



P A R I V A A R
NATIONAL CONFEDERATION OF PARENTS' ORGANISATIONS
For Persons with Intellectual and Developmental Disabilities
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**APPEAL TO HON. PRIME MINISTER TO CONTINUE WITH
THE NATIONAL TRUST ACT 1999 AND ASSOCIATED SCHEMES**

The objective of this press note is to apprise the public regarding the proposal of Department of Expenditure, Ministry of Finance, to do away with The National Trust Act - 1999 in the process of austerity measures. This will have devastating effect on Persons with Intellectual & Developmental Disabilities (PwIDDs) and their families.

The PwIDDs are the most marginalized persons in the society among General population, SC/ST, Women, and Economically disadvantaged population. They are at the bottom of disability matrix being non vocal and unable to advocate for themselves unlike other disabilities. This legislation was enacted in 1999 (christened as millennium gift) after considerable advocacy by tens of thousands of parents of PwIDDs associated with Parivaar www.parivaarnfpa.org & other civil society organizations. Smt. Menaka Gandhi, then minister of Social Justice in the cabinet of late Shri Atal Bihari Vajpai's government moved the bill and called it a historical step towards the welfare and empowerment of most disadvantaged population of our country. The Act was passed by parliament on the last day of 20th century marking a beginning for PwIDDs to enjoy their legal capacity thru guardian and being able to open bank account, own/ inherit property, and avail benefits from the schemes of The National Trust.

NATIONAL TRUST ACT COVERS HIGHLY MARGINALIZED CITIZENS

The National Trust Act prioritized rehabilitation of PwIDDs who are abandoned, destitute, orphan or belonging to old/ infirm/ crisis ridden families. Four out of eight objectives [Sections 10 (c), 10(d), 10(e), 10(f) of National Trust Act] for which the National Trust Act was enacted are meant to take care of above population. In addition Section 11(5) of The National Trust act regulations provides sue moto authority to address concerns of PwIDDs by appointing a Registered Organization as guardian. In addition

every grass-root scheme of The National Trust caters for the rehabilitation of abandoned/ orphan/ destitute PwIDDs.

DISABILITIES & EXTENT OF POPULATION COVERED

The disabilities covered under the National Trust Act are Mental retardation (now called Intellectual Disability - ID), Autism, Cerebral Palsy and Multiple disabilities; also known as developmental disabilities. As per INCLEN Study ^{Appendix 1}, co-supported by The National Trust, an average of 9.2% children in age group of 2 to 9 years in India have neuro developmental disabilities that can manifest in abovementioned disabilities. A recent study published by AIIMS, Delhi, mentioned incidence of 1 autistic child among every 69 children born in AIIMS. Therefore with such high incidences of development disabilities it is absolutely essential that provisions of special care are given high priority. The National Trust Act essentially fulfill that role and is therefore critical for focusing on special requirements of PwIDDs. The PwIDDs have special needs vis a vis mainstream persons and other Divyangjan, because of lower cognitive ability (difficulty in learning), differences in sensory integration, lower attention span and manifested behavior. Because of these impairments the PwIDDs (children and adults) get neglected and discriminated at grass-root level in most schemes of government; be it Samagra Shiksha Abhiyaan, Pradhan Mantri Kaushal Vikas Yojna under National Skill building Program, MGNREGA, NRLM etc. This again highlight the necessity for an Act to enable PwIDDs to access the mainstream schemes of the government taking support of their parents.

PROVISIONS NOT COVERED IN ANY OTHER ACT

The specific requirements and schemes required for PwIDDs that are not covered in any other Act or Schemes of government, except under The National Trust Act are described below. The schemes for PwIDDs developed under the provisions of The National Trust Act are appended at Annexure C. These are critical for their dignified existence and purposeful living.

- a. **Guardianship of PwIDDs through Local Level Committees:**
Because of lower cognitive abilities and issues with sensory integration most adult PwIDDs require life-long & perpetual support from guardian for decision making and to exercise legal rights as guaranteed in constitution and RPD Act 2016. The support may vary based on the extent and type of disability. The National Trust Act laid down formation of Local Level Committees (LLC) in every district to award guardianship. The whole process is mostly driven by parents/ NGOs undertaking due diligence and awarded by LLC chaired by district collector. This time tested LLC has proved to be a boon for PwIDDs as well as relieves worry of the aged parents.

- b. **Residential center facilities for orphan/ destitute PwIDDs or whose parents are too old or poor to be able to manage their PwIDD ward:** One of the biggest worry of every parent of PwIDDs is who will take care of my son/ daughter after my death. The destitute PwIDDs face miserable plight in the society. The National Trust Acts provides provisions that are formulated into Gharonda scheme. Under this scheme many parents get together, form charitable society with an aim to develop residential centers for PwIDDs. The National Trust Act schemes provide technical, financial and organizational support for this special requirement of adult PwIDDs
- c. **Niramaya Group Insurance for PwIDDs:** Children with developmental disabilities require early intervention therapeutic care. If provided within the age of 6 years such care can work wonders to enable the child to achieve his/ her potential. The Niramaya health insurance caters for early intervention care and transport cost. In addition Niramaya provisions for dental care which is an issue with almost all PwIDDs. If uncared it leads to secondary morbidities for PwIDDs. As on date more than a lakh PwIDDs are being benefitted by Niramaya scheme.
- d. **Monitoring the Assets and life care:** The National Trust Act and its Rules stipulate monitoring of assets and life care of PwIDDs. Again this being the major worry of every parents, at least they are rest assured that National trust will create such mechanism of monitoring the assets and their utilization for the care of PwIDD. This may look insignificant but is an essential special requirements for dignified living of PwIDDs after the death of both parents.
- e. **Vocational Training and Assisted Workshops for Adult PwIDDs:** The PwIDDs take much longer time to pick up simple vocational skills. Therefore generally PwIDDs cross over the age of 18 years and are still trying to master vocational skills. Thereafter majority of them work in assisted workshops run by parents/ community volunteers. The ministry of social justice & empowerment has even removed such scheme from their portfolio because it did not occur in other disabilities. The National Trust has to cater for it.

List of schemes of The National Trust along with representative benefits are shown in Appendix B

PARIVAAR's APPEAL TO HON. PRIME MINISTER

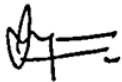
The Department of Expenditure, Ministry of Finance has asked all ministries of government of India to consolidate offices under their jurisdiction and operating under different legislations for complimentary schemes. One of the legislation mentioned by DOE is The National Trust Act. Perhaps, DOE failed did not appreciate or understand the critical role of The National Trust Act. While austerity measures are appreciated in times of COVID but they should

never adversely affect the basic living & existence of disadvantaged population.

We earnestly appeal to our Hon. Prime Minister Shri Narendra Modi to direct Ministry of Social Justice & Empowerment to retain the National Trust Act and associated schemes.

In December 2019 the MSJE had initiated process to amend The National Trust Act adopting Rights based approach instead of Welfare model that the Act originally envisaged and followed when it was enacted in 1999. Parivaar members formed the majority of the expert committee for drafting the amendments. This process should continue unhindered and The National Trust Act should continue to enable PwIDDs to lead an inclusive life with opportunities for employment and dignified life even when the parents are no more.

On behalf of PwIDDs, over 80,000 Parents and 300 parent organizations affiliated to Parivaar, we once again appeal to Hon. Shri Narendra Modi ji to cancel the proposal to extinguish The National Trust Act and continue with the schemes provisioned by the Act.



Cdr. Shrirang Bijur (Retd.)
President, Parivaar NCPO

6th October 2020

Appendices:

- A. Neuro-developmental Disorders in India – An INCLLEN study
- B. Schemes under National Trust Act 1999

APPENDIX A

http://www.neurology.org/cgi/content/meeting_abstract/80/1_MeetingAbstracts/IN6-2.001

4IN.001 Global Impact of Non-communicable Diseases Data Blitz Presentations **Neuro-Developmental Disorders in India – An INCLLEN Study (IN6-2.001)**

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NDDs included are Attention deficit hyperactivity disorder (ADHD), Autism Spectrum Disorders (ASD), Epilepsy, Learning disorders (LD), Mental Retardation (MR), Neuro-motor Impairment including cerebral Palsy (CP), Speech and Language Disorders, Hearing Impairment and Vision Impairment.

OBJECTIVE: The objectives of our research are: 1) estimate the prevalence of NDDs among children aged 2-9 years in India; 2) gather information on risk factors; 3) develop and disseminate methodology that may be useful in other low income countries.

BACKGROUND: The domains studied were: Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorders, Intellectual Disability, Epilepsy, Learning Disability, Neuromuscular Disorders including cerebral palsy, Speech and Language Disorders, and Hearing and Vision Impairment.

DESIGN/METHODS: A 39 question NDST was developed in English and Hindi, translated into 8 regional languages and validated among 593 subjects in 9 regions of India. The test-retest and inter-rater reliability of the NDST was assessed at two centers in New Delhi, and at the Child Development Center in Thiruvananthapuram, testing 192 children. The test re-test reliability coefficient was above 0.8 for 35 of the 39 questions (89.7%) among both doctors and research assistants. The inter-rater reliability correlation co-efficient was above 0.8 for 21 questions (53.8%). The content validity of the refined tool was then validated in four different strata: rural, urban, hilly areas and tribal areas at five field sites. Conventional clinical diagnostic methods, including expert opinion were used to establish or rule out the presence of NDD's. A total of 593 subjects participated in this piloting.

RESULTS: A total of 4,000 households in 6 regions of India were sampled.

CONCLUSIONS: Subject to extensive ongoing analysis, it appears that 7.5% to 18.5% of children ages 2-9 years suffer from one or more NDD, including those who exhibited more than one NDD. If one excludes isolated hearing impairment, the overall prevalence of NDD's seems to be from 4.7 to 13.7%.

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APPENDIX B

LIST OF NATIONAL TRUST SCHEMES & PROVISIONS

Residential Care

SCHEME	BENEFIT
Gharonda	Group home for adults @ Rs 10000/pm
Samarth	Respite Care @ Rs 7000/pm
Vikaas	Day care @ Rs 3850/ pm

Continuous Care

SCHEME	BENEFIT
Disha	Early Intervention & School readiness @ Rs 4500/pm
Gyan Prabha	Educational support Different rates for different courses
Niramaya	Health Insurance @ Rs 100,000/- max claim per year
Sambhav	Aids & Assistive Devices

Capacity Building

SCHEME	BENEFIT
Guardianship of PwIDDs	Awarded by Local Level Committee in each district chaired by Collector
Prerna	Marketing Assistance
Sahyogi	Care giver training Primary @ Rs 4200/pm Advanced @ Rs 8000/ pm
Badhte Kadam	Awareness and Community Interaction

Note :

1. The amount shown are indicative, may change from time to time.
2. The organization should have been in existence for minimum 3 years and providing services to persons with disabilities [MR/ID, Autism, CP, MD]
3. The organization should get registered with the National Trust
4. After registration the registered organization (RO) should apply for specific schemes, as applicable. Full details are given in attached prospectus of the National Trust.
5. Except Niramaya Health Insurance scheme all other schemes are for ROs