Developing a global framework to provide access to services for individuals with Autism Spectrum Disorder and their families

David T. Helm, PhD[1,3], Tara A. Lavelle, PhD[2], Beverley Gilligan, MA MSW[1,3], Muhammad Waqar Azeem MD[4], Kerim M. Munir, MD [1,3,5]

[1] Institute for Community Inclusion, LEND Program, Boston Children's Hospital MA, USA [2] Center for the Evaluation of Value and Risk in Health, Tufts Medical Center, Boston, MA, USA;; [3] Division of Developmental Medicine, Boston Children's Hospital, Boston, MA, USA; [4]Sidra Medical Center, Doha, Qatar; [5]Harvard Medical School, Boston, MA, USA

BACKGROUND

❖ Growing global prevalence of Autism Spectrum Disorder (ASD)

❖ International governments and community members have struggled to meet the increasing needs of individuals with ASD, and their families.

OBJECTIVE

❖ Identify challenges currently facing communities worldwide in meeting the needs of individuals with ASD,

❖ Offer policy recommendations that would support these individuals and their families.

METHODS

❖ Winter and spring of 2016: 23 semi-structured telephone interviews

❖ Convenience sample of clinicians, researchers, policymakers, and non-profit workers with knowledge regarding ASD services in their country, or internationally.

❖ Participants were from 12 countries, ranging from low and middle income to high-income countries worldwide.

❖ Gathered information:

- current level of services provided in their country,
- barriers faced in expanding services,
- established practices for overcoming barriers

❖ Interview data were analyzed using thematic analysis.

❖ Research was sponsored by the Qatar Foundation's World Innovation Summit in Health (WISH).

RESULTS: challenges and opportunities

❖ **Five main themes** emerged related to challenges faced in meeting the growing needs of individuals with ASD

❖ Opportunities to overcome barriers utilize resources in the health, educational and social sectors of countries

1. Early Diagnosis

Challenges:

❖ Not enough professionals to perform screenings and evaluations

❖ Lengthy assessment tools

❖ Cultural stigma

Opportunities:

❖ Clinician training: identification, screening, evaluation

❖ Simplified diagnostic tools

❖ Teacher and parent education

2. Evidence-based therapies

Challenges:

❖ Not enough professionals to provide services- particularly in rural areas

❖ High cost

Opportunities:

❖ Training programs, adapting high intensity programs

❖ Parent training

3. Family support

Challenges:

❖ Lack of connection with other families

❖ Too few programs to support children and families

Family support

Opportunities:

❖ Connecting families to each other and to policymakers

❖ Educating families about child's disorder

4. Public education

Challenges:

❖ Too few teachers and resources

❖ Lack of data on outcomes

Opportunities:

❖ Training programs, learning resources. individualized education plans

❖ Data collection on child outcomes

5. Research and Surveillance

Challenges:

❖ Very little research on ASD in low-middle income countries

❖ Lack of research capacity, no national research agenda

Opportunities:

❖ Link between high and low income countries to develop ASD research

Recommendations for policymakers

1. Create an interagency coordinating commission to address ASD nationally
2. Establish interdisciplinary training and research centers for excellence in ASD
3. Establish a global partnership framework to address ASD across the lifespan.