



forumforautism

REGISTERED UNDER THE SOCIETIES REGISTRATION ACT, 1860 VIDE REGN. NO. 31/2002
REGISTERED UNDER THE INDIAN TRUST ACT, 1950 VIDE REGN. NO. F 23880, 11/4/2002

forumforautism@gmail.com Tel : 022-32949595 www.forumforautism.org

24 October 2014

ADVISORY COMMITTEE:

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Developmental
Disorders

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Senior
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Ms. Merry Barua
Director,
Action For Autism

To,
The Director,
Lok Sabha Secretariat,
Room No. 606, Parliament House Annexe,
New Delhi-110001

**Subj: Response to the PRESS COMMUNIQUE of loksabha.nic.in
(<http://164.100.24.219/BillsTexts/RSBillTexts/asintroduced/I2014RS.pdf>)**

Dear Sir,

Forum for Autism (FFA), is a Parent Support Group for families of children with Autism Spectrum Disorder (ASD) in Mumbai and its suburbs and has been working towards creating autism awareness, empowering parents and advocating for the rights of persons with ASD for over two decades. Parents from FFA have been civil society representatives in the process of the Revision of the Persons with Disabilities Bill at both the Regional and the National level and we have advocated the cause of autism with the government on varying issues over the last two decades.

Below are our suggestions/objections to the draft that has been circulated under the above mentioned PRESS COMMUNIQUE. Inclusions/revisions in the said Bill that are non-negotiable to the Autism Community and Forum for Autism are appended in a tabular form herewith. In addition, FFA would like to suggest the following:

- Under Chapter III, Education: to include a section about ASD as mandatory study to the syllabus of medical and para-medical courses.
- To have separate count for persons with ASD in the Census count.
- To provide persons with ASD with a, identity badge, if they so wish, that will make it easy to identify and address their needs. The id can clearly state the type and method of help required by them.

Sincerely,

Parul Kumtha
President

Babita Raja
Secretary

Chitra Iyer
Treasurer

Beena Modak
Jaya Sudhakar
Rajendra Kshirsagar
Sharada Rao
Fatima Shaikh
Paramita Mazumdar
Niranjana Shah

And Core-Group of Parents

Alka Baghdadi
Chandra Shetty
Manjusha Sawant
Venugopal
Anand Kumtha
Kunda Salvi
Sunita Sharma.

S. Ranganathan
Sunil Salvi
Sulekha Doshi
Chandrika Shetty
Vanishree V.
Ashok Shah
Vijayashree R.

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Sl No	Section	Comment/ Concern	Recommended change / addition / deletion
1	2(c)	Amend definition of "barrier" The definition does not include the entire spectrum of barriers encountered by PwDs	2(c) "Barrier" means any factor that impedes, prevents or obstructs the full and effective participation, of persons with disabilities in society. These factors include attitudinal, communicational, cultural, economic, environmental, institutional, political, religious, historical, social, legal, physical or structural, which hampers the full and effective participation of persons with disabilities in society.
2	2(f)	Revise definition of "communication"	2(f) "Communication" includes means and formats of communication, languages including sign language, display of text, Braille, tactile communication, signs, large print, accessible multimedia, written audio, plain- language, human-reader, augmentative and alternative modes and accessible information and communication technology, video & visually display.
3	2 (j)	Amend definition of "High support" to include requirement of support Present definition omits the important aspect of requirement of support for independent and informed decision making	2(j) "High support" means an intensive support, physical, psychological and otherwise, which may be required by a person with benchmark disability for daily activities; independent and informed decision making; accessing facilities and participating in all areas of life including education, employment, family and community life and treatment and therapy
4	2(l)	Scope of activities needs to be expanded by inserting 'activities, including but not restricted to'	2(l) "institution" means an institution for activities, including but not restricted to, the reception, care, protection, education, training, rehabilitation and any other activities for persons with disabilities;



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5	2 (q)	Amend definition of persons with disability in keeping with UNCRPD definition : The present definition is not in conformity with the definition given in UNCRPD as it does not include the phrase "in interaction with barriers in the environment may"	2(q) "Persons with disability" means a person with long term physical, mental, intellectual, or sensory impairment which in interaction with barriers in the environment may hinder his/her full and effective participation in society on an equal basis with others
6	2(v)	Change the term 'psychiatric' to 'psychological' in the definition of 'Rehabilitation': The word 'psychiatric' used in the definition is misplaced and does not convey the meaning.	2(v) "Rehabilitation" refers to a process aimed at enabling persons with disabilities to attain and maintain optimal physical, sensory, intellectual, psychological , or social function levels
7	2(t)	Revise definition of 'reasonable accommodation' The current definition allows subjective and arbitrary refusal to make modification or adjustment by any authority and is not in conformity with the spirit of UNCRPD.	2(t) "reasonable accommodation" means necessary and appropriate modifications and adjustments where needed in a particular case , to ensure persons with disabilities the enjoyment or exercise of rights equally with others
8	2(w)(l)	Change and delete 'suffering'	2(w)(l) Persons who seek to engage employees from amongst persons with disabilities
9	2(z)	Add 'also' after 'design and shall'	2(z) "universal design" means the design of products, environments, programmes and services to be usable by all people to the greatest extent possible, without the need for adaptation or specialised design and shall also apply to assistive devices including advanced technologies for particular group of persons with disabilities.
10	3 (3)	Omit discriminatory phrase in Equality and Non discrimination: The phrase '...unless it is shown that the impugned act of omission is appropriate to achieve a legitimate aim,' is discriminatory and needs to be deleted	3 (3) No person with disability shall be discriminated on the ground of disability.



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11	12	Aspect of plenary guardianship needs open discussion by people with psychosocial disabilities and their care givers	
12	15	The Section 'Duty of Educational Institutions' to include all educational institutions: The present provision excludes the private educational institutions not receiving funds from the Government, which is contrary to other laws particularly RTE etc	15. The appropriate Government and the local authorities shall endeavor that all educational institutions recognized by them provide education to children with disabilities and towards that end shall –
13	16(f)	Insert 'signs' Some populations use sign language while some use signs	16(f) to promote the use of appropriate augmentative and alternative modes including means and formats of communication, Braille, signs and sign language to supplement the use of one's own speech to fulfill the daily communication needs of persons with speech, communication or language disabilities and enables them to participate and contribute to their community and society;
14	16(g)	This provision limits availability of books and learning materials to students of benchmark disabilities upto 18years. However since section Section 31(2) states ' Persons with benchmark disabilities shall be given an upper age relaxation for admission in institutions of higher education', it acknowledges that students with benchmark disabilities may complete education at 23 years. This must be reflected in section 16(g)	16(g) To provide books, other learning materials and appropriate assistive devices including group hearing aids, visual aids to students with benchmark disability free of cost till the completion of their school education and either free or at affordable cost thereafter.
15	16(i)	This provision refers to scribes or amanuensis as the only means of writing examination papers. Some individuals with autism who have difficulty in writing may have even greater difficulty in dictating answers to another person. However many who have difficulty writing would be comfortable answering using a computer.	(i) to make suitable modifications in the curriculum and examination system to meet the needs of students with disabilities such as extra time for completing of examination paper, facility of scribe or amanuensis or computer , exemption from second and third language courses;



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16	25	<p>Insert provision to prevent refusal of insurance. The present provision does not provide any safeguard against refusal to extend insurance policies on the ground of disability as well as against discrimination in the matter of extending benefits and charging extra premium on the ground of disability</p>	<p>25 (2) No insurance company whether private or public shall refuse any insurance cover or policy on the ground of any disability and also shall not charge any extra premium on the ground of disability and also shall not refuse any benefit forming part of the given policy on the ground of disability</p>
17	30	<p>Insert 'compulsory' and a fresh provision. Education for benchmark disabilities should also be compulsory. Reasonable accommodation has to be provided for this.</p>	<p>30. (1) Notwithstanding anything contained in the Rights of Children to Free and Compulsory Education Act, 2009, every child with benchmark disability between the age of six to eighteen years shall have the right to free and compulsory education in a neighbourhood school, or if necessary in a special school (2) provide reasonable accommodation according to the individual's requirements; (3) The appropriate Government and local authorities shall ensure that every child with benchmark disability has access to free education in an appropriate environment till he attains the age of eighteen years.</p>
18	32	<p>To be redrafted: This section links identification with reservation and creates an impression that reservation is to be done only with respect to the identified post. Such a situation in the existing act also exists which came up for consideration of the Hon'ble apex court in the case titled as Govt. of India Through Secretary Vs. Ravi Prakash Gupta and UOI Vs. National Federation of the Blind and their Lordships were pleased to hold that reservation is independent of the identification and the identification is only for limited purpose to utilize vacancies for filling up reservation by giving appointment in such post</p>	<p>32(1) Every appropriate govt. shall - (i) identify posts which can be held by respective categories of disabilities only for the purpose of using the vacancies in such identified posts for making appointments of respective category of persons With Disabilities against 1% reservation for each of them as contained in Sec.33. (ii) constitute an expert committee consisting of at least one representative of a respective DPO or a parent organisation working in the field of each of the categories of benchmark disabilities entitled to get the benefit of scheme of reservation. (iii) review and update the list of identified posts, taking into</p>



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			<p>consideration the developments in technology, at periodical intervals not exceeding five years.</p> <p>(iv) notify in the official gazette the list of identified posts which may be used for appointment of respective category of person with disability after his selection against the reservation for his/her category of disability.</p> <p>(v) treat the notified list of identified post as an illustrative list of posts which can be held by persons With disabilities and not as an exhaustive list.</p> <p>(vi) ensure that no person with Disability shall be denied consideration for appointment or appointment against any post which is not included in the notified list of the identified post, if he is otherwise eligible for such post as per the notified eligibility criteria for the same.</p>
19	39	<p>Insert "and enforce" in the given provision on Accessibility. To strengthen the provision of Accessibility it is essential that the National Commission not only formulates but also enforces regulations for the persons with disabilities laying down the standards....</p>	<p>39. The National Commission shall, formulate and enforce regulations for the persons with disabilities laying down the standards of accessibility for the physical environment, transportation, information and communications, including appropriate technologies and systems, and other facilities and services provided to the public in urban and rural areas.</p>
20	45	<p>Definition of service provider needs to be inserted. The definition has to clearly include the private sector</p>	<p>Formulation to be created</p>
21	53	<p>To be deleted : By exempting the institutions run by Central or State Govt. from the provisions of registration under this chapter, it may compromise the quality of services in such institutions.</p>	<p>Section 53 Delete</p>



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22	57	<p>Insert a new section.</p> <p>Migrant population in many states face great difficulty due to disability certificates that vary across states. Disability certificates must be valid across the country</p>	<p>57(2)</p> <p>(b) a certificate thus issued will be valid across states, boards and departments</p> <p>(c) inform him in writing that he has no specified disability.</p>
23	61 (b) 67 (b)	<p>Delete existing clause on unsound mind:</p> <p>This provision recognizes the unsoundness of mind as a disqualification for holding or continuing to hold the office of member of Central Advisory Board and State Advisory Board whereas the bill is premised on the legal capacity of all groups of persons with disabilities. Thus, such a disqualification on that ground runs counter to the spirit of the UNCRPD and the bill</p>	<p>SECTION 61 (b) & 67 (b)</p> <p>Delete</p>
24	76 (1) (c) & 89(1) (c)	<p>Delete the clause:</p> <p>This provision disqualifies a person to hold the office in the Commission on the ground of physical or mental incapacity, thereby implying that certain benchmark disabilities would not be entitled to be represented on this commission which is against the very spirit and foundation of UNCRPD and the bill.</p>	<p>SECTIONs 76 (1) (c) & 89(1) (c)</p> <p>Delete</p>
25	1 of the Schedule	<p>The definition of Autism Spectrum Disorder as proposed in the bill is conceptually wrong and incorrect</p>	<p>SECTION 1 of SCHEDULE</p> <p>'Autism Spectrum Disorder' means a neuro-developmental condition typically appearing in the first three years of life that significantly affects a person's ability to communicate, understand relationships and relate to others, and is frequently associated with unusual or stereotypical rituals or behaviours.</p>