



Innovating for Autism in India

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This presentation



A journey of a not-for profit in providing care for families of young children with autism

India



POPULATION :1.4 BILLION

www.worldpopulationreview.com

22 Official Languages

Population comparing countries to states
in India

Source :[http: mapsonthe web-zoom](http://mapsontheweb-zoom)

World Bank



Autism Legislation in India

1991: Parents began to lobby to create awareness for autism

1994: Action for Autism 1st specialist school with services established

1995: Persons for Disabilities Act passed: No Autism

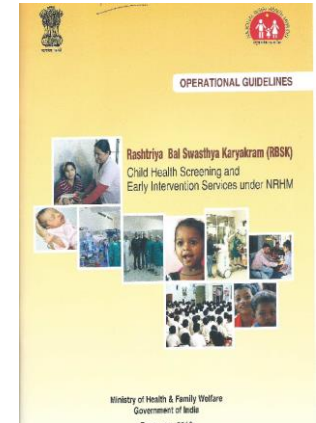
2000: National Trust Act established recognised Autism, but no method for certification

2009: Right for Education Act, mandated inclusion for all

2013: Launch of the Rashtriya Bal Swasthya Karykram

2016: Right for Persons with Disabilities Act passed which recognises autism as a developmental disability and constituted a process for certification

Patchy implementation is still a critical problem



About us

Sangath is an Indian non-governmental organisation, estd. in 1996, committed to transform mental health for all. We are committed to improve access to mental healthcare and address psychological and social needs of people across the life course



Sangath : Working across the life course



Today's focus



1996 till the present

Commenced as a Child Development Center in Goa

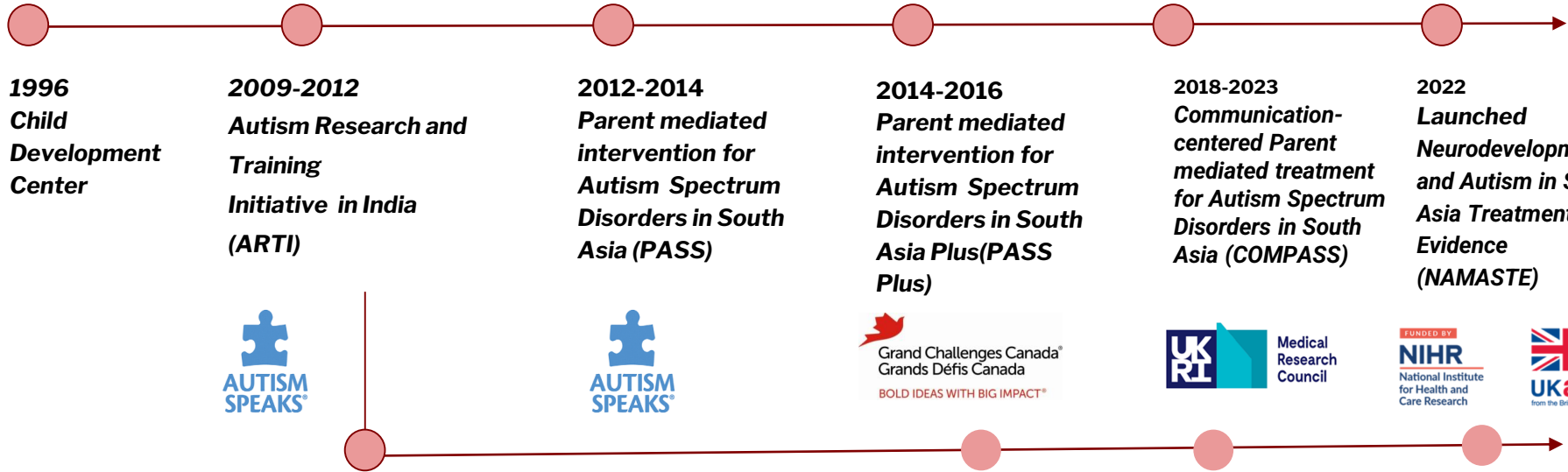
- Providing traditional center based services
- Tremendous demand for services
- Clinical practice was seeing a large number of children with diverse developmental disabilities
- Families of children with developmental disorders were struggling to understand their children's needs and match them to services

Key challenges

- Recruiting and retaining specialist staff
- Low follow up rates for children with developmental disabilities



Public Health Research journey to generate solutions for families of young children with autism



1996
Child Development Center

2009-2012
Autism Research and Training Initiative in India (ARTI)



2012-2014
Parent mediated intervention for Autism Spectrum Disorders in South Asia (PASS)



2014-2016
Parent mediated intervention for Autism Spectrum Disorders in South Asia Plus(PASS Plus)



2018-2023
Communication-centered Parent mediated treatment for Autism Spectrum Disorders in South Asia (COMPASS)



2022
Launched Neurodevelopment and Autism in South Asia Treatment and Evidence (NAMASTE)



2017-2019
Screening Tools for Autism Risk Using Technology (START)



2017-2019
Integrated Assessment of Cognitive Health (REACH)



2018-2024
Scalable TRansdiagnostic Early Assessment of Mental health (STREAM)



Acknowledging collaborators and colleagues



Prof Vikram
Patel



Prof Jonathan
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Vivek Vajaratkar



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Kathy Leadbitter



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Dr Monica
Juneja



Gopika Kapoor



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Funders



● Autism Research and Training Initiative in India (ARTI) (2009-12)



What we wanted to do

- Understand the true numbers of young children with autism through a prevalence study
- To understand family experiences and their key challenges



Autism Research and Training Initiative (ARTI); Prevalence Study



RESEARCH ARTICLE

Neurodevelopmental disorders in children aged 2–9 years: Population-based burden estimates across five regions in India



- @ 4000 children evacuated, community based survey in 5 sites
- Used indigenously adapted tools as the clinical goal standard
- Total disabilities 12 %
- Autism: @ 1 %
- Very large numbers of children **with autism who need treatment**

Autism Research and Training Initiative in India: Caregiver experiences

When I came to know about the (diagnosis) Autism, it was shock to me, my husband went totally went mad.

Mamma you spend so much time with him and (not on) me

In the office, my work wasn't up to the mark. I had to leave my job

I can't go to church because he screams and shouts and that is the place where you have to be quite and calm

When he was 6 years, he had this problem. At the centre they told us that there is no need of giving him tablets, he only requires to be given speech therapy. However it was not possible to go every day so we went for only a few days.

Two key challenges for families

Families spent significant time getting an accurate diagnosis



Families had no access to evidence based treatments



Parent-mediated intervention for Autism Spectrum Disorders in South Asia (PASS) Project (2012-2014)



Prof Atif
Rahman



Prof Jonathan
Green



Prof Vikram
Patel



Gauri Divan

Parent-mediated intervention for Autism Spectrum Disorders in South Asia (PASS) Project

We set out answer the following questions

What do we deliver?



Who will deliver it?



Where will we deliver it?



Parent-mediated intervention for Autism Spectrum Disorders in South Asia (PASS)

We set out answer the following questions

What do we deliver?



Identifying and evidence intervention for non-specialist delivery

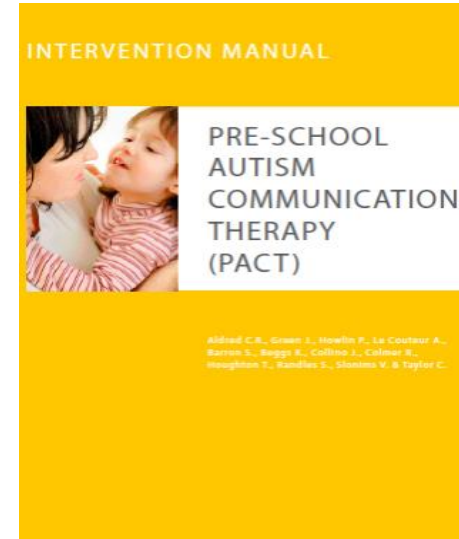
Developmental Social Communication intervention

Low intensity

Parent mediated

Video feedback

Strong theoretical base with mediation via parent synchrony and child communication initiation



Developed in the UK, evidence with long term results

Parent mediated Interventions

*Chain of effect:
Parent change*

leads to

*Child interaction change
with parent*

leads to

*Improved child interaction
with others – symptom
reduction*



Parent and therapist interaction changes parent behaviour



Changing parental synchrony impacts child initiations in dyad



Changing initiations by child affects interaction with researcher in ADOS



Parent-mediated communication-focused treatment in children with autism (PACT): a randomised controlled trial

Jonathan Green, Tony Charman, Helen McConachie, Catherine Aldred, Vicky Slonims, Pat Howlin, Ann Le Couteur, Kathy Leadbitter, Kristelle Hudry, Sarah Byford, Barbara Barrett, Kathryn Temple, Wendy Macdonald, Andrew Pickles, and the PACT Consortium



Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial

Andrew Pickles, Ann Le Couteur, Kathy Leadbitter, Erica Salomone, Rachel Cole-Fletcher, Hannah Tobin, Isobel Gammer, Jessica Lowry, George Vamvakas, Sarah Byford, Catherine Aldred, Vicky Slonims, Helen McConachie, Patricia Howlin, Jeremy R Parr, Tony Charman, Jonathan Green



References: The Lancet (2010), 375, 9732; 2152-2160 The Lancet (2016); 388: 2501-2509

Parent-mediated intervention for Autism Spectrum Disorders in South Asia (PASS)

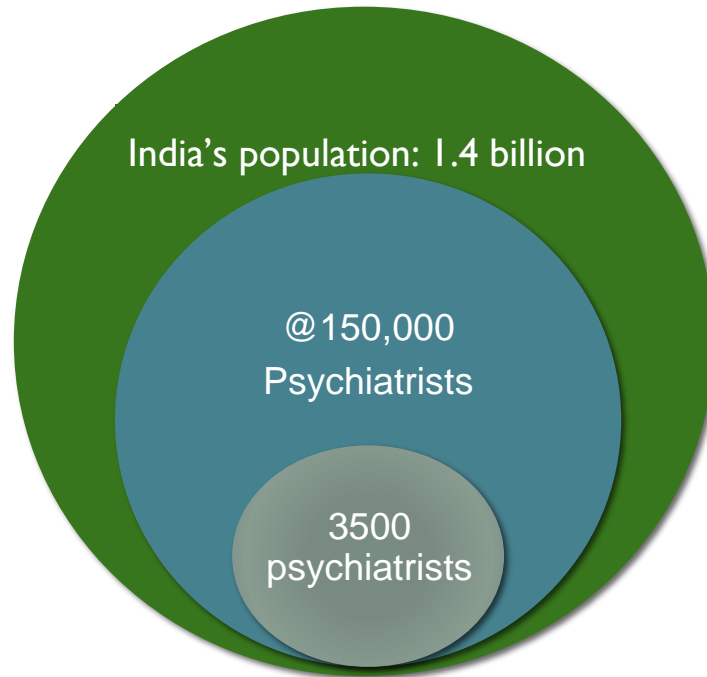
We set out answer the following questions

Who will deliver it?





Who will deliver these interventions?



Developmental
Pediatricians
Speech and Language
Therapists
Occupational Therapist
Special Educators



How will non-specialist deliver a complex intervention?

- ▶ Using TASK SHARING
 - ▶ the strategy of rational redistribution of tasks among health workforce teams
 - ▶ specific tasks are moved, where appropriate, from highly qualified health workers to health workers with shorter training and fewer qualifications in order to make more efficient use of the available human resources for health





Adapting the intervention for non-specialist delivery

- Making the intervention appropriate for **task sharing**
 - Simplification of language (non technical term for communication)
 - Introducing analogies to explain key concepts
 - Competency measure
 - Strong supervisory framework
- Addressing needs of families
 - Location of delivery flexible
- Clear referral instructions
- Key features of original PACT preserved





Training and Supervision cascade

Developmental Specialists



Non-specialist providers



Parents/caregivers



Child with Autism

Build and maintain competencies at each level of the cascade



Parent-mediated intervention for Autism Spectrum Disorders in South Asia (PASS)

We set out answer the following questions

Where will we deliver it?



PASS Trial: Our Findings

- Evaluation through a comparative trial with 65 children in India and Pakistan
- Non-specialists were project based graduates with no exposure to child development or disabilities
- Very high acceptability . 80% families completed the intervention
- Non-specialists were able to deliver the intervention to very high quality
- Improvement in both parent synchrony and child communication

This was the first definitive RCT of a systematically adapted evidence-based intervention delivered through the process of task sharing by non-specialists in a LMIC setting

Vaibhav's mothers concerns



I found the intervention allowed me to understand how to support Vaibhav's communication difficulties

However I was still finding it difficult to manage his levels of activity and his reluctance to eat a variety of foods

Picture use consented by parent

Parent-mediated intervention for Autism Spectrum Disorders in South Asia Plus (PASS Plus)(2016-18)



Gauri Divan

Vivek vajaratkar



Prof Jonathan
Green



Prof Vikram
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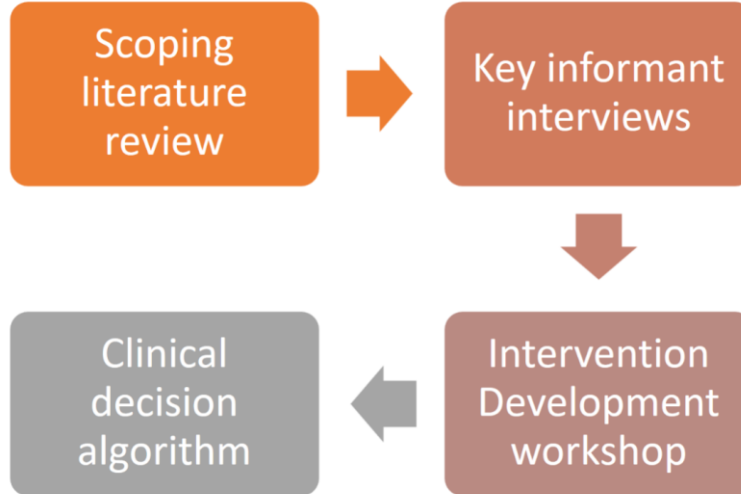
Parent-mediated intervention for Autism Spectrum Disorders in South Asia Plus (PASS Plus)(2016-18)

What we set out to do

- Expanding the PASS social communication intervention to address common non medical co-occurring conditions
- Evaluating the expanded intervention in a rural setting in India

PASS Plus Intervention Development

What we did



Clinical decision algorithm for Non Specialist navigation around : Sensory sensitivities, Behavioural issues, Feeding, Toileting and Sleep difficulties and Parental well being

PASS Plus Trial : Our Findings

- Evaluation through a comparative trial with 40 children in rural India
- Non-specialists were project based graduates with no exposure to child development or disabilities delivered at home
- Very high acceptability. 70% families completed the home based intervention
- Non-specialists in rural India were able to deliver the intervention to very high quality using 2 manuals
- Improvement in both parent synchrony and child communication



Communication-centered Parent mediated treatment for Autism Spectrum Disorders in South Asia (COMPASS) (2018-2024)



Prof Jonathan
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Prof Vikram
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Prof Richard
Emsley



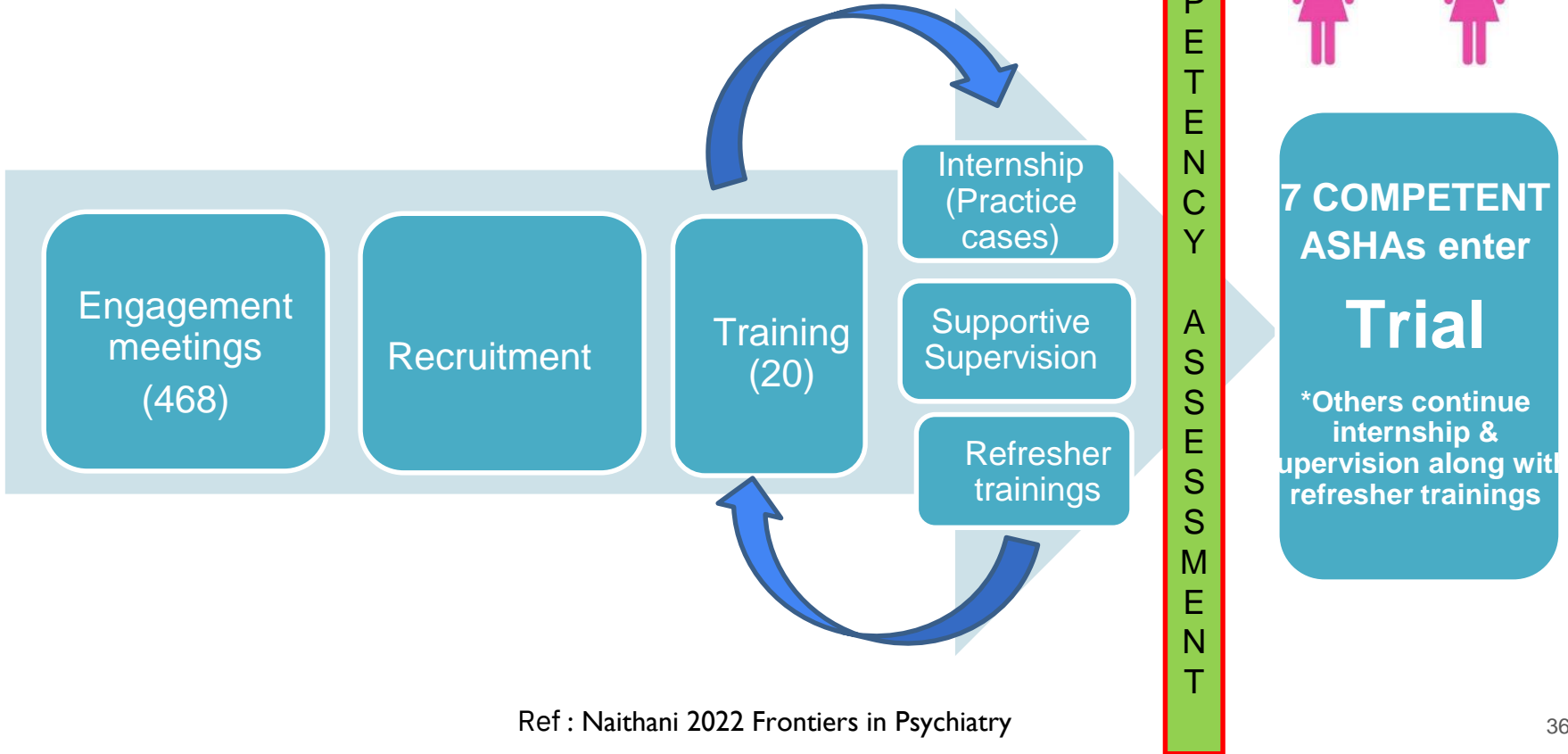
Medical
Research
Council

● **Communication-centered Parent mediated treatment for Autism Spectrum Disorders in South Asia (COMPASS) (2018-2024)**

What we set out to do

- Work with existing healthcare nonspecialist workers (and not just project based non-specialists) through a collaboration with the health system
 - Accredited Social Health Activists (ASHA)
 - Women resident 18-40 years, Education level 8th grade minimum
 - No exposure to child development
- Recruit from public tertiary care centers
- Work in National Capital Region
- Investigate a range of costs impacting families and caregivers

Training and supporting delivery



Communication-centered Parent mediated treatment for Autism Spectrum Disorders in South Asia (COMPASS) : Update

- Recruited 261 children into the trial
- Trained 7 health system frontline workers to deliver the PASS Plus intervention under supervision
- Showed resilience through the pandemic and the associated lock downs
- Awaiting trial completion in August 2023



Frontline workers speak

A mother, who I am delivering the intervention to, often calls and tells me how her child used to struggle to sit even for a minute or two, but now the child and mother enjoy longer durations of play together.

One of the mothers called me at midnight to share that when his father came back from work, her child (for the first time) excitedly shared with him how mummy and he had a great (time) playing

It is difficult for a woman as a parent with a child with autism, as the family does not pay heed to their concerns and does not understand what they are going through. In such circumstances, the mother feels good interacting with us during the sessions. She feels there is someone she can talk to because of the connect we share.

Two key challenges for families

Families spent significant time getting an accurate diagnosis



Families had no access to evidence based treatments

Acknowledging colleagues



Prof
Vikram
Patel



Dr Tara
Thiagarajan



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Bhavnani



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Gladstone



Prof
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Gareth
McCray



Elin
Williams



Nick
Thompson



Dr Mathew
Belmonte



Dr Sheffali
Gulati

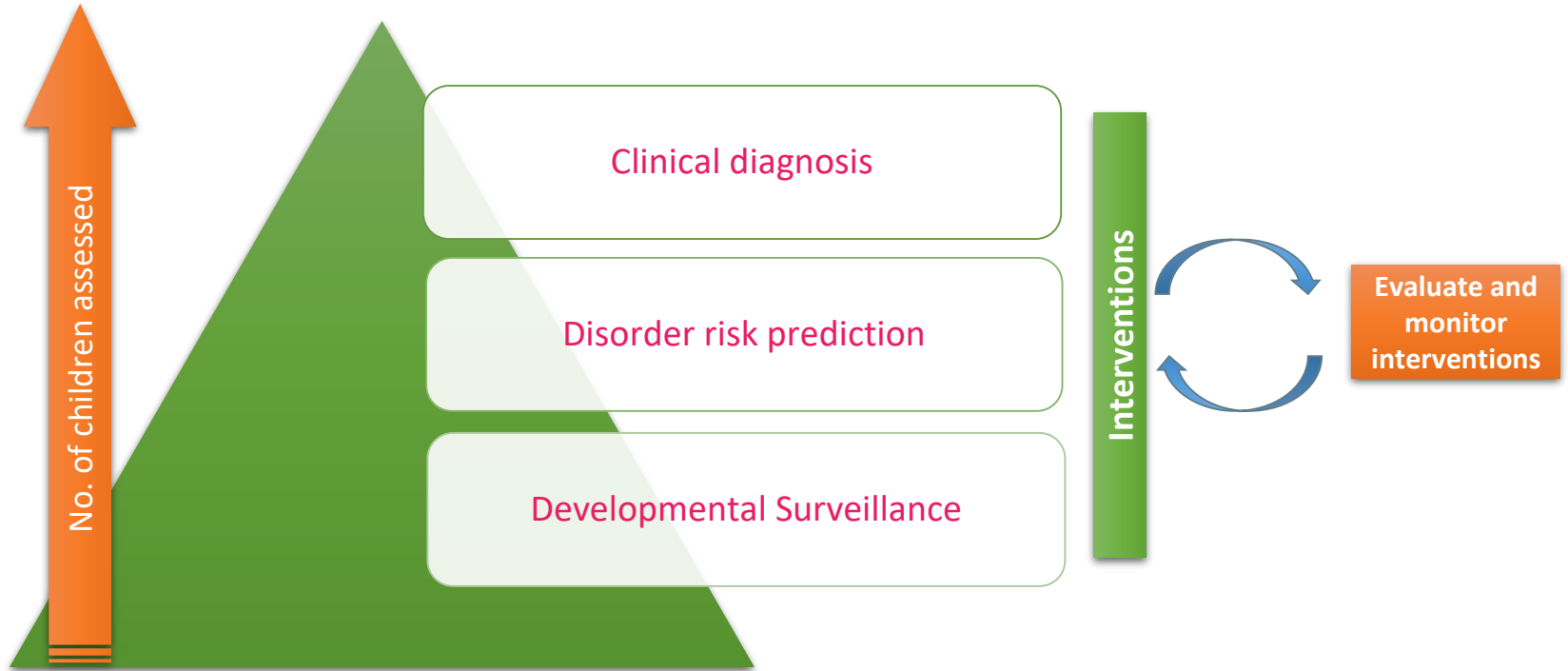


Dr Sharat
Chandran

Funders



Our vision for early child development



Developmental assessment on an E-Platform (DEEP): Cognition: predict BSID-III cognitive domain score

1. LOCATION RECALL (LR)



2. SINGLE TAP (ST)



3. ALTERNATE TAP (AT)



4. POPPING BALLOONS (PB)



5. GROW YOUR GARDEN (GYG)



6. HIDDEN OBJECTS (HO)



7. ODD ONE OUT (OOO)



8. SPOT THE DIFFERENCE (SD)



9. MATCHING SHAPES (MS)



10. JIGSAW (JIG)



11. SORTING OBJECTS (SO)



12. SERIES COMPLETION (SC)



13. PATTERN MAKING (PM)



14. SEQUENCE RECALL (SR)



Low cost devices



No WIFI



Free of assessor judgment



No written instructions

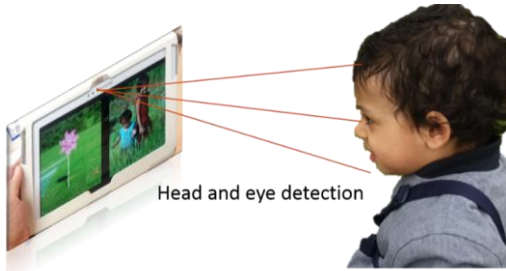


Modular



Open source

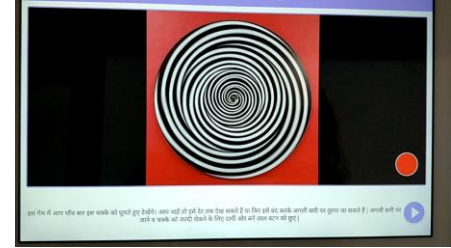
Screening Tools for Autism Risk Using Technology(START)



Eye-tracking social preference



Social motivation



Sensory stimulation

Motor Following

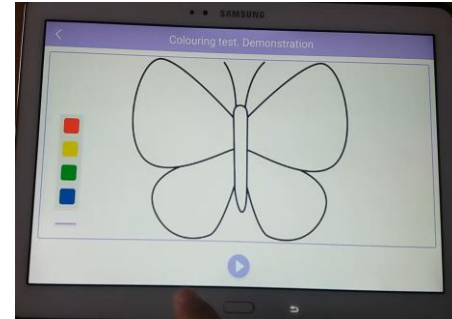


Pop the bubble



Visuomotor integration

Colouring task



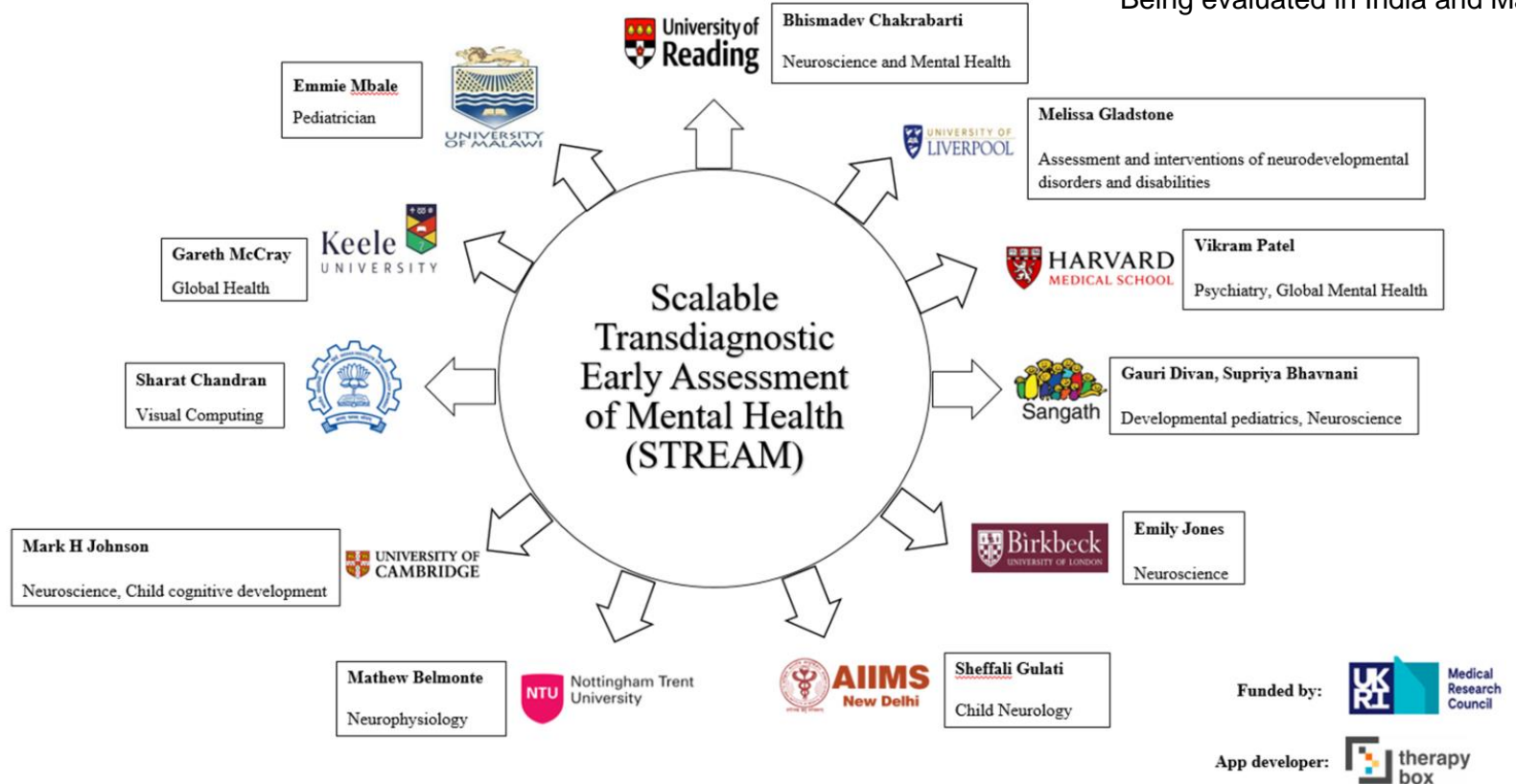
Ongoing work - STREAM

Scalable Transdiagnostic Early Assessment of Mental health

Combining tools onto a single platform

Expanding age range to 0-6-years using the Malawi Developmental Assessment Tool

Being evaluated in India and Malawi



In conclusion

Bridge the detection and treatment gap by designing tools and interventions that can be used in the community by non specialists to address immense needs in low resource settings

Consider how we can leverage technology to provide **cost-effective, easily scalable** evidence-based solutions

Aim to design for a **stepped care approach** for families of young children with developmental disabilities

Build on **global evidence** and design **local solutions**

Encouraging the north to consider innovation from the south



Acknowledgements and thanks to our families that trust us enough to participate in the science of generating evidence.



NAMASTE!



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