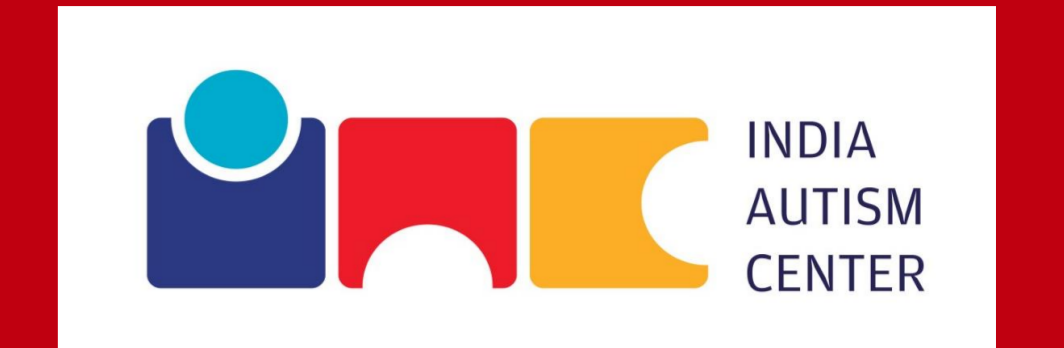# AUTISM COMMUNITY PRIORITIES IN DIVERSE LOW-RESOURCE SETTINGS: A COUNTRY-WIDE SCOPING EXERCISE IN INDIA

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Introduction

- Studies mapping the priorities of the autism community mostly takes place in high-income countries (HICs) (1). Such studies focus largely on research priorities.

- >5 million autistic individuals are estimated to live in India alone. There has been no systematic scoping exercise to map the priorities of this community.

- This study is the first attempt to assess priorities of the Indian autism community in different domains.

Objective

- To provide a systematic, empirical summary of the priorities of the Indian autism community in domains of skills training, interventions and research.

Design

Sample:

- Individuals with a clinical diagnosis of Autism Spectrum Disorder (ASD) using DSM criteria; or,

- Parents/guardians of individuals diagnosed with ASD;
  - Individuals had to have received a diagnosis at least six months before filling out the survey,
  - Participants who are residents of India.

Measures:

Questionnaire from N=280. One question each on skills, intervention, and research.

Follow-up interviews from a subset of N=40.

The survey was made available in three languages: English, Bengali and Hindi to allow for wider participation.
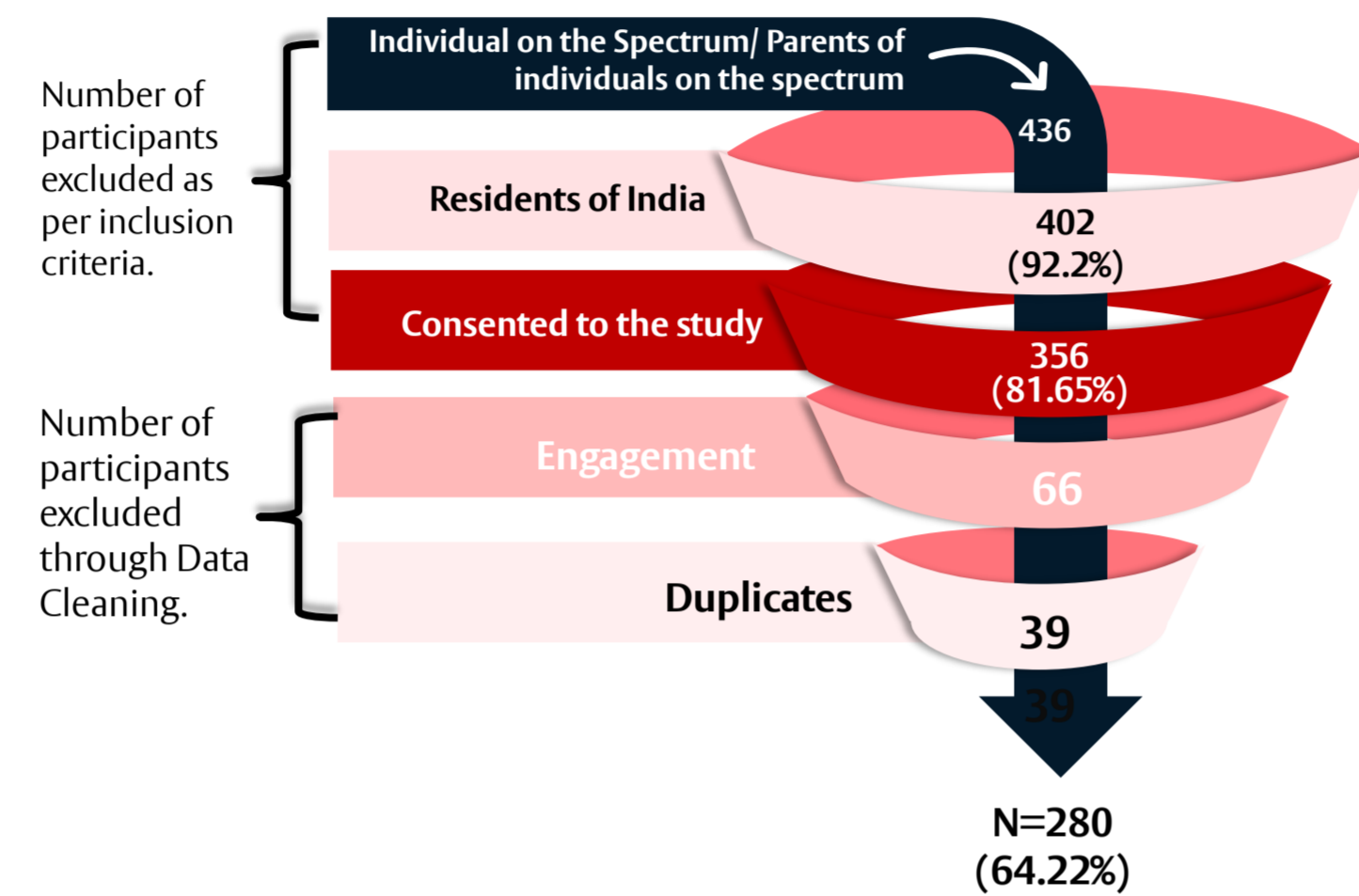
Data Analysis:

Quantitative
Mean rank and **standard deviation** for each option for each question (skills, intervention, research)
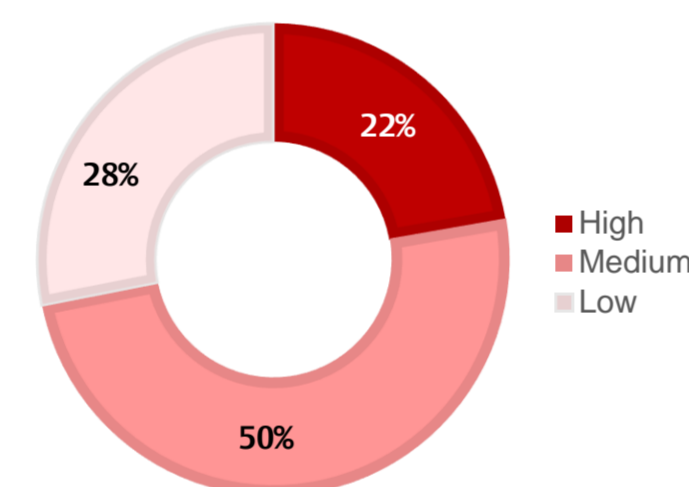
Qualitative
Illustrative quotes from **interviews** highlighting reasons to choose a specific rank order
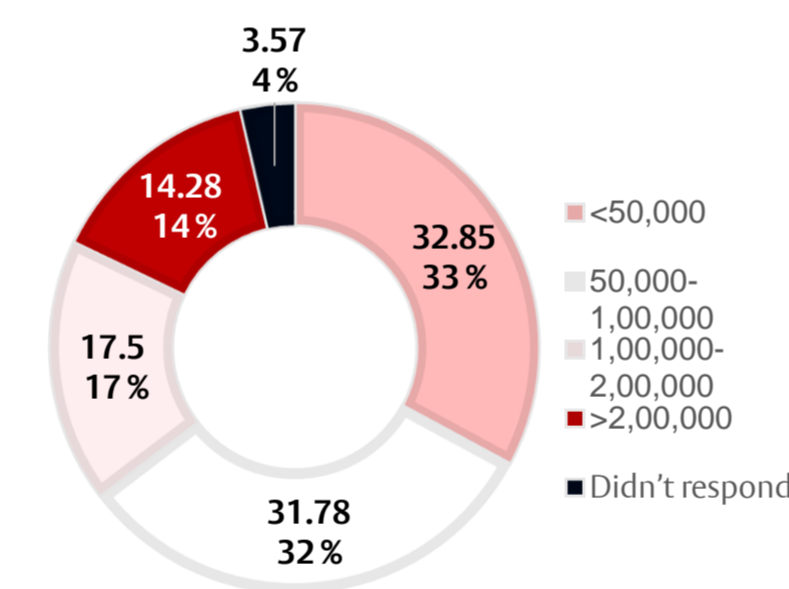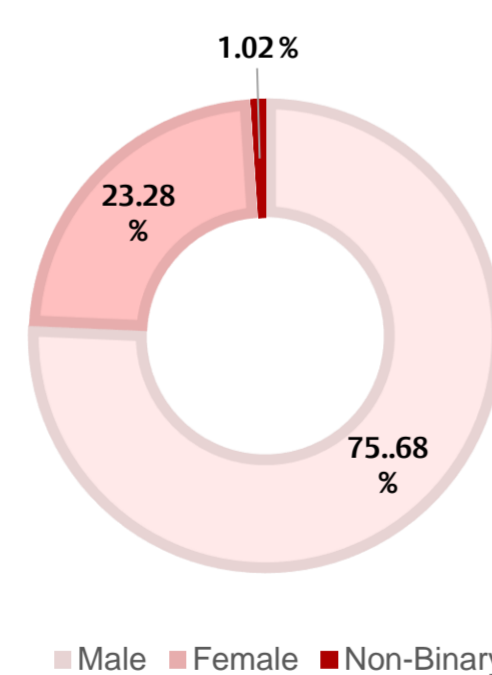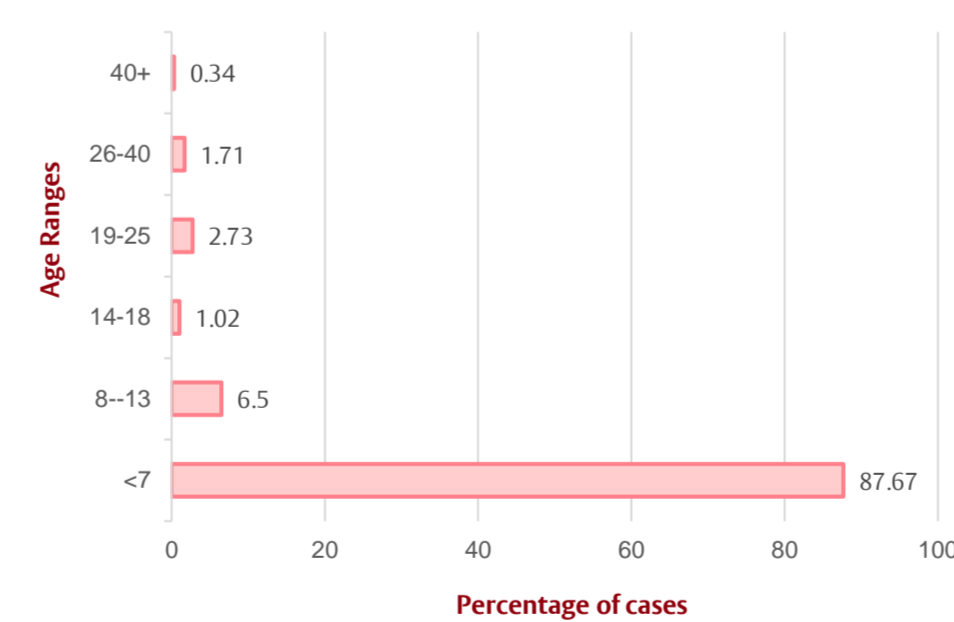
Results

Sample description:

Number of participants excluded as per inclusion criteria.

Number of participants excluded through Data Cleaning.

- Individual on the Spectrum/ Parents of individuals on the spectrum — 436
- Residents of India — 402 (92.2%)
- Consented to the study — 356 (81.65%)
- Engagement — 66
- Duplicates — 39

N=280 (64.22%)

Support Needs

- High 22%
- Medium 50%
- Low 28%

Socioeconomic status

- <50,000 — 32.85 33%
- 50,000-1,00,000 — 31.78 32%
- 1,00,000-2,00,000 — 17.5 17%
- >2,00,000 — 14.28 14%
- Didn't respond — 3.57 4%

Gender of autistic individuals

- Male 75.68%
- Female 23.28%
- Non-Binary 1.02%

Age of Diagnosis

(Percentage of cases)
- 40+ — 0.34
- 26-40 — 1.71
- 19-25 — 2.73
- 14-18 — 1.02
- 8–13 — 6.5
- <7 — 87.67

Age of autistic individuals

(Percentage of cases)
- 40+ — 1.71
- 26-40 — 5.47
- 19-25 — 17.46
- 14-18 — 7.87
- 8–13 — 36.64
- <7 — 30.82
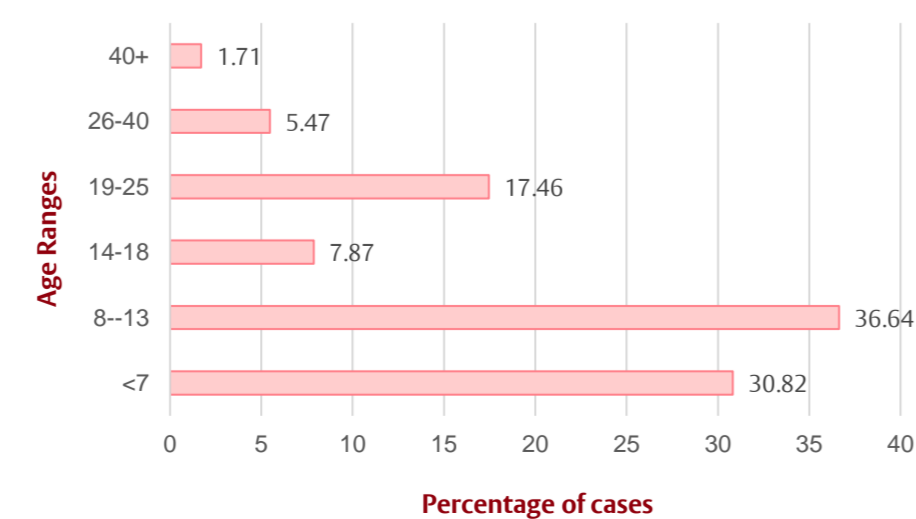
Language representation

- English 88%
- Bengali 10%
- Hindi 2%
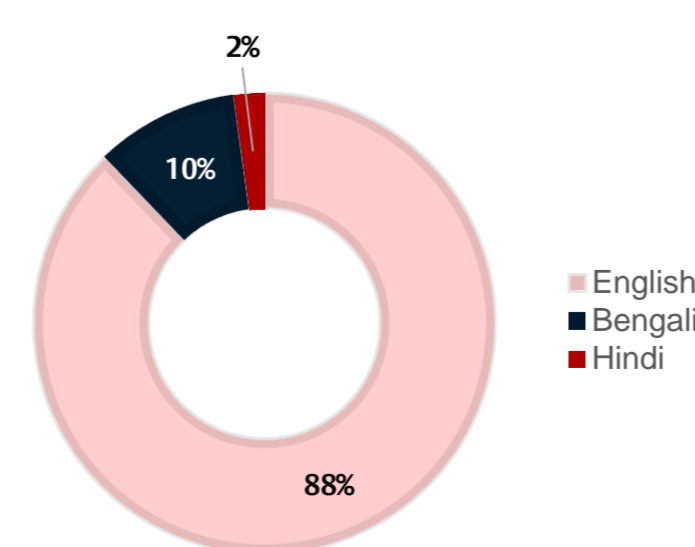
Priorities:
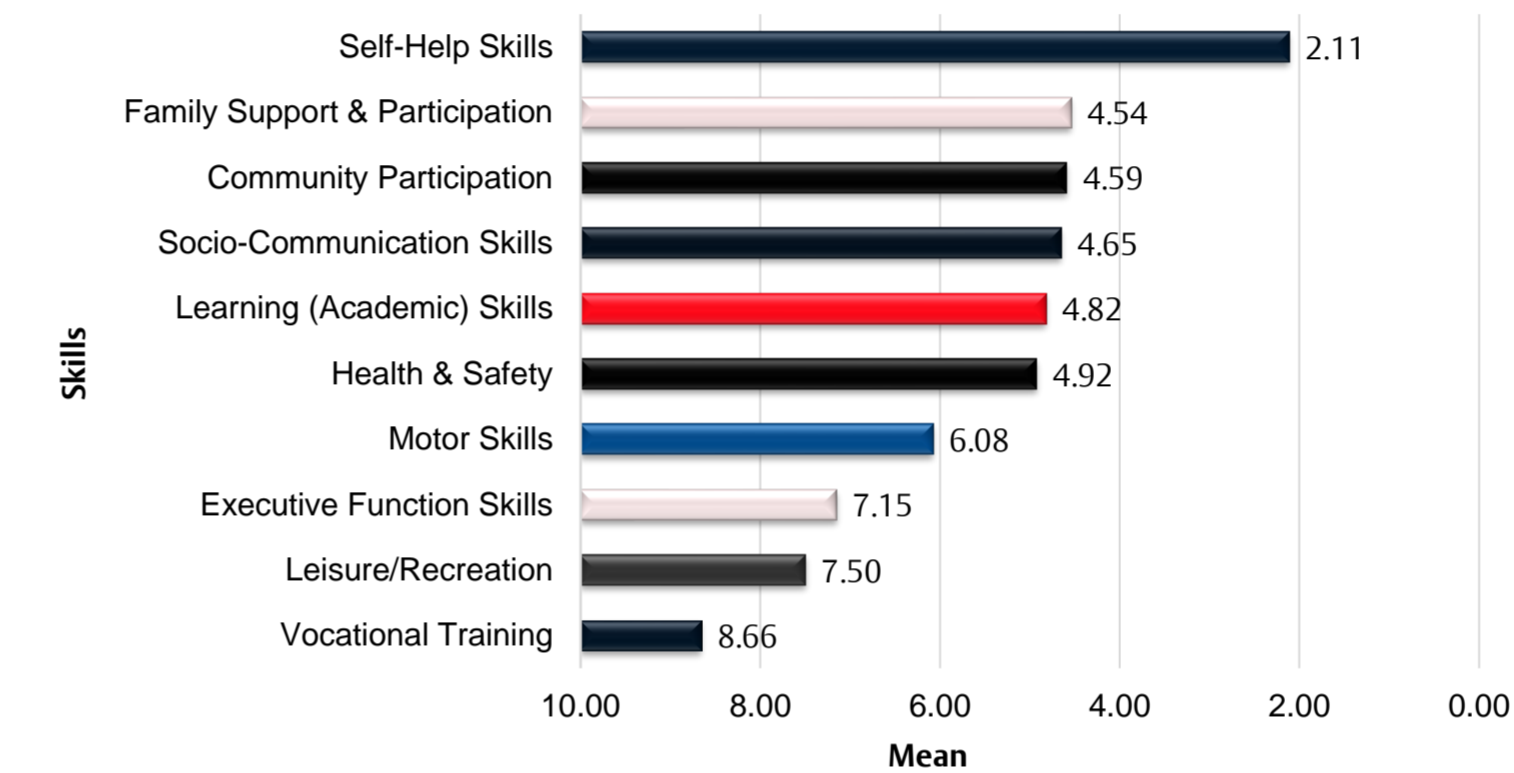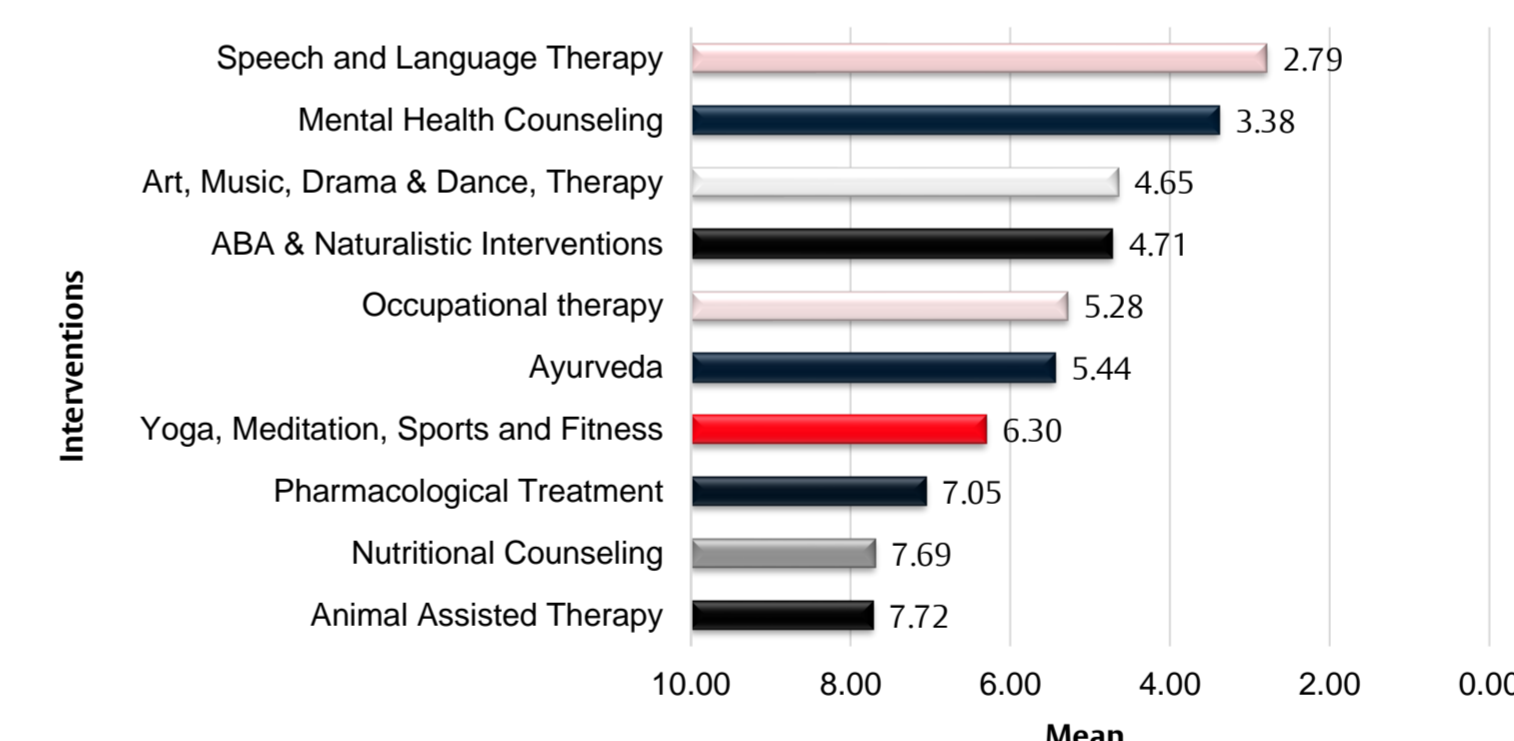
- Mean scores representing the order of preference with the most preferred option at the top (lowest mean score).
- Illustrative quotations from interviews highlighting reason for preference.

Skills:

- Self-Help Skills — 2.11
- Family Support & Participation — 4.54
- Community Participation — 4.59
- Socio-Communication Skills — 4.65
- Learning (Academic) Skills — 4.82
- Health & Safety — 4.92
- Motor Skills — 6.08
- Executive Function Skills — 7.15
- Leisure/Recreation — 7.50
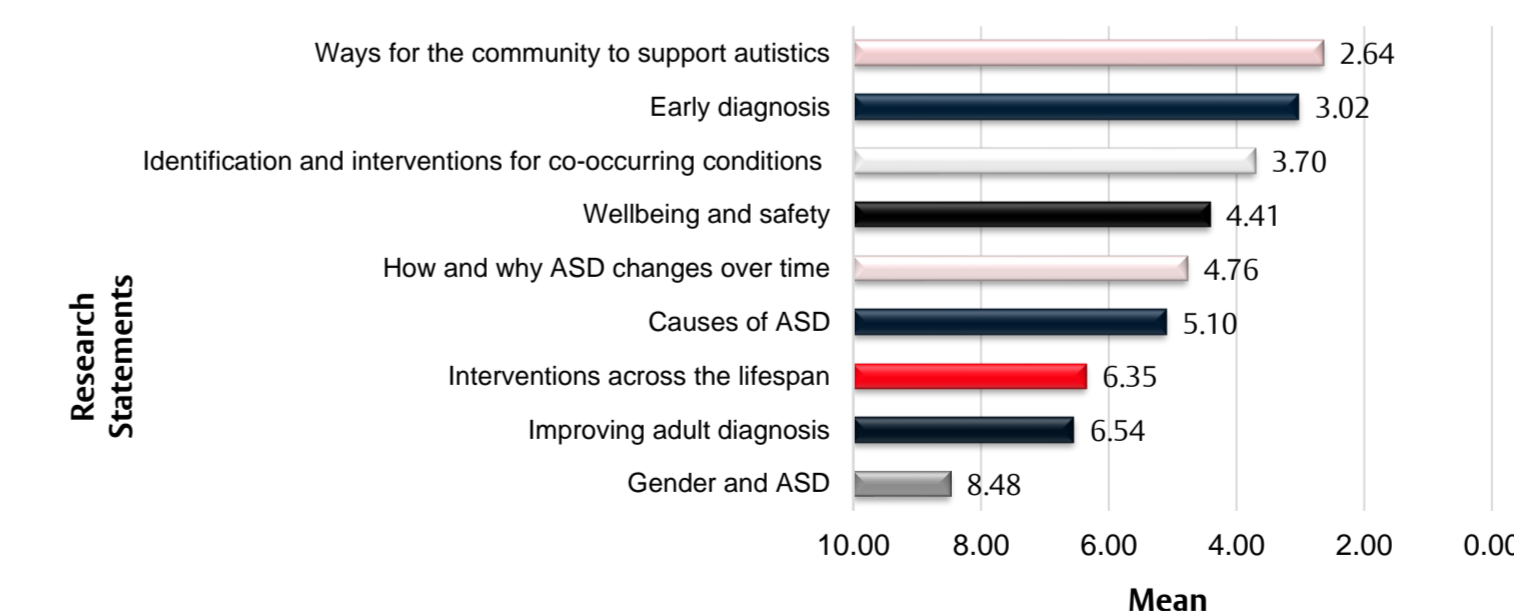- Vocational Training — 8.66

"To the child something like even eating food on your own...once they do these things on their own, it does give them a sense of accomplishment...for the parents or the caregivers who have worked very hard to have them, see them master that skill." (mother of a 13 year old autistic girl)

Interventions:

- Speech and Language Therapy — 2.79
- Mental Health Counseling — 3.38
- Art, Music, Drama & Dance, Therapy — 4.65
- ABA & Naturalistic Interventions — 4.71
- Occupational therapy — 5.28
- Ayurveda — 5.44
- Yoga, Meditation, Sports and Fitness — 6.30
- Pharmacological Treatment — 7.05
- Nutritional Counseling — 7.69
- Animal Assisted Therapy — 7.72

"...I will want him to tell or approach me or somebody else. I will want him to at least verbalize what he needs or expresses his feelings." (mother of a 3 year old autistic boy)

Research:

- Ways for the community to support autistics — 2.64
- Early diagnosis — 3.02
- Identification and interventions for co-occurring conditions — 3.70
- Wellbeing and safety — 4.41
- How and why ASD changes over time — 4.76
- Causes of ASD — 5.10
- Interventions across the lifespan — 6.35
- Improving adult diagnosis — 6.54
- Gender and ASD — 8.48

"This is something that is important for them: to live properly. If the family is not able to support the individual with ASD, then there should be some kind of a social supportive framework which will take care of such people who require daily support." (mother of a 6 year old autistic boy)

Discussion

- Self-help skills is believed to be the foundation for acquiring all other skills. Vocational skills training is given the lowest priority, possibly owing to the age group of the present sample.

- Speech and Language Therapy was identified as the most important intervention for autistic individuals, highlighting the importance of social communication. It is consistent with similar results in a North American survey (2).

- Interestingly, several parents identified Mental health counselling as being more relevant for themselves rather than for their children. It indicates the need to develop facilities in India to ensure the mental wellbeing of parents/caregivers.

- Research focusing on the ways for the wider community to support autistic individuals was considered the top research priority. This result contrasts with findings from research priority mapping exercises in HIC (1).

- Research on gender and autism received a low priority in the questionnaire. Interviews revealed that this ranking may be driven by a potential gap in understanding.

References

1. Roche, L., Adams, D., & Clark, M. (2021). Research priorities of the autism community: A systematic review of key stakeholder perspectives. *Autism*, 25(2), 336–348. https://doi.org/10.1177/1362361320967790

2. Frazier, T. W., Dawson, G., Murray, D., Shih, A., Sachs, J. S., & Geiger, A. (2018). Brief Report: A Survey of Autism Research Priorities Across a Diverse Community of Stakeholders. *Journal of Autism and Developmental Disorders*, 48(11), 3965–3971. https://doi.org/10.1007/s10803-018-3642-6

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