

# Neuroscience Engagement and Outreach on Neurodevelopmental Disorders: A Report from India

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[journals.sagepub.com/home/aon](http://journals.sagepub.com/home/aon)Divya Bhatia<sup>1</sup> 

## Abstract

The current project was funded by the Global Engagement Seed Grant from the International Brain Research Organisation (IBRO) as part of the IBRO-led Global Engagement Initiative. The project was focused on public awareness about neurodevelopmental disorders (NDDs) as well as neuroscience engagement. Thus, the project had two specific aims: (a) public awareness about epidemiology, diagnosis, risk factors, prevention of NDDs and relevant government guidelines and available policies (b) public engagement in neuroscience. Therefore, the current project report with an emphasis on the requirement of neuroscience engagement and outreach at the societal level, highlights several activities such as population-based workshops and webinars, carried out as part of the project in both rural and urban areas to enhance the public engagement in neuroscience and awareness on several NDDs.

**Key message:** India is an extremely diverse country with significant variations in cultural, educational, financial, socioeconomic status and linguistic aspects. With about 27% of its population living below the poverty line, India accounts for about 23 million children suffering from a disability, most of whom do not seek medical help. These data highlight the gravity of the situation which calls for urgent actions from governments, healthcare professionals, researchers and policymakers to design adequate public awareness programs regarding several prevalent NDDs. Therefore, the current project was an effort to bring public awareness about brain health and the epidemiology, diagnosis and prevention of NDDs and relevant government guidelines and available policies.

## Keywords

Neuroscience, neurodevelopmental disorders, well-being, outreach, public awareness

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## Introduction

Neurodevelopmental disorders (NDDs) are a group of disorders affecting the development and function of the nervous system. NDDs are considered to have a heterogenous aetiology which leads to impaired cognition, communication, adaptive behaviour and motor skills. A few common NDDs include vision impairment (VI), hearing impairment (HI), speech and language impairment, epilepsy, autism spectrum disorder (ASD), learning disorders (LDs), attention deficit hyperactivity disorder (ADHD) and so on. NDDs constitute a major health problem in society affecting more than 3% of children worldwide. In India, the 2011 census of the Government of India suggests that more than 6 million children below the age of nine are affected by disability. However, a very recent study suggests this number to be as high as 23 million.<sup>1</sup> NDDs are

caused by a wide range of genetic mutations and environmental factors (e.g., infections, immune dysfunction, intoxication, endocrine and metabolic dysfunction, nutritional factors, trauma, etc.).<sup>2</sup> Several factors such as the birth conditions, mother's nutrition during pregnancy, low birth weight (LBW) and genetics can contribute towards the development of NDDs. The current project, therefore, through a series of events and

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<sup>1</sup>E-Cog: Emotion & Cognition Psychology Research Centre, Jindal School of Psychology and Counselling, O.P. Jindal Global University, Sonapat, Haryana, India

### Corresponding author:

Divya Bhatia, Jindal School of Psychology and Counselling, O.P. Jindal Global University, Sonapat, Haryana 131001, India.  
E-mail: [dbhatia@jgu.edu.in](mailto:dbhatia@jgu.edu.in)



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workshops aimed at neuroscience engagement by bringing awareness about brain health and the epidemiology, diagnosis, prevention of NDDs, and relevant government guidelines and available policies.

With the courtesy of the International Brain Research Organisation (IBRO), the current project was supported by the Global Engagement Seed Grant. Global Engagement Seed Grants offered as part of the IBRO-led Global Engagement Initiative support neuroscience societies, groups, and organisations in the Asia/Pacific, African, Latin American, Middle Eastern and Pan-European regions that aim to conduct outreach and engagement activities in the local areas. IBRO focuses on promoting neuroscience around the world through training, education, research, outreach and engagement activities since its inception in 1961. IBRO's governing council constituted of 90 international, regional, and national scientific members by joining forces with the IBRO executive committee and 5 regional committees, advance the work of neuroscientists and research communities around the world. IBRO also partners with like-minded scientific organisations to identify priorities and help bridge gaps in knowledge, investment and resources in the field of neuroscience.

In line with IBRO's mission and vision of neuroscience engagement and outreach, the current project included several workshops, meetings, and webinars in a phased manner over 6 months, along with a simultaneous social media campaign to address public concerns regarding several prevalent NDDs. The topics of discussions ranged from healthy vs. unhealthy brain functioning and issues and myths related to several NDDs including epilepsy and learning disability. Additionally, the current project aimed at promoting neuroscience and engaging the school students (particularly from grades 9th to 12th) through several activities.

In the first phase of the current project, a 5-day long neuroscience engagement event was organised virtually for the urban/semi-urban population in India. Thereafter, in the second phase, 2 independent workshops were organised for the rural population in villages in Northern India to educate the local communities on several issues related to brain health and NDDs. In the third phase, neuroscience engagement workshops were organised to engage the high school students and introduce them to the miraculous functioning of the nervous system as well as the malfunctioning. Moreover, the current project also incorporated a social media campaign on general awareness of brain functioning along with the awareness of several prevalent NDDs. The simultaneous social media campaign provided a wider range of audience with regular updates about brain functioning and NDDs over 9 months.

## Participants/Audience

A total of nine social media posts were created and circulated under the social media campaign for information dissemination

regarding brain functioning and NDDs which led to a total of 2,97,297 post impressions across the country.

Moreover, a total of 762 (462 female, 299 male) participants participated in several workshops and activities held over 6 months in hybrid (webinars and meetings) and in-person modes. Participants from most of the states and union territories (UT) of India participated in these programs.

## Specific Needs for Neuroscience Engagement and Outreach in India

India is an extremely diverse country home to about 1.39 billion people varying in culture, language, food, socio-economic status and education. Approximately 27% of this population lives below the poverty line defined by lack of nutrition, clothing and hygienic dwelling/residence. According to recent data, 23 million children in India develop a disability in the first few years of their lives.<sup>1</sup> Disabilities such as the NDDs have their epidemiology throughout the globe but are more prevalent in low and middle-economic countries such as India.

Child-rearing practices in India differ across regions but have certain common factors. Children in India are often regarded as "a form of God" and considered "gifts from God". Children with NDDs are sometimes considered the result of previous life's sins or a stranger or neighbour giving the "evil eye".<sup>3</sup> Cultural belief is often found to be a determining factor in parents' perceptions of their child's disability. Beliefs in the concepts of *karma* (God's will, fate and destiny) and *dharma* (traditional established order including all individual, moral and religious duties) are common among not only traditional but also modern Indian families and serve as important determinants of many events of one's life including disability and suffering.<sup>4-6</sup> Therefore, parents often are not aware of the importance of early diagnosis and early intervention and thus rarely turn to the expert medical professionals for help.<sup>3,6</sup>

Another common belief about NDDs such as epilepsy is that it is a curse of bad evils, and thus, epileptic patients are sometimes abandoned and discriminated against the society.<sup>7</sup> Epilepsy is one of the most common brain disorders characterised by recurrent seizures, sometimes followed by unconsciousness and involuntary bowel and bladder movement. More than 85% of epilepsy cases are reported in low-income countries such as India.<sup>7</sup> According to a recent report published in the Times of India, about 95% of such cases are untreated either due to the lack of medical facilities or lack of knowledge about the epidemiology and treatment of the disease.<sup>8</sup> Epilepsy has always been a social stigma in societies such as India due to which people often turn to faith healers, black magic practitioners and exorcists and not to a medical expert such as a neurophysician. The major factors driving superstitious beliefs in India are illiteracy, low standards of life, low socioeconomic status, treatment gap

and religious faiths.<sup>9</sup> Therefore, it is essential that members of the public are informed enough about NDDs, their prevalence, risk factors and the importance of early diagnosis. To achieve this, neuroscience awareness and outreach programs are crucial at the societal level.

Therefore, the current project was aimed at public awareness regarding prevalent NDDs and engagement in Neuroscience. The project was inaugurated in sync with the global brain awareness week on 14th March 2022, wherein a webinar on “Brain and Behaviour” was organised, where the audience was introduced to the fundamentals of the functioning of the brain and how it gives rise to overall behaviour. The project was then kickstarted initiating its events in phase 1, wherein a series of webinars was organised over 5 days to enhance public awareness of several issues related to specific NDDs. The webinars were organised around the following themes: Introduction to the Brain, Introduction to Neuroscience, Brain and Mental Health, Learning Disorder and ADHD, Speech and Language, ASD, NDDs: Screening, Evaluation and Diagnosis and Epilepsy. Several experts were invited from prominent institutes in India such as the Indian Institute of Technology (IITs) and National Institute of Mental Health and Neurosciences (NIMHANS) as well as international institutions such as the University of Reading, UK, University of Padova, Italy to address the audience.

Phase 2 of the project targeted the rural population from Northern India, where high school students were engaged in neuroscience and introduced to the intricacies of the nervous system. The Chief Block Education Officer (CBEO) was approached and presented with the full proposal containing the purpose and activities included in the workshop. After seeking permission from the CBEO, a few schools in the Ramgarh Block of Alwar District (Rajasthan) were contacted. Finally, two schools were selected to organise the workshop. The workshop was then conducted in two Government Senior Secondary Schools, with the permission of the respective principals. The workshop was targeted at educating the local communities by engaging the young students in understanding healthy vs. unhealthy brain functioning as well as the most prevalent NDDs and the importance of early diagnosis. Each workshop started with an inaugural ceremony with the prayers of the Hindu deity Saraswati which is considered the deity of knowledge in Hindu mythology and was followed by the address of the school principal who introduced the students to the importance of mental health and healthy brain functioning. The workshop was divided into three parts: the first session was focused on mental health and well-being where the audience was introduced to the importance of mental health and early symptoms of depression and anxiety. The second session was focused on the healthy vs. unhealthy functioning of the brain as well as the anatomy and physiology of the brain. The workshop included several hands-on activities such as a nervous system-related cross-word puzzle activity taken from Mindboggling-2018 from IBRO-DANA

resources for instructors. Students were handed a printout of the cross-word puzzle and were asked to find out as many nervous system-related words as they could in 10 min. Students were then asked to count the number of words they could find and winners were announced. Winners were presented with exciting prizes such as a brain-printed t-shirt and a similar coffee mug. In the third session, students were introduced to several prevalent NDDs such as epilepsy, learning disability and ASD. The workshop ended with the speakers sharing contact details of mental health professionals and institutes such as NIMHANS with the students and teachers.

Phase 3 was a set of two neuroscience engagement workshops entitled “Know Your Brain: A Neuroscience Engagement Day” with an aim to promote neuroscience and engage young students in neuroscience-related activities. Groups of students from different private schools in the Delhi-National Capital Region (Delhi-NCR) were invited to participate in the workshops. The session began with a welcome address, where the students were introduced to the purpose of the workshop and emphasis was laid on the importance of mental health and well-being as well as on a healthy brain. The workshop was divided into three parts. Part 1 focused on emphasising the importance of mental health and the importance of addressing mental health concerns under an interactive talk entitled “Befriending our Concerns: A dialogue for mental health”. Part 2 of the workshop was focused on introducing the importance of a healthy brain, as well as the basic anatomy and physiology of the nervous system. Additionally, this part also focused on some of the most prevalent brain disorders such as epilepsy and Alzheimer’s disease. Part 3 was designed as a fun-filled learning activity for students titled “Draw YOUR Brain”, where students were divided into a group of 5–6, and each group was handed a coloured print of a human brain and required stationary, and they were asked to create a poster with a slogan, quotation or poetry which best represented their poster. Posters were assessed on the following criteria by a team of judges: (a) Originality, (b) Clarity, (c) Creativity and (d) Group synergy. The winning team was awarded Amazon Vouchers. The workshop ended with the speakers sharing contact details of mental health professionals and institutes such as NIMHANS with the students and teachers.

## Discussion

NDDs are emerging as a major health concern globally and are more prevalent in low and middle-income countries including India. A recent landmark study which collected data from 3964 children from five geographically diverse populations in India reported that 1 in 8 children might be suffering from at least one NDD sampled by the researchers.<sup>1</sup> Such a high prevalence of NDDs highlights the major public health problems faced by the country. The study further highlighted several risk factors

for NDDs such as children with a history of delivery at home, delayed crying or difficulty breathing at birth (perinatal asphyxia), neonatal illness requiring hospitalisation, neurological/brain infections, LBW and/or birth before 37 weeks of gestation (prematurity) and stunting. The authors reported that the NDD burden on national health care can be reduced substantially by addressing the risk factors which are amenable to public health interventions such as place of delivery, perinatal asphyxia, neonatal illness, post-natal neurological or brain infections, stunting and LBW. In line with these ideas, the current project was also aimed at public awareness and neuroscience engagement as well as addressing

public health concerns about NDDs through a series of activities including webinars and workshops.

### Limitations

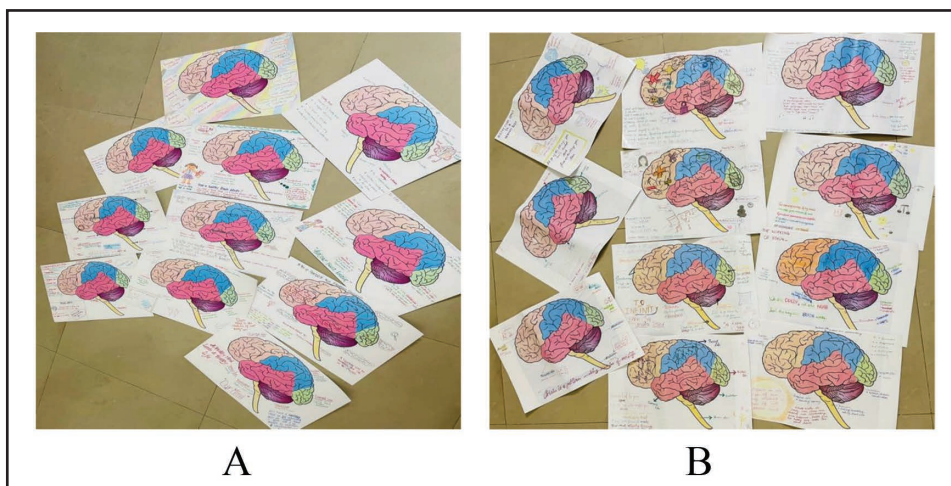
Though the current project was a great effort towards public awareness about NDDs, it had certain limitations. The current project did not measure the impact of the activities and awareness campaigns, however, the general feedback from the participants was received when they were asked to list key takeaways from the event. A systematic impact assessment would have been helpful to map the impact of the project and modify future activities accordingly.

**Table I.** Number of Participants Engaged Over Several Workshops, Meetings, Activities, and Social Media Campaigns.

Type of Event	Audience/Participants Engaged
Hybrid/in-person workshops, meetings and webinars	762
Social media campaign	2,97,297



**Figure 1.** (A) Students Engaged in Solving a Nervous System Related Cross-word Puzzle Activity from Mindbogglers-2018 from IBRO-DANA Resources for Instructors (B) Students Engaged in Understanding the Anatomy and Physiology of the Brain.



**Figure 2.** The Brain Posters Created by all the Groups During their Participation in the “Draw YOUR Brain” Activity.

Nevertheless, the current project highlights the requirement of similar public health awareness campaigns specifically focused on neurological conditions as well as addressing the unexpected impact of neurotoxic factors in the local environment. Therefore, future projects should focus on designing and implementing systematic public engagement and awareness campaigns focused on neurological conditions.

## Conclusion

The current project emphasises the requirement of neuroscience engagement and outreach at the societal level, and public awareness of several prevalent NDDs. The project report further highlights several activities carried out as part of the project in both rural and urban areas to enhance public engagement in neuroscience and awareness of several NDDs.

## Abbreviation

International Brain Research Organisation: IBRO  
 Neurodevelopmental Disorders: NDDs  
 Vision impairment: VI  
 Hearing impairment: HI  
 Autism spectrum disorder: ASD  
 Learning disorders: LDs  
 Attention deficit hyperactivity disorder: ADHD  
 Indian Institute of Technology: IIT  
 National Institute of Mental Health and Neuro-Sciences: NIMHANS  
 United Kingdom: UK  
 Chief Block Education Officer: CBE0  
 Delhi-National Capital Region: Delhi-NCR  
 Union territories: UT  
 Low birth weight: LBW

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## Authors' Contribution

DB had conceptualised the project and written the manuscript.

## Statement of Ethics

All the data and figures used in the manuscript are author's own work. No data is collected and used in the manuscript. The

manuscript is a work of public awareness and engagement events.

## Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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## ORCID iD

Divya Bhatia  <https://orcid.org/0000-0002-7017-2276>

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