Update: Global Autism Public Health Initiative (2010-2024)
Meeting of the Interagency Autism Coordinating Committee

Andy Shih, PhD
Chief Science Officer
April 17th, 2024
Global Autism Public Health Initiative (GAPH)

Support local leaders to address local priorities, using locally-customized solutions

**Research**
- Prevalence studies (Mexico, South Korea, China, Qatar)
- Family Needs Assessment Questionnaire (Canada, Serbia, Brazil, Bulgaria)
- Open Source Screening & Diagnostic Tools (NASQ)
- Caregiver-mediated intervention (PACT)

**Policy**
- National action plans (Bangladesh, Egypt, Aruba)
- Clinical Practice Guidelines (Malaysia, Serbia)
- Global Report on Children with Developmental Disabilities

**Capacity Building**
- Albania, Ethiopia, Saudi Arabia, China, Kazakhstan
- WHO Caregiver Skills Training (CST)

**Advocacy**
- Advocacy Leadership Network (ALN)
- Chinese American Association for Autistic Community
- African Research Consortium for Neurodevelopmental Disabilities
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Team (2008 – Present)

Pamela Dixon  Lucia Murillo Chacko  Michael Rosanoff  Amy Daniels
WHO Caregiver Skills Training Program

• Empowers caregivers with skills they can use in daily routines to promote development (social communication, daily living, positive behavior)

• Implemented in more than 35 countries
Scope of WHO Caregiver Skills Training (CST)

For whom
Caregivers of children aged 2–9 years who have developmental delays or disabilities with a specific focus on caregivers of children with delays or impairments in social and communication domains.

Aims
Increase caregivers’ skills to promote their children’s development and well-being through joint engagement in play and home routines.
Structure and Content

9 Group sessions

3 Home visits

Engaging children in everyday activities and games

Understanding and promoting children’s communication

Understanding behaviour and helping the child show more positive behaviour

Teaching skills for everyday life

Caregiver wellbeing & problem-solving
Content

• Naturalistic/Developmental behavioural approaches for promoting shared engagement and communication
  ▪ JASPER (Joint Attention Symbolic Play Engagement Regulation)
  ▪ PRT (Pivotal Response Treatment) – behavioural intervention

• Positive parenting approaches for promoting positive child behaviour/management of challenging behaviour

• Promotion of caregiver problem solving & well-being
eLearning CST (eCST)

- Self-directed eLearning for caregivers
- Based on WHO CST skills and strategies
- Total 8 hours, self-paced
- Supports low bandwidth, suitable for mobile devices
- Currently being translated in Arabic, Chinese, Spanish, Hindi, Marathi, Yoruba, and Portuguese
- Also used to support hybrid delivery of CST

To access eCST: https://openwho.org/courses/caregiver-skills-training
CST Sites Worldwide (2016-2024)

- Implemented in >35 countries
- Trained ~250 Master Trainers
CST U.S. Sites

Current sites: 8 states with additional sites in planning phase
Learnings from field testing (in HIC and LMIC)

- High levels of feasibility of implementation
  - facilitators’ fidelity in interaction with child
  - caregivers’ adherence to home practice
  - viability of delivery

- Excellent acceptability to caregivers

- Can be adapted for remote-delivery

**Improves:**
- caregiver skills in interaction
- caregiver self-efficacy and stress
- child communicative gestures (predictor of language development)
- parent-reported child behavior
- daily living skills
**Goals for Scaling up CST**

Near/long-term goals for the scaling up CST in the **U.S. and worldwide**

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<tr>
<th>Near-term</th>
<th>Long-term</th>
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<td>➢ Explore incorporation of CST into US programs and systems <em>(e.g. Head Start, Part C Early Intervention, PTICs, HMOs)</em></td>
<td>➢ Broad nation-wide accessibility</td>
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<td>➢ Increase the number of communities and countries implementing CST globally via broad, multistakeholder collaborations</td>
<td>➢ Facilitate, enhance and sustain global CST accessibility, implementation, and innovation through an online community of practice</td>
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• Accomplished international leaders
• Self-advocates, families, professionals, policy makers
• Social media-facilitated real-time community engagement. Biennial in-person meetings and virtual working groups to facilitate knowledge exchange and collaboration
• Focus on advocacy, dissemination, implementation and research
• High impact network collaboration
  o UN/WHA resolutions
  o Caregiver Skills Training (CST)
  o Global Report for Children with Developmental Disabilities
Inaugural meeting (New York City, 2010)
Biennial (Washington DC, 2016)
Africa Regional (Addis Ababa, 2020)

autism speaks®
ALN - Near Term Goals

• Advocacy Training Package – by and for Autistic Adults
• Launch African Research Consortium for Neurodevelopmental Disabilities
  ▪ Quarterly webinars
• Biennial Meeting 2025
Thank you!!!