

Updates from NAMASTE to design and develop a community engagement toolkit for Autism and Intellectual Disability in South Asia

About NAMASTE



Autism Spectrum Disorder also known as autism, is a neurodevelopmental disability with lifelong consequences for care and support. It is estimated that there are more than 2 million young children with autism in India. However, only a small fraction of children with autism and intellectual disability can access services, due to gaps in diagnosis and treatments in most places. Low awareness levels and stigma related to disability also interfere with help-seeking. NAMASTE aims to address the lack of community and professional awareness of autism and intellectual disability through the development and piloting of a range of community awareness tools which will be co-produced with persons with lived experience of autism and ID and health care providers.

Updates from research activities

We met with community stakeholders including adults living with autism, parents and parent advocates of children living with autism, doctors and health workers across Delhi, Goa, Colombo and Kathmandu to understand their priorities and needs on accessing information related to neurodevelopmental disorders (NDDs). This research is being conducted in partnership with Quicksand Design Studio.



All-site CAB meeting - 25th August, 2023



Early Signs

Social stigma persists even though it may appear differently according to one's beliefs

Detection + diagnosis

There is widespread misconception and misinformation about NDDs and ASD with limited and sometimes stigmatising beliefs about causes of NDDs.

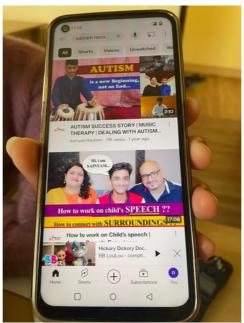
Intervention

 Interventions and success are often misunderstood. There needs to be expectation setting and understanding of what long term therapy and interventions look like. Parent and caregiving well-being is important but unaddressed in the healthcare systems.

October >>>

PROTOTYPE TESTING







Images from prototype testing sessions at various sites

We presented insights learned from our initial research to NAMASTE's Community Advisory Boards and used recommendations to develop a set of initial ideas and prototypes of awareness building tools which are being tested with representative stakeholder groups at each project site. These included: leaflets on child developmental milestones, trackers, and posters with similar information. From mid-October to November we were able to test these examples, referred to as prototypes, to understand the ways these materials will be useful or not useful going forward.

Moving forward...

We have gathered insights from across sites about the usefulness and relevance of these materials and will be synthesising the findings to develop the final NAMASTE Community Engagement toolkit.

This would not have been possible without you, so for that, we have immense gratitude for your contribution!

Participate in NAMASTE

We at NAMASTE are actively creating opportunities for relevant stakeholders to contribute to our research through participation in workshops, interviews and sharing of personal narratives. If you'd like to participate:

Click to register

or Scan here:



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