

## **A large scale, two phase study to estimate prevalence, and raise awareness, about Autism Spectrum Disorders in India**

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Despite being the second most populous country in the world, there is a serious dearth of epidemiological research on Autism Spectrum Disorders (ASD) in India. While estimates suggest that India could have more than 2 million people with ASD, this has never been directly tested. The current project represents a large-scale attempt to estimate the prevalence of ASD in India, by focusing on three major cities of India. In Year 1, the group proposes to create a central secure online database with phenotypic details and clinical notes of patients between 4-7 years of age, from pediatric outpatient departments of multiple government/charitable and private hospitals in each city. The members of the online database would then be contacted to take part in a screening study using translated versions of the Social Communications Questionnaire (SCQ) and Autism Spectrum Quotient (AQ) in Hindi, Bengali, or Marathi depending on the local language of the city. Those children who meet the cut-off scores for ASD will then be approached in years 2 and 3 for in-person testing using translated versions of the Autism Diagnostic Observation Schedule (ADOS) and measurement of further socio-cultural variables. These case ascertainment methodology will be used to conduct a pilot epidemiology study that will result in a multi-city prevalence estimate of ASD in India. In parallel, a structured program to raise autism awareness in the country will be carried out, which will include: a) organizing yearly workshops for medical professionals, teachers, and parents of children with ASD, b) making a documentary film, c) translating existing awareness material into regional languages, and d) assessing awareness about ASD in the general population, both at the beginning and at the end of our program. As the first major epidemiological study of autism coupled with a structured autism awareness drive in three major cities of India, as well as being driven by the leading autism advocacy organization in India, Action for Autism, this project has the potential to hugely improve the state of autism research and awareness in India.