

***A GLOBAL PERSPECTIVE ON AUTISM AND ITS TREATMENT
ACROSS GEOGRAPHICAL AND CULTURAL CONTEXTS***

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AUTISM IS A GLOBAL PHENOMENON



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AUTISM IS A GLOBAL PHENOMENON

- Autism has been reported everywhere in the world, with an estimated 52 million people with autism globally
- Increasing awareness of ASD in low-income and middle-income countries (LMICs), as declines in mortality among children under 5 result in more children with developmental delays/disabilities including ASD
- However, child health programs in LMICs still focused predominantly on life-threatening issues, with more limited attention to developmental disabilities



AUTISM IS A GLOBAL PHENOMENON

- Little evidence that ethnic, cultural or socioeconomic factors affect the prevalence of autism when confounding factors are taken into account - not a “first world problem”
- No compelling evidence of different phenotypes in different countries, but disproportionate amount of severe cases in LMICs
 - more limited appreciation of the milder end of the spectrum and/or
 - comorbidities and secondary disabilities may emerge as a result of inadequate care, stigma, and isolation

AUTISM RESEARCH IS NOT A GLOBAL PHENOMENON

- Most knowledge on autism and autism intervention is based on research conducted in Western Countries
- Most individuals with autism do not live in Western Countries
- Issues
 - Relevance of findings (e.g., genetic findings, child-rearing practices)
 - Relevance of tools (e.g., ADOS)
 - Cultural differences in expression?
 - Cultural differences in perception of strengths & needs
 - Impact of stigma, governance, resources
 - Implementation of dx and intervention programs across geographically diverse systems

CONSEQUENCES OF LIMITED GLOBAL RESEARCH

- Limited research from low- and middle-income countries (LMICs) makes it difficult to draw policy-maker attention and public resources to autism
- Potential issues with validity, utility, and accessibility of “gold standard” diagnostic/assessment tools and of evidence-based interventions
- Shortage of experienced professionals
- Resistance to adoption of evidence-based practices even when accessible in some professional circles

APPROACHES TO AUTISM REFLECT CULTURAL DIFFERENCES



- Societal factors other than access to research/science shape approaches to autism and its treatment across geographical/cultural contexts (e.g., cultural hegemony of psychoanalysis in several Western countries, low acceptability of ABA in specific cultures)

TURNING POINTS - EXAMPLES



ITALY, 1998

TURNING POINTS - EXAMPLES



BUTHAN, 2017

Early intervention for autism: Are we prioritizing feasibility at the expenses of effectiveness? A cautionary note

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After awareness – the implementation dilemma

- Making interventions more affordable by reducing training requirements may facilitate initial acceptability and feasibility of interventions, especially in chronically under-resourced communities
- However there is evidence of lower adherence to protocols and poorer intervention outcomes when interventions are delegated to non-specialized workers
- Less expensive interventions not meeting recommended standards are routinely implemented based on the argument that provision of intervention to any standard is preferable to not delivering any intervention.
- This might provide an excuse for public agencies to fail to mobilize the resources needed for appropriate intervention.

CULTURALLY INFORMED APPROACHES TO AUTISM INTERVENTION

Another dilemma – Western-centric (or US-centric) conceptualizations of adults' roles and style in education

- Evidence-based early interventions often rely on joint activity routines – i.e., social-emotional dyadic exchanges during peek-a-boo routines, tickle games, face-to-face interactions during bath time, mealtime, deliberate 1:1 play routines
- These routines might be the expression of Western child-rearing and educational practices - sensitive responsiveness in child caregiving is manifested differently in different cultures, and shaped by different priorities and contextual factors.
- Implications on what we ask caregivers to do - also within Western Countries (e.g., Holzinger et al., 2019)



CONTEXTUAL INFLUENCES ON CAREGIVER'S SYMPTOMS' PERCEPTIONS

Contextual factors may influence the understanding of autism-related behaviors as the manifestation of a neurodevelopmental disorder, and therefore, the degree of caregivers' concern.

- US families from Mexican-heritage may expect their typically developing children to show respect for their elders by not speaking to them unless they are spoken to. Similar for pointing in Japan, and eye-contact in Aboriginal Australians
- Significantly fewer developmental concerns and ASD symptoms in children diagnosed with ASD reported by Latin-American mothers living in the US, compared to Anglo-American mothers, possibly due to lower ASD awareness or parental practices concealing the recognition of symptoms (Blacher et al. 2019).

PRIORITIES FOR ADDRESSING GLOBAL CHALLENGES IN ASD RESEARCH

Broader populations should be included in autism research, including individuals from LMICs, but also more representation of the ethnic, linguistic and socioeconomic diversity of high-income countries

Research conducted locally by scientists from LMICs more likely to “ask the right questions” and formulate/evaluate programs that can be feasibly implemented locally.

But issues with methodological rigor/research training, so that inferences can be made from data.



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EARLY CAREER COMMITTEE

INSAR initiated an Early Career Committee (ECC) in 2017. The purpose of the ECC is to support early career INSAR members looking for resources, mentorship, and training to build their careers and facilitate networking.

- **INSAR Early Career Global Representative Initiative Pilot (GRIP)**

The main goal of this initiative is to expand and support involvement of early career researchers from diverse backgrounds and geographical locations. Representatives are the point of reference for early career researchers from the same country and liaise directly with the Early Career Committee Global Outreach Officers.

Their function is to help INSAR better meet the needs of early career members in their home country through training and professional development activities.

- **Early Career Mentorship Program**

The Mentoring Initiative is designed as a tiered mentorship program, where early career researchers can get mentorship from senior established researchers & mentor student-trainees.

Barriers to screening for Autism Spectrum Disorders (ASD) in Paediatric Settings in Ecuador



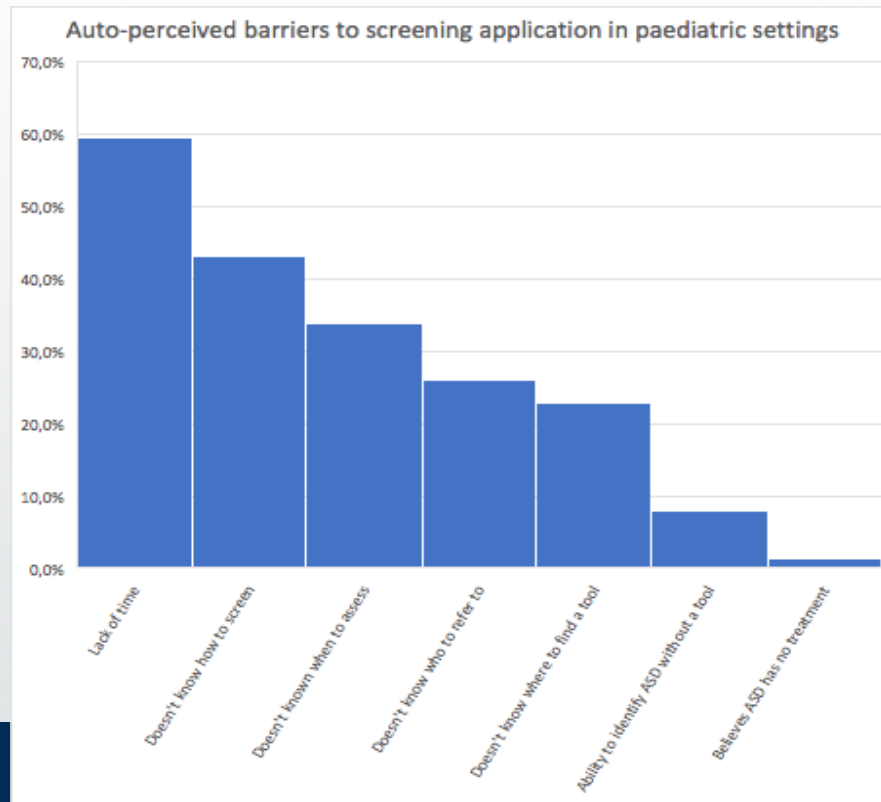
In Ecuador :

Population of less than 18 years old estimated: 6,298,788

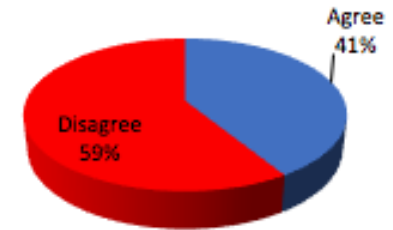
ASD estimated in a population aged 5 years old or less: 0.28%

1266 cases registered in 2016

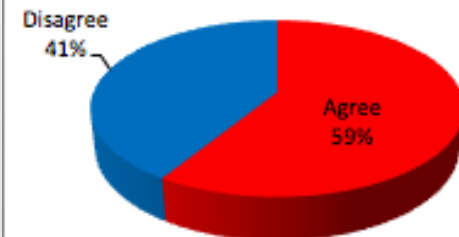
Survey on 153 medical doctors on ASD screening



Feel confident discussing early warnings with parents



Concerned about alarming parents



How are early signs of autism perceived and interpreted in Ecuador?: An exploratory study in the general population?



Survey on general population in Ecuador on ASD signs

- Most participants did not endorse socio-communicative difficulties as concerning.
- Only language impairment and self-injurious behaviors endorsed as concerning by more than half of the respondents.
- Only language impairment identified as having its origin in a developmental disorder.
- Most respondents attributed the causes of autistic behaviors to factors unrelated to ASD, such as child personality or, less frequently, supernatural explanations



SUMMARY & CONCLUSIONS

- The vast majority of individuals with autism in the world today live in low and middle income countries
- These countries have been largely unrepresented in autism research.
- This is a problem for all - our knowledge of autism is incomplete and may be biased
- Dissemination of research conducted in the high-income Countries is not sufficient – rigorous research that takes place in LMICs and is conducted by researchers locally is critical

Thank you for your attention!



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