

Diagnostic Practices and Awareness of Autism Among Indian Pediatricians: A Decade of Data

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Research Corporation

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Action For Autism



COI: None.

INDIA: THE NUMBERS

- Current population estimate: 1,139,964,932
- One third the size of US with 3.5 times the population
- Accounts for 21% of world's population growth
- Epidemiological studies underway
- Typically cite Western prevalence rates

“We produce the second largest number of autistics in the world.” – an Indian psychiatrist, 1998

DIAGNOSIS OF AUTISM IN INDIA

- Autism not “new” to India
 - Over 125 published articles to date (from 1959 onwards)
 - National organization started in 1991
- Not commonly diagnosed through early 1990s
- Diagnosed but idiosyncratic through mid-'90s (Daley, 2002)
 - Average of 2 years from first concern
 - Up to 6 additional (incorrect) diagnoses
 - Up to 10 doctors prior to dx (average about 4)

PROFESSIONAL AWARENESS CAMPAIGN

- Administered by Action for Autism
- Targeted pediatricians to improve diagnostic pathway
- Conducted in 1997-98 and 2007-08
- Provided free posters, brochures, FAQ book, and materials to distribute to parents
- Intended to document:
 - **Beliefs** about autism
 - **Experience** with diagnosis
 - **Practices** associated with diagnosis and referral

PROFESSIONAL AWARENESS CAMPAIGN



Poorukh bhaya ya apneme me chhote se lagana |



Wastuon ke pratibhijun lagana |



Aadho se samvaha banane ka parishar |



Dure baahon ke saath mel-jool aur khelne me khatimard |



Aloof in manner |



Inappropriate attachment to objects |



Doesn't respond when called, sometimes appears to be deaf |



Inappropriate laughing and giggling |



Mad, wahan ya wahan ke khare ke samvaha ya jhann n hona |



Wahon wahan khelne ka umar avastha adard aur asphuray wahon |



Jhann ke baad apne apne khelne ke baad dena ya khilne ke baad apne khilne se chhude aur apni khilne ke baad apne khilne se chhude |



Khilne ya khilne me samvaha parwad karne aur parishar ko narwad karne |

ऑटिज़म के लक्ष नज़र रखिए जल्दी पता ल

ऑटिज़म का प्रभाव बरिष्क द्वारा सूचना से व्यतिरिक्त द्वारा से देखकर, सुनकर अने से बाध करता है।

ऑटिज़म एक ऐसी अवैधान रहने वाली जटिल खिल से आज भारत में लग-लग 20 लाख प्रारम्भिक निदान और उपचित प्रशिक्षण द्वारा भाव देवे जा सकते हैं।

हमका ज्ञान और सामाजिक असमर्थता से लेकर ए का परिहार हो सकते हैं।

Action For Autism, Pocket 7 & 8, Jassu VI
Tel: 65347422, 4054099192, E-mail: actionforautism@gr

Watch for the signs of autism. Detect early.

1. Autism affects the way the brain processes information and prevents individuals from properly understanding what they see, hear or otherwise sense, leading sometimes to challenging behaviour
2. Autism affects more than 2million persons in India
3. Early diagnosis and appropriate training can show significant progress
4. Symptoms range from mild learning and social disability to severe impairment

Action For Autism (AFA) The National Centre for Autism
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No understanding of fear and real dangers

Lack of pretend play or unusual and repetitive pretend play

Indicates needs by leading adults by the hand

Likes sameness in everyday routine, does not enjoy change

Sometimes doesn't like to be hugged or touched

Not responsive to normal teaching methods

Enjoys spinning and rotating objects

Apparent insensitivity to pain

Extreme restlessness, hyperactivity or extreme passivity

Crying tantrums, extreme distress for no apparent reason


Unusual behaviour or body movement such as flapping hands or rocking and jumping

Autistic Spectrum Disorders


A Guide for Paediatricians in India

AAHAN ACTION FOR AUTISM



PROFESSIONAL AWARENESS CAMPAIGN

ACTION FOR AUTISM 


You Are
Not Alone



AUTISM



There
is more
than meets
the eye
in a
diagnosis
of Autism

ACTION FOR AUTISM 



Persons with Autism
have to 'learn'
normal patterns
of communication
and ways
to relate to people

ACTION FOR AUTISM 

What is the current status of beliefs, experience, and practices related to diagnosis of autism among Indian pediatricians, and

How does this compare to pediatricians in India a decade ago?

METHOD AND SAMPLE

- Members of Indian Academy of Pediatrics invited to participate
 - Only association of pediatricians in India
 - In 1998: 10,000 members
 - In 2008: 15,000 members
 - Has State, District, and City level branches
- Sample size
 - 1998: N=643
 - 2008: N=584

SURVEY INSTRUMENT

- Respondents provided 3 page survey
 - Based on The Autism Survey (Stone, 1987) used by others (e.g., Stone & Rosenbaum, 1988; Campbell et al, 1996; Heidgerken et al, 2005)
- Participants asked:
 - Location of practice (urban/rural)
 - Years of experience
 - 30 statements about autism (agree/disagree)
 - Number of cases seen and diagnosed
 - Recommendations upon diagnosis
 - 20 characteristics: considered necessary, helpful but not necessary and not helpful in making a diagnosis

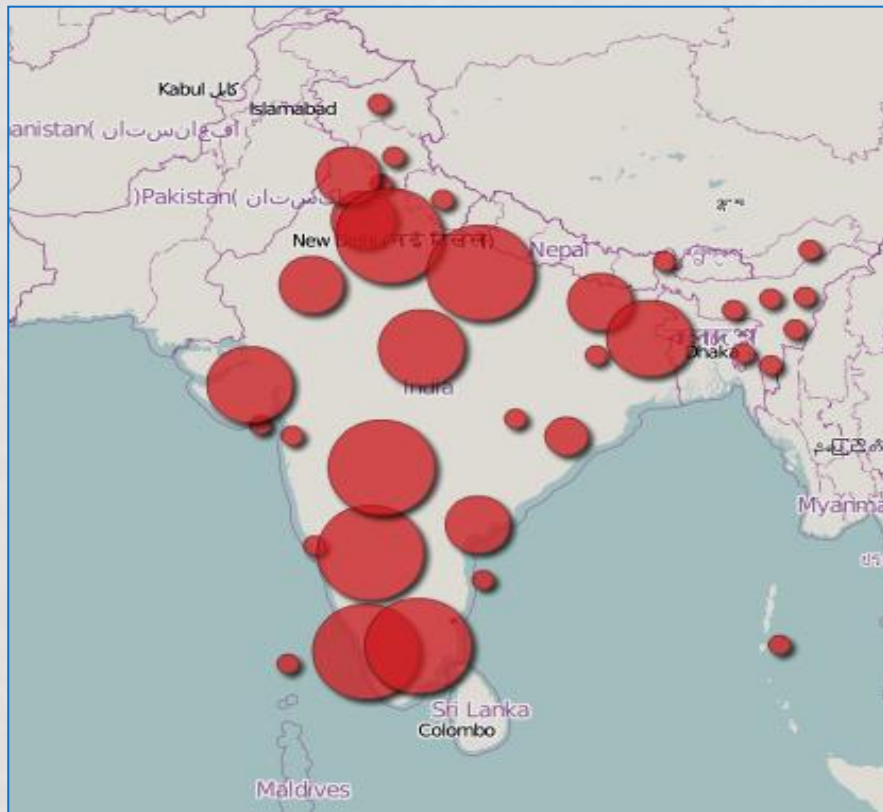
SAMPLE CHARACTERISTICS

	1998	2008
Sex		
Male	74.8	74.4
Female	25.2	25.6
Area		
North	17.7	20.2
South	33.7	36.4
Central	13.8	12.9
East	12.3	7.7
West	22.4	22.8
Urbanicity		
Urban	80.9	78.8
Rural	19.1	21.2

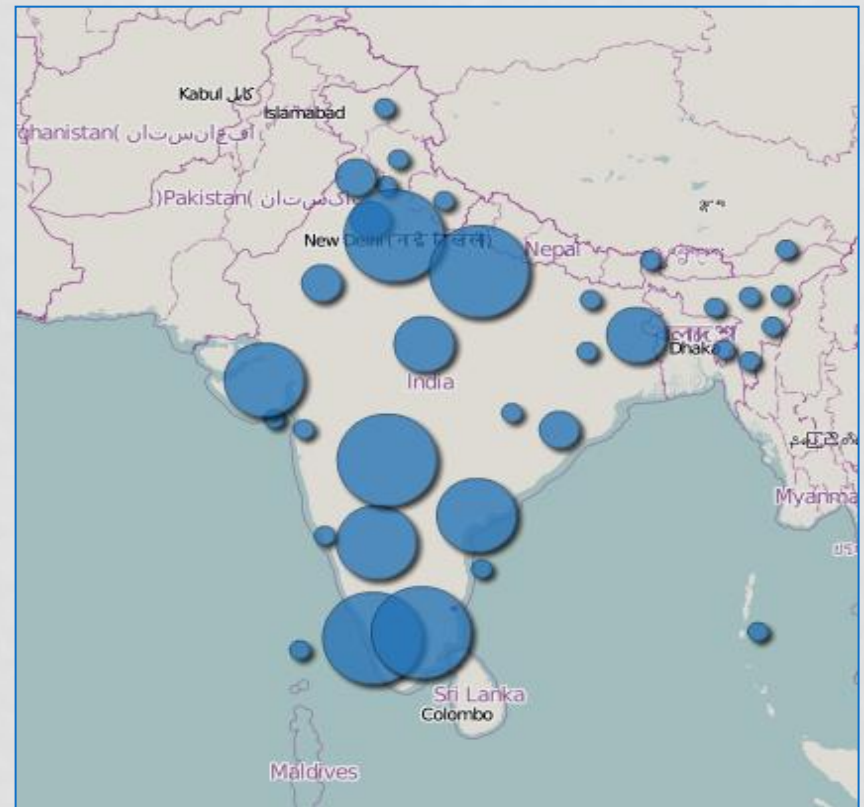
- No differences in background characteristics
- 2008 cohort had significantly more years of practice
M=16.9 (SD=10.7)
compared to M=14.5 (SD=9.7)
 $p < .0001$

GEOGRAPHIC DISTRIBUTION OF SAMPLES

1998 Sample



2008 Sample



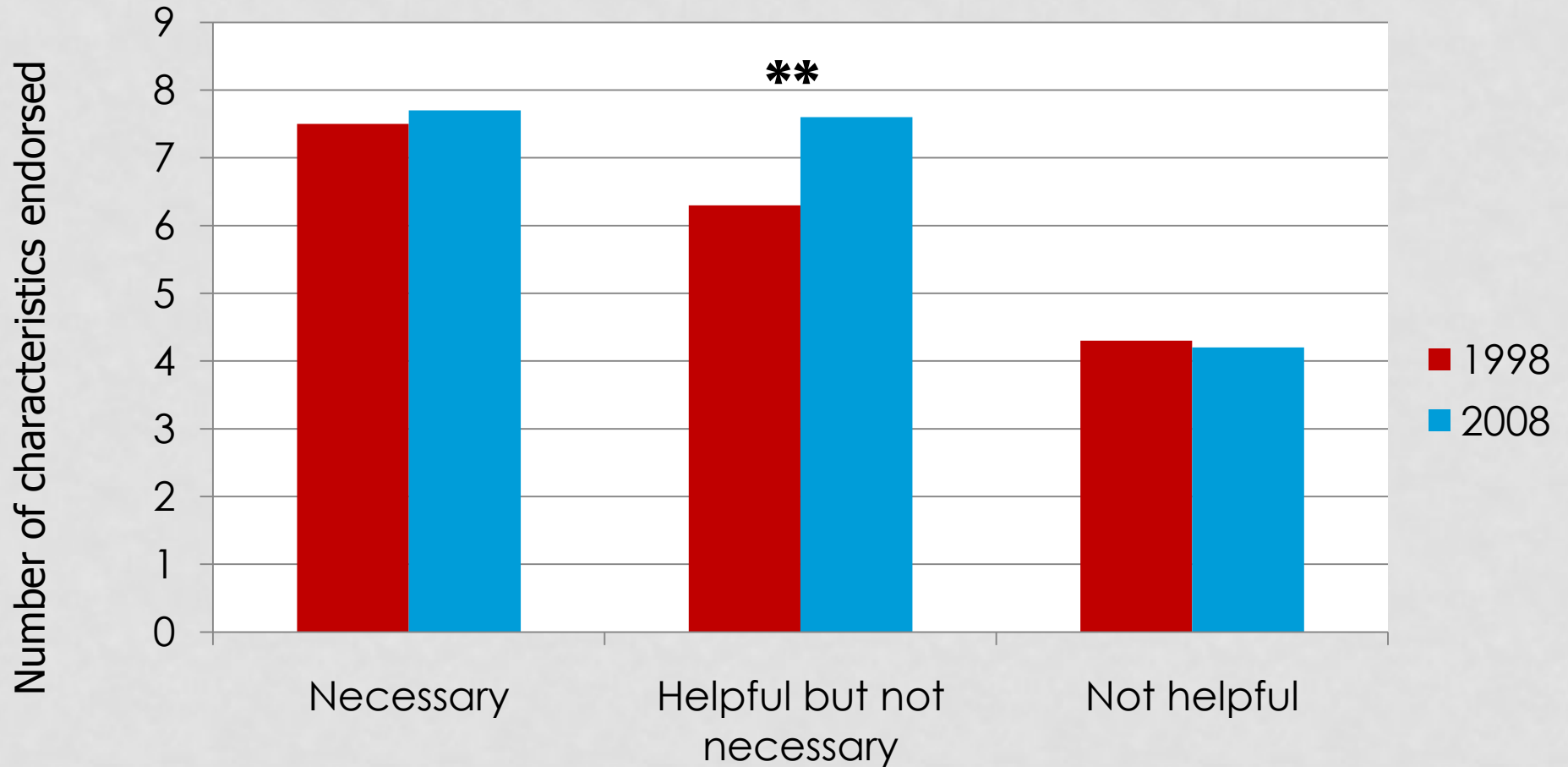
BELIEFS: GENERAL TRENDS

- An overly positive perspective of autism
 - With the proper treatment, most autistic children eventually “outgrow” autism:
61.2% (significant ↑)
 - Most autistic children have special talents or abilities:
74.3% (significant ↑)
 - Autism exists only in childhood:
37.8% (significant ↓)

BELIEFS: GENERAL TRENDS

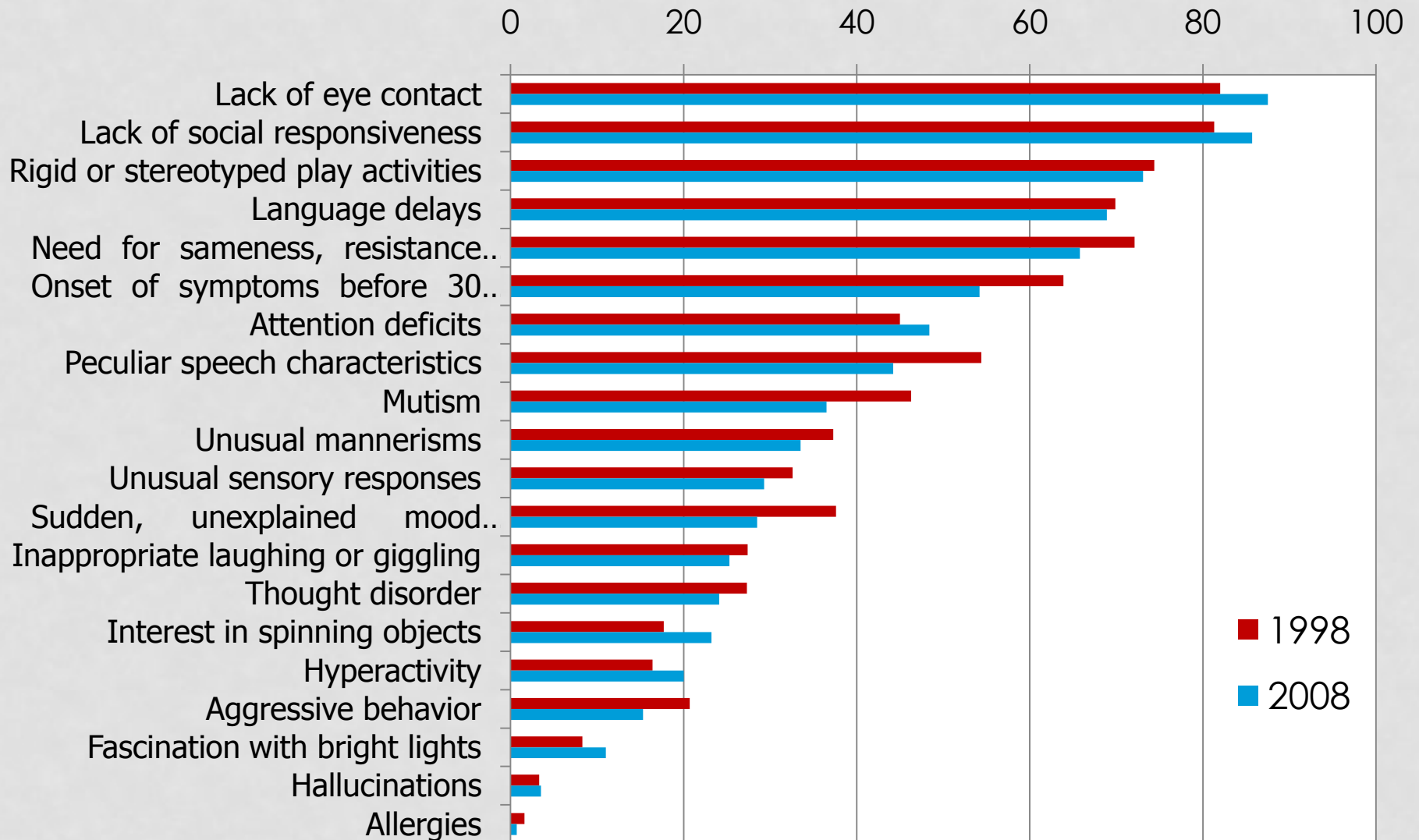
- Outdated beliefs
 - It is difficult to distinguish between Autism and childhood schizophrenia:
46.4% (significant ↓)
 - Emotional factors play a major role in the etiology of Autism:
52.2%
 - Autistic children's withdrawal is mostly due to cold, rejecting parents.
28.6%

DIAGNOSTIC PRACTICES



DIAGNOSTIC PRACTICES

Percent endorsed as necessary



DIAGNOSTIC PRACTICES

Core features of autism identified as necessary
(50% or more of 2008 sample)

- Lack of eye contact
- Lack of social responsiveness
- Rigid or stereotyped play activities
- Language delays
- Need for sameness, resistance to change in routine
- Onset of symptoms before 30 months

DIAGNOSTIC PRACTICES

Continued reliance on additional characteristics that broaden the scope of autism

- Attention deficits 48.4%
- Peculiar speech characteristics 44.2%
- Mutism 36.5%
- Unusual mannerisms 33.5%
- Unusual sensory responses 28.3%
- Sudden, unexplained mood changes 28.5%

EXPERIENCE WITH AUTISM

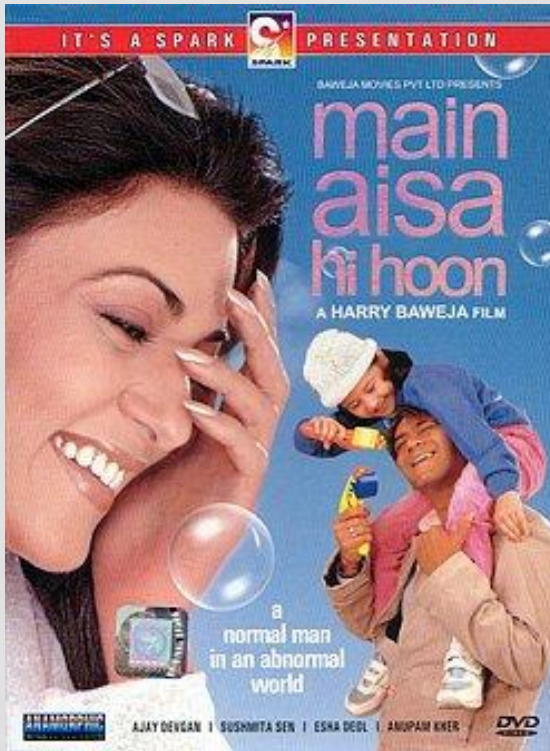
- In 2008, 10% of pediatricians had never seen a case of autism vs. 30% in 1998 ($p < .0001$)

	1998	2008
Mean number of cases seen	15.3 (SD=35.8)	30.9*** (SD=64.4)
Mean number of cases diagnosed	9.4 (SD=19.8)	17.4*** (SD=41.2)
Mean number of cases diagnosed, past 5 years	5.0 (SD=10.2)	11.0*** (SD=23.8)

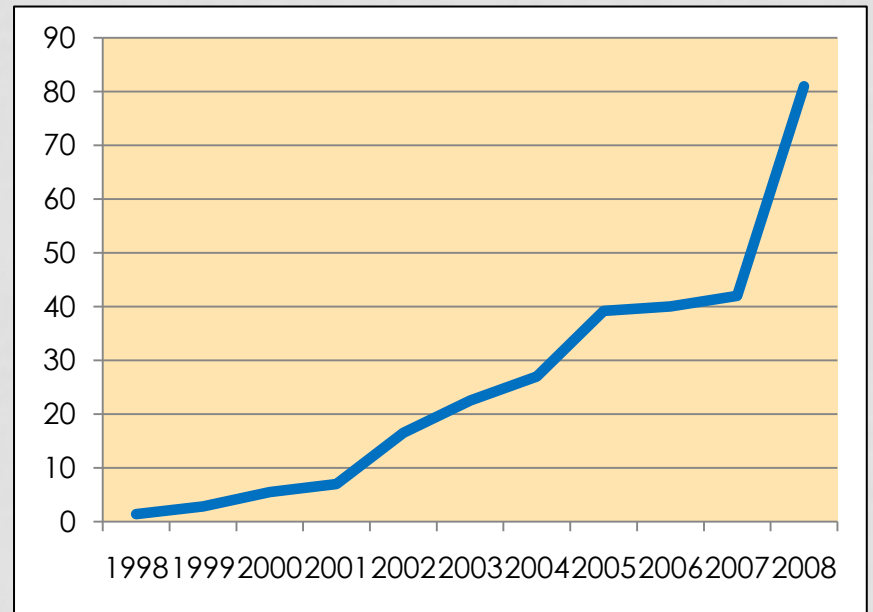
*** $p < .0001$

WHAT IS GOING ON?

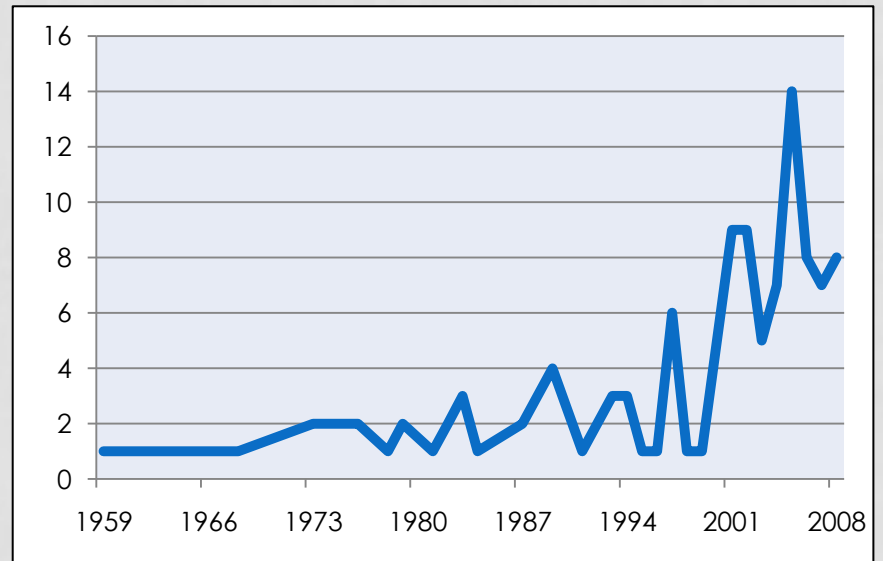
- AFA Awareness campaign
 - Families → center
- Popular media
 - *Koi Mil Gaya* ("Finding someone"), 2003
 - *Main Aisa Hi Hoon* ("I am like this only"), 2005
 - Newspapers
- Increased services & organizations
 - 1998: 2 schools, 3 orgs vs. 2008: 50+ orgs and schools
- Research articles
- Internet usage



Internet usage (in millions)



Research publications



FUTURE DIRECTIONS

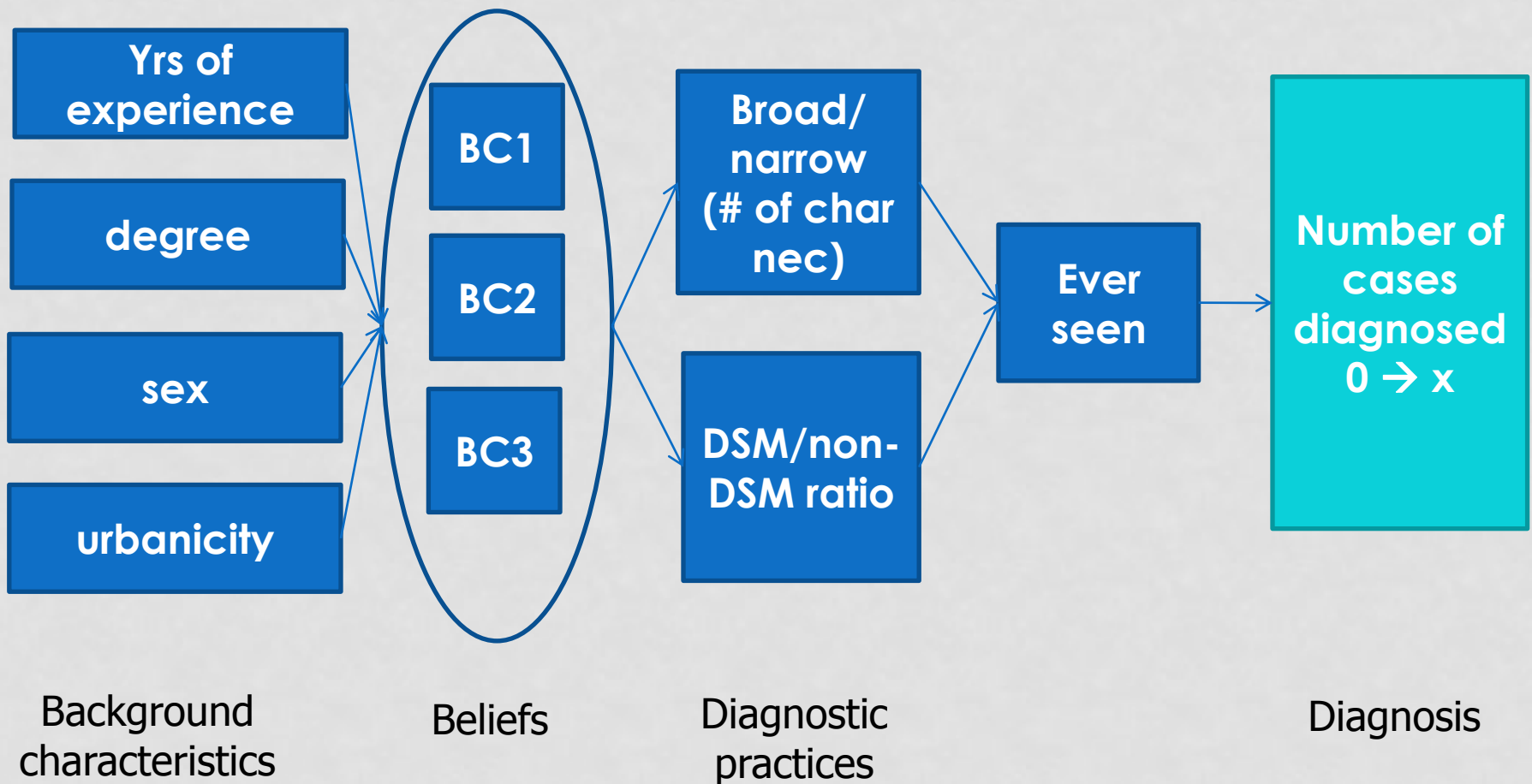
Awareness:

- Expand campaign to other professions
- Incorporate training on developmental disabilities in medical school curriculum

Analysis:

- What is the relationship between beliefs about autism, criteria used in diagnosis, and practitioner experience in diagnosis?
 - Factor analysis of beliefs
 - Path model

RELATIONSHIP BETWEEN BELIEFS, PRACTICES AND DIAGNOSES



SUMMARY

- Numerous changes in beliefs about autism between pediatricians in 1998 and 2008
 - Current perspective both overly positive and perhaps overly negative
- Indian Pediatricians consider similar core features of autism necessary
 - But also rely on characteristics that broaden the scope of what they identify as autism
- A significant increase in the number of cases of autism pediatricians are seeing and diagnosing
 - Dramatic changes in public awareness through multiple strands

WHY SHOULD WE CARE?

- This is not about India
 - Public awareness impacts families AND professional beliefs everywhere
 - Beliefs affect practices everywhere
 - Pediatricians are a key group everywhere
 - Epi work needs groundwork
 - India is a model of other low resource countries
- This *is* about India
 - Anything that happens is on a different scale
 - Development of diagnostic tools, recommendations, interventions must consider the majority world

THANK YOU!

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