Against Global Inequity: Global Autism Public Health Initiative

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Overview

- Introduction: approach and outcomes
- An example of current international priority
  - World Report on Developmental Delay, Disorders and Disabilities
- An example of current US priority
  - Family Needs Assessment – Community data platforms

Introduction

Approach and outcomes

Global *Autism* Public Health (GAPH) Initiative

A Decade of Global Collaboration to Enhance ASD Research, Practice and Policy (2009 – 2019

GLOBAL AUTISM PUBLIC HEALTH INITIATIVE

Technical support to committed government and NGO partners

Started with 2 countries in 2009, now supporting over 80 countries

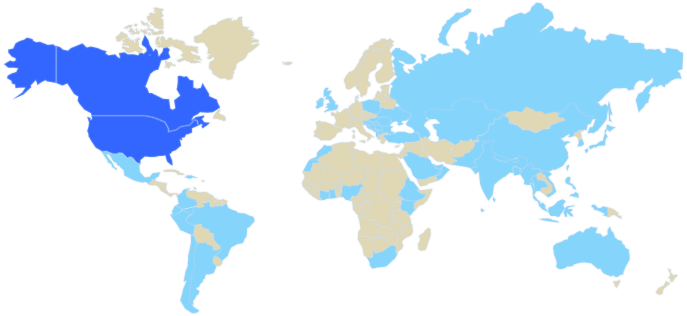
Help mobilize local leaders and resources for sustainable change

Our Partners-

AUTISM SPEAKS ADVOCACY LEADERSHIP NETWORK

Advocacy Leadership Network (ALN)

Engine for Change - A Global Network of Accomplished Advocates



- Local leaders with record of innovation and facilitating change.
- Self-advocates, caregivers, researchers, professionals, policymakers, friends and families.
- Continuous social media interactions; Biennial meetings to facilitate knowledge exchange/transfer collaboration.
- High impact collaboration (e.g., WHA, CST).
- 54 countries in 2018; transition to regional sustainability

Africa Regional Advocacy ***Leadership*** Network (ALN)

Regional Meeting
Addis Ababa, Ethiopia 1/2020

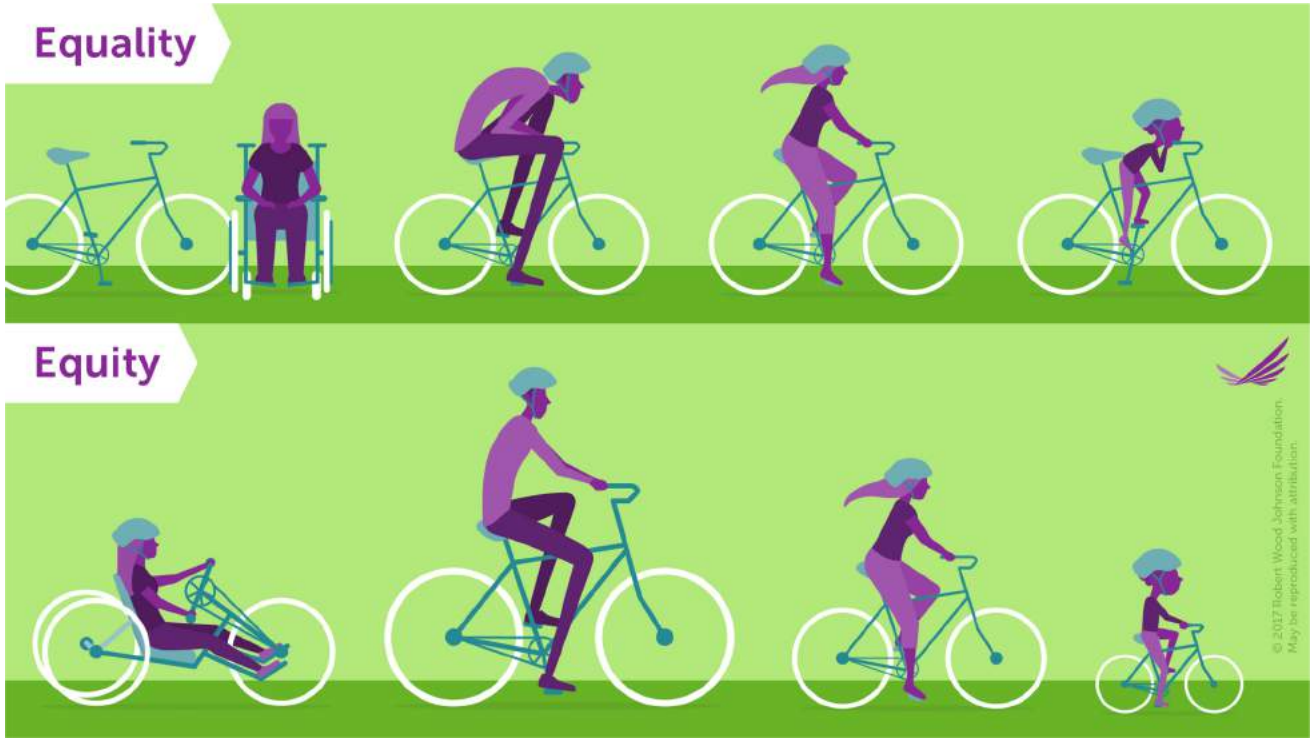
AUTISM SPEAKS ADVOCACY LEADERSHIP NETWORK

Africa Regional Advocacy ***Leadership*** Network (ALN)

AUTISM SPEAKS
ADVOCACY LEADERSHIP NETWORK

BE-A VOICE

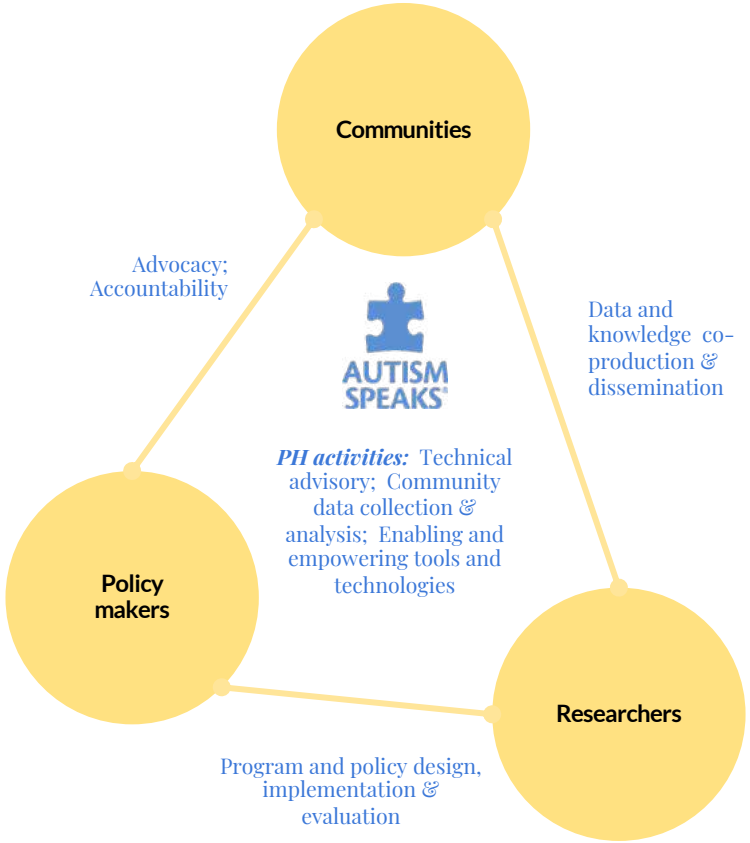
Our Approach ***Equity focused***



AUTISM SPEAKS
ADVOCACY LEADERSHIP NETWORK

Our Approach

Data-driven Advocacy and Knowledge Mobilization



Priorities:
Development, implementation and evaluation of community-based services with a focus on health equity

Strategy:
Relevance and impact through multi-stakeholder collaboration and leveraging

Products:
Data + tools to help mobilize knowledge, empower communities and enable better outcomes at individual, family and community levels

Examples:

- *Screening and diagnostic tools*
- *Intervention/Inclusion programs*
- *Policy/economics tools*
- *Services navigation tools*
- *Community data platforms*

Advocacy Leadership Network (ALN)

Engine for Change - A Global Network of Accomplished Advocates

- UN and World Health Assembly autism resolutions
  - *Autism Speaks role: Content expert; advocate (via ALN)*
- 1st national prevalence estimate in South Korea, Mexico, India, Qatar and China
  - *Autism Speaks role: Co-funder; technical advisor*
- National action plans, guidelines & training programs: Qatar, Albania, Bangladesh, Malaysia, Serbia, China
  - *Autism Speaks role: Technical advisor*
- Often-cited "cost of autism" study (Knapp + Mandell, 2012)
  - *Autism Speaks role: funder*
- 1st randomized controlled trial (RCT) using "task-sharing" strategy to deliver evidence-based autism intervention in low resource communities
  - *Autism Speaks role: Funder*
- Caregiver Skills Training program, 1st WHO-UNICEF intervention package using "task-sharing" strategy to deliver evidence-based autism intervention in low resource communities
  - *Autism Speaks role: Co-funder, co-technical lead, trainer*

An ***International*** Priority

World Report on Developmental Delays, Disorders and Disabilities

World Report on ***Developmental Delay***, Disorders and Disabilities

Overview

- Global multi-stakeholders collaboration driven by a WHO, UNICEF and Autism Speaks partnership.
- First report of its kind. Prioritizes conditions not well covered elsewhere, including autism, ADHD, intellectual disabilities and cerebral palsy.
- A lifespan perspective.
- Targets Ministries of Health and Education, policy makers, advocates, nongovernmental organizations, researchers, health workers, the media, and the general pubic.
- Highlights opportunities for multi-sectorial coordination and action in early childhood development (ECD), health and disabilities
- Inclusion of users perspectives (i.e., primary data collection from the community): Bulgaria, Canada, Argentina, Turkey, Brazil
- Draft due November, 2020 (COVID-informed), with official launch planned in 2021

World Report on ***Developmental Delay***, Disorders and Disabilities

Aims

- Increase awareness of the public health significance of developmental delays, and disabilities for children and their families.
- Compile data on epidemiology, human resources, services, policies, and users' perspectives regarding child-onset developmental delays, disorders and disabidisorderslities.
- Provide guidance on strengthening health systems and multisectoral actions towards provision of nurturing care and enabling environment for children with developmental delays, disorders and disabilities and their families.
- Document good (evidence-based) and innovative practices.
- Provide guidance on collection of data through health information systems and population-based monitoring.
- Provide baseline data on policies and services for developmental delays, disorders and disabilities in selected countries along with indicators and strategy to track progress.
- Call upon partners for international and national advocacy efforts.

World Report on ***Developmental Delay***, Disorders and Disabilities

Content and Process

Report outline:

I. Introduction

I. Epidemiology

I. Policies, plans and legislations

I. Care pathways

I. Promotion of enabling environment

I. Public health monitoring

I. Way forward

Good innovative practices

Country profiles

World Report on ***Developmental Delay***, Disorders and Disabilities

External collaborators/advisors – June, 2019

- Maureen Durkin (US)
- Jonathan Green (UK)
- Peter Rosenbaum (Canada)
- Charles Newton (Kenya)
- Don Wertlieb (US)
- Kate Milner (Australia)
- Merry Barua (India)
- Hans Forssberg (Sweden)
- Phillipa Bragman (UK)
- Petrus de Vries (South Africa)
- Helen McConachie (UK)
- Laurence Taggart (N Ireland)
- Vibha Krishnamurthy (India)
- Bolajoko Olusanya (Nigeria)

More collaborators, especially reviewers, are being identified for better coverage in geography and perspective, including self-advocates.

A ***Domestic*** Priority

Community data resources and needs assessment

A basic *Question*

What do we know about autistic people and their families in our community…

Where's the ***data***???

Basic information important for policy development, implementation and evaluation:

- Who are they (i.e. users)?
- Where are they?
- What are their needs? What services are provided?
- What are the challenges in meeting those needs?
- What are the outcomes?

Where's the ***data?***

Administrative datasets (cities, counties, state, federal)

Health (Medicaid, HMO, etc.) | Education | Vocational Rehab | Child welfare | Criminal justice

Data that inform policy development, implementation and evaluation:

- *Who are they (i.e. users)?*
- *Where are they?*
- *What are their needs?* What services are provided?*

But, we are not effectively capturing...

- What are the challenges in meeting those needs?
- What are the outcomes?

Access and key variables differ by community (e.g., state); Linkage at community level?

Structural/process barriers (e.g., access), cultural factors, socio-economic factors, knowledge disparities, quality, etc

Autism Speaks ***Public Health*** Research

Understand needs and evaluate impact

Family Needs Assessment Survey

Autism Speaks ***Public Health*** Research

Family Needs Assessment

J Autism Dev Disord
DOI 10.1007/s10803-017-3145-x

ORIGINAL PAPER

Autism in Southeast Europe: A Survey of Caregivers of Children with Autism Spectrum Disorders

Amy M. Daniels[1] · Ariel Como[2] · Sabri Hergüner[3] · Krasimira Kostadinova[4] · Jasmina Stosic[2] · Andy Shih[5]

Original Article

autism

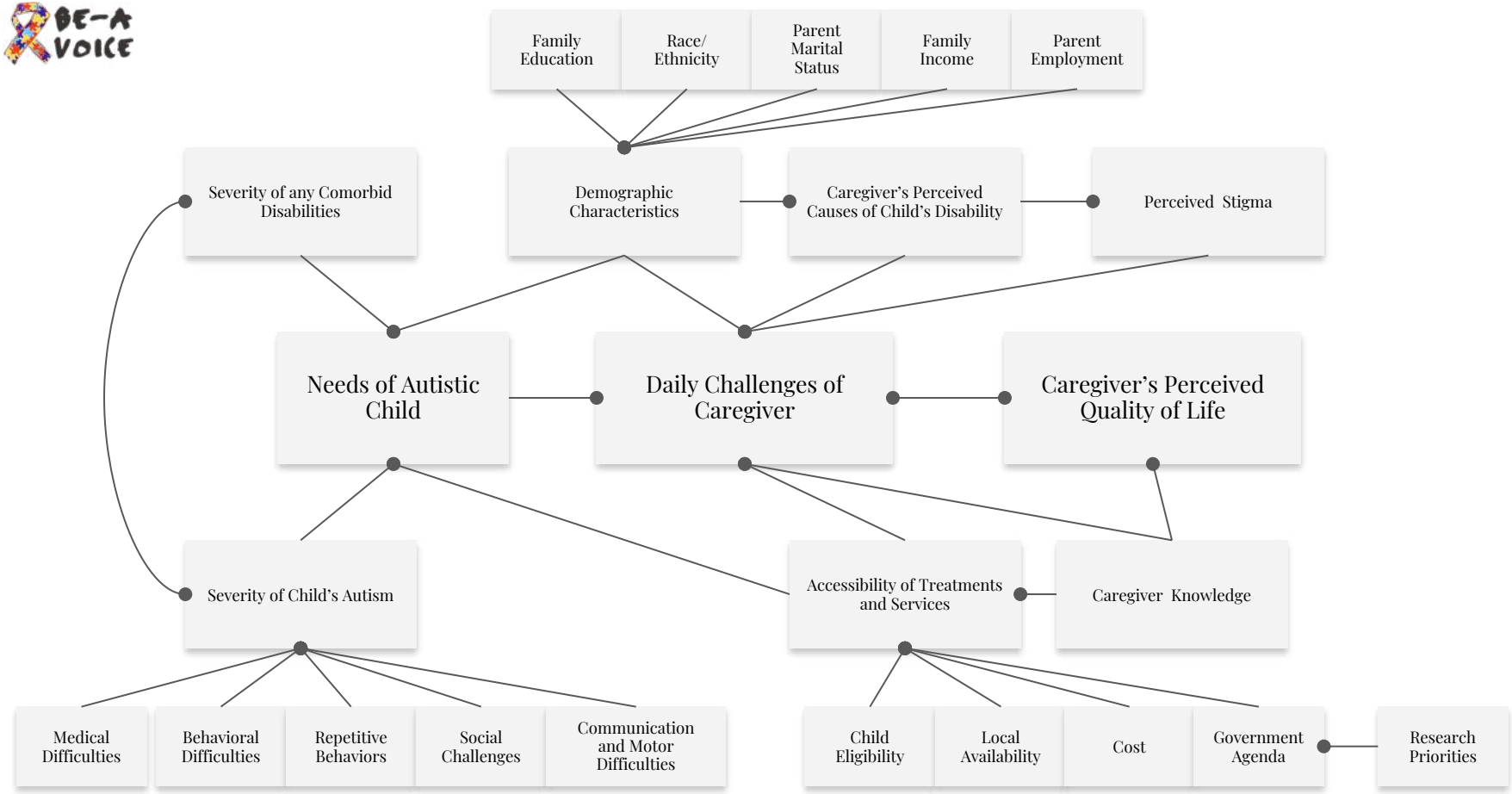
Challenges, priorities, barriers to care, and stigma in families of people with autism: Similarities and differences among six Latin American countries

SAGE

Cristiane Silvestre Paula[1,2], Sebastián Cukier[3], Graccielle Rodrigues Cunha[1], Matias Irarrázaval[4,5], Cecilia Montiel-Nava[6], Ricardo García[6], Analia Rosoli[7], Daniel Valdez[8,9], Daniela Bordini[1], Andy Shih[10], Gabriela Garrido[11] and Alexia Rattazzi[3]

Family Needs Assessment Survey at-a-glance:

- *Revised version of Autism Speaks Caregiver Needs Assessment tool fielded in 11 Southeast European (5) and South American countries (6)*
- *Improved alignment with existing frameworks in needs assessment*
- *Based on well-established needs surveys*
- *Modular (e.g., addition of stigma module)*
- *Designed to be translated/adapted to enhance user experience and data quality*


Family Education
Race/ Ethnicity
Parent Marital Status
Family Income
Parent Employment
Severity of any Comorbid Disabilities
Demographic Characteristics
Caregiver's Perceived Causes of Child's Disability
Perceived Stigma
Needs of Autistic Child
Daily Challenges of Caregiver
Caregiver's Perceived Quality of Life
Severity of Child's Autism
Accessibility of Treatments and Services
Caregiver Knowledge
Medical Difficulties
Behavioral Difficulties
Repetitive Behaviors
Social Challenges
Communication and Motor Difficulties
Child Eligibility
Local Availability
Cost
Government Agenda
Research Priorities

Autism Speaks ***Public Health*** Research

Family Needs Assessment

Next steps:

- Pilot online version (Q1, 2020)
- Adapted for collection of user data in Argentina, Brazil, Bulgaria, Canada, China, Turkey and Uganda to inform WHO World Report (Q3, 2020)
- Pilot additional modules (e.g., stigma)

Thank ***You***

Autistic people and their families are @ the ***Heart of Everything*** *We Do!*