AUTISM SPECTRUM DISORDERS (RECOGNITION AND TREATMENT) BILL, 2017

By

SHRIMATI SUPRIYA SULE, M.P.

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BILL

to recognise the rights of person suffering from autism spectrum disorders and making the treatment accessible and affordable and for matters connected therewith.

BE it enacted by Parliament in the Sixty-eighth year of the Republic of India as follows:—

 $\mathbf{1.}$ (1) This Act may be called Autism Spectrum Disorders (Recognition and Treatment) Short title, Act, 2017.

extent and commencement.

- (2) It shall extend to the whole of India except the State of Jammu and Kashmir.
- (3) It shall come into force on such date as the Central Government may, by notification in the Official Gazette, appoint.

Definitions.

- 2. In this Act, unless the context otherwise requires:—
- (a) "appropriate Government" means in the case of a State and Union Territory with Legislative Assembly, the State Government and the Administration of the Union Territory, respectively, and in all other cases, the Central Government;
 - (b) "ANM" refers to Auxiliary Nurse Midwife health worker at village level;
- (c) "ASHA" refers to Accredited Social Health Activist employed under National Rural Health Mission;
- (d) "autisms spectrum disorders" refer to neuro-developmental disorders resulting from the delay in the maturation of the central nervous system that significantly affects a person's ability to communicate, understand relationships and relate to others, and is 10 frequently associated with unusual or stereotypical rituals or behaviours;
- (e) "Committee" refers to the Autism Spectrum Disorders Monitoring Committee constituted under section 4;
- (f) "local authority" means the Municipal Corporation or Municipal Council or Nagar Panchayat or Zila Parishad or any Urban Local Body;
- (g) "mental health care professionals" refer to clinical psychologists, counselling psychologists, psychotherapists, psychiatric social workers and nurses trained in mental healthcare;
 - (h) "notification" means notification as published in the Official Gazette; and
 - (i) "prescribed" means prescribed by rules made under this Act.

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the right of affordable treatment of persons suffering with autism spectrum disorders.

Recognising

 ${\bf 3. \, The \, Central \, Government \, shall \, ensure \, availability \, of \, affordable \, treatment \, to \, every \, person \, suffering \, from \, autism \, spectrum \, disorders \, in \, such \, manner \, as \, may \, be \, prescribed.}$

Constitution of Autism Spectrum Disorders Monitoring Committee

- 4. (1) The appropriate Governments shall, by notification in the Official Gazette, constitute a Committee to be known as the Autism Spectrum Disorders Monitoring Committee for carrying out the purposes of this Act.
- (2) The Committee shall consist of District Medical Officers, District Collectors and an eminent doctor to be appointed by the appropriate Government in such manner as may be prescribed.
- (3) The head of the Committee shall be the eminent doctor who shall be appointed for a period of four years, and shall be eligible for re-appointment upon the decision of the simple majority of the members of the Committee present and voting.

Monitoring and evaluation of implementation of the provisions of the Act. **5.** The Committee shall assist the appropriate Government in effective implementation and evaluation of the provisions of this Act.

Annual Report.

6. The Committee shall prepare an annual report on the progress in the mental healthcare services provided under this Act and submit it to the appropriate Government to decide the 35 criteria for evaluation of the mental healthcare service delivery.

7. The appropriate Government shall appoint adequate mental healthcare professionals in the public hospitals to maintain the doctor patient ratio of at least 1:40 for patients suffering from autism spectrum disorders.

Mental healthcare professionals.

8. The Central Government shall provide the necessary infrastructure to the State Governments for training of mental healthcare workers and nurses in mental healthcare.

Central Government to provide necessary infrastructure

9. The appropriate Government shall, with the assistance of the Committee, provide for training of mental healthcare workers and nurses to facilitate the mental healthcare service delivery at the public health centres.

Training of mental healthcare workers and nurses

10. The local authority shall appoint ASHA and ANM healthcare workers for providing primary care to persons suffering from autism spectrum disorders and collection of the data on neuro-developmental disorders.

Non-specialist professionals in mental heathcare delivery.

11. The local authority shall conduct skill development programmes for healthcare workers and sensitize them about the symptoms faced by persons suffering from autism spectrum disorders.

Skill
Development
programmes to
sensitize autism
spectrum
disorders.

12. The appropriate Government shall provide treatment of autism spectrum disorders including counselling, therapeutic sessions and rehabilitative care including medicines free of cost at the public health centres.

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Appropriate Government to provide free of cost treatment at public health centres.

13. (1) The local authority shall organise public awareness camps and free mental health checkup camps in their local areas.

Public Awareness and free mental health check up camps.

- (2) While setting up the free mental health checkup camps under sub-section (1), special attention shall be given to areas where people with less income and lower levels of education reside.
- **14.** The appropriate Government shall sensitise the communities about autism spectrum disorders and their actions or behaviour when associating with persons with autism spectrum disorders.

Steps to deal with the social stigma.

15. The Central Government shall provide adequate funds for medical research in the field of autism spectrum disorders and other neuro-developmental disorders.

Funds for Medical research in the field of autism spectrum disorders.

16. The appropriate Government shall collect the data on autism spectrum disorders in such manner as may be prescribed.

Data on autism spectrum disorders.

17. The Central Government shall, after due appropriation made by Parliament by law in this behalf, provide requisite sums to the State Governments for carrying out the purposes of this Act.

Central Government to provide necessary funds.

18. The provisions of this Act shall have effect not withstanding anything inconsistant therewith contained in any other law for the time being inforce.

Overriding effect of the Act.

19. The provisions of this Act shall be in addition to and not in derogation of any other law for the time being in force dealing with subject matter of this Act.

Act not in derogation of other laws.

Power to make rules.

- **20.** (1) The appropriate Government may, by notification in the Official Gazette, make rules for carrying out the purposes of this Act.
- (2) Every rule made by the Central Government under this Act shall be laid, as soon as may be after it is made, before each House of Parliament, while it is in session, for a total period of thirty days which may be comprised in one session or in two or more successive sessions, and if, before the expiry of the session immediately following the session or the successive sessions aforesaid, both Houses agree in making any modification in the rule or both the Houses agree that the rule should not be made, the rule shall thereafter have effect only in such modified form or be of no effect, as the case may be; so, however, that any such modification or annulment shall be without prejudice to the validity of anything previously done under that rule.
- (3) Every rule made by the State Government under this Act shall be laid, as soon as may be after it is made, before the State legislature.

STATEMENT OF OBJECTS AND REASONS

Autism Spectrum Disorders (ASDs) refer to umbrella group of developmental disorders, resulting from the delay in the maturation of the central nervous system. This developmental disorder is associated with delay in the functions of central nervous system. Children inflicted by this suffer from impaired reciprocal socio-communicative interaction. They also show a tendency for repetition of restrictive repertoire of activities.

According to the report of World Health Organization (WHO) every 1 in 160 persons worldwide is afflicted from ASDs. This makes the global disease burden of the developmental disorders to be about 0.3 per cent. This high degree of prevalence is despite the fact that the data on people troubled with ASDs is not comprehensive and excludes many. Thus the actual number of the people with ASDs is much higher than that projected by WHO and requires urgent attention by the Government.

National Mental Health Survey 2015-16 supported by the Ministry of Health and Family Welfare, estimated the burden of mental and neurological disorders in India between April 2015 and 2016 for adults (above 18 years of age) at 10.6 per cent. This means that at given point, there are one hundred and fifty million Indians requiring intervention in their mental health status. It estimates that in the adolescents of aged 13-17 the prevalence of ASDs is at 1.6 per cent. The report also brings to the fore, the acute shortage of the mental health care professionals in India-clinical pyschologists, counselling psychologists, psychiatric social workers, nurses trained in mental health. It also brings to our notice the divergence in the prevalence rates of mental disorders in rural and urban areas, and the higher disease burden of people with less income and low levels of education.

There is need for investing in the research and development of the surveillance and information systems to capture the data on ASDs. Better knowledge about the actual prevalence of the developmental disorders will help ascertain the causes of the ASDs. Research on the causes of ASDs is also equally crucial. With such research findings, the Government can then undertake preventive steps in reducing the disease burden.

Research on the factors causing ASDs suggests that in majority of the cases, ASDs manifest themselves in children below one year of age. The Government can mitigate the incidence of ASDs through measures such as encouraging screening of pregnant women and ensuring pregnant women get their vaccinations and maintain nutrition and hemoglobin levels. The pediatic doctors, parents and the communities must be sensitised about the symptoms of these developmental disorders, so that the children are diagnosed and treated from early age.

These interventions help the children suffering from ASDs and also assit the families and local communities in dealing sensitively with the people with developmental disorders.

At present, India does not have a comprehensive law on dealing with autism spectrum disorders. The District Mental Health Programme, though being implemented since 1996 its coverage is varied across the States. As per the National Mental Health Report 2015-16, only one-third of the surveyed States had coverage of more than fifty per cent. of the population. In order to effectively address the above issues, this Bill is contemplated.

Hence this Bill.

New Delhi; *June* 28, 2017.

SUPRIYA SULE

FINANCIAL MEMORANDUM

Clause 3 of the Bill seeks to provide for accessible and affordable treatment for person suffering from autism spectrum disorders. Clause 4 provides for the constitution of Autism Spectrum Disorders Monitoring Committee by the appropriate Government. Clause 7 provides for the recruitment of mental health care professionals. Clause 8 provides for Central Government to provide necessary infrastructure for the training of health care workers and nurses. Clause 9 provides for training and facilitation of mental health care service delivery. Clause 10 provides for appointment of accredited Health Activist (ASHA) and Auxiliary Nurse Midwife (ANM) health care workers for providing primary care for persons suffering from autism. Clause 11 provides for skill development and sensitising programmes of health care workers. Clause 12 provides for free treatment including medicines for person suffering from autism spectrum disorders at public health care centres. Clause 13 provides for organising public awareness and free medical health check up camps. Clause 15 provides for funding by the Central Government in medical research to ascertain the causes of autism spectrum disorders and neuro-developmental disorders. Clause 16 provides for collection of data on autism spectrum disorders. Clause 17 provides for the Central Government to provide funds to the State Governments to carrying out the provisions of the Act. The Bill, therefore, if enacted, would involve expenditure from the Consolidated Fund of India. It is estimated that a sum of rupees five thousand crore would be involved as recurring expenditure per annum.

A non-recurring expenditure of rupees one hundred crore is also likely to be involved.

MEMORANDUM REGARDING DELEGATED LEGISLATION

Clause 20 of the Bill empowers the appropriate Government to make rules for carrying out the provisions of the Bill. As the rules will relate to matters of detail only, the delegation of legislative power is of a normal character.

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