

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>

Lesson 4: Communication

 **Key Message**

These are some of the ways children communicate:

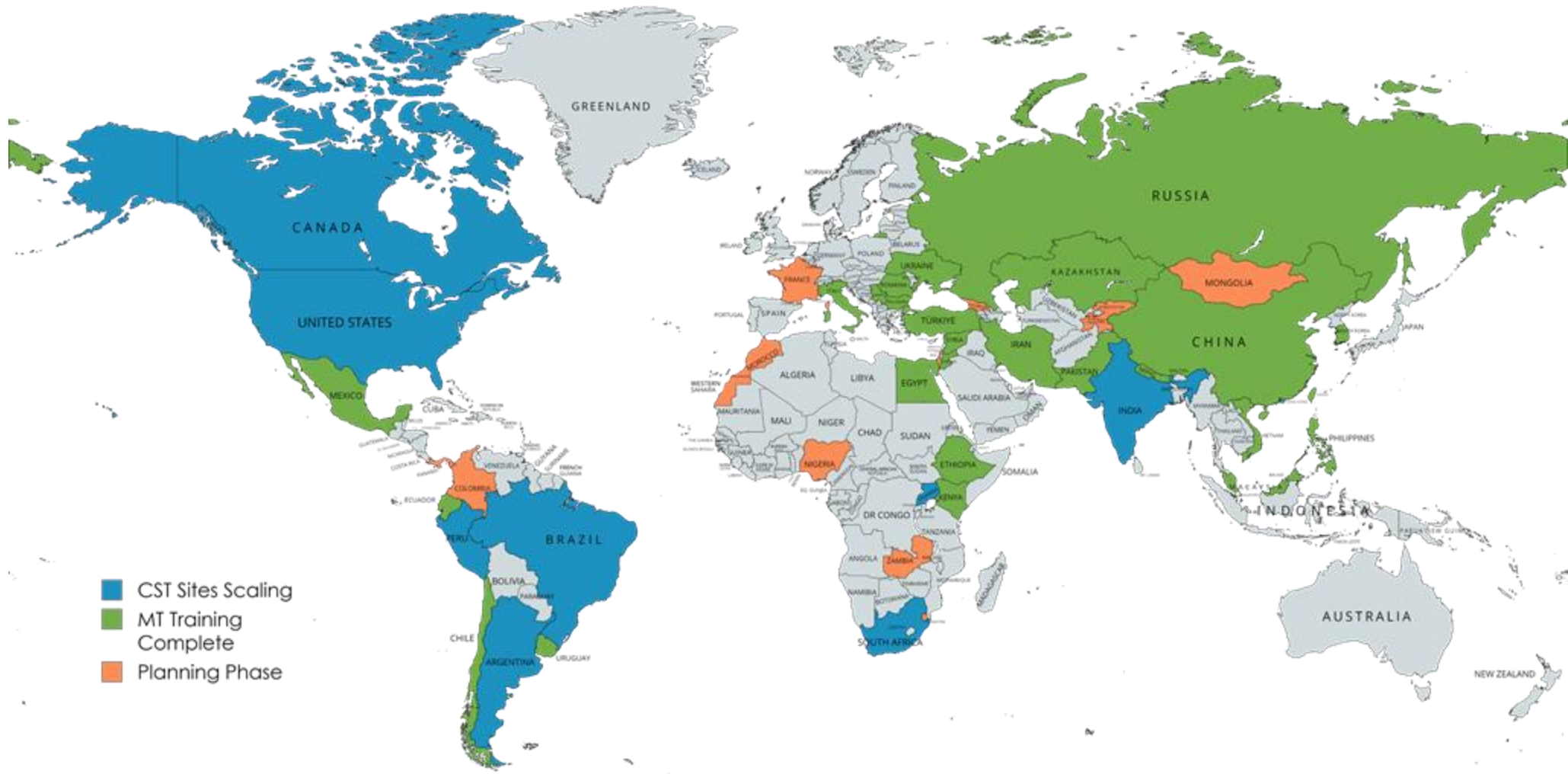


BODY: Turning or moving towards something, taking someone's hand to put it on an object (to get help), pulling someone by the hand, turning or nodding the head, gesturing with the head

HANDS: Pointing to something, showing or giving an object to someone, reaching, grabbing or pushing something away

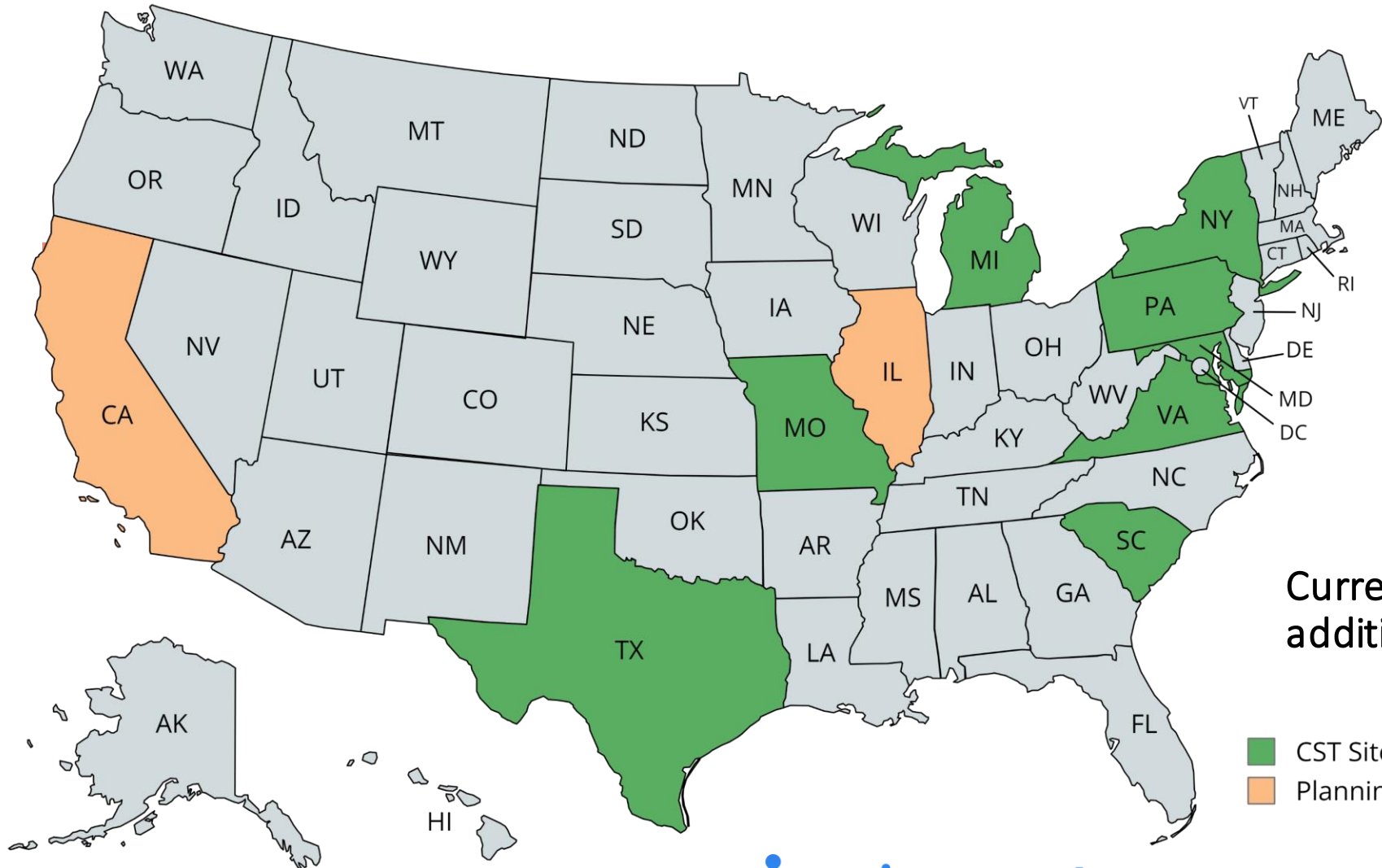


CST Sites Worldwide (2016-2024)



- Implemented in >35 countries
- Trained ~250 Master Trainers

CST U.S. Sites



Current sites: 8 states with additional sites in planning phase

- CST Sites
- 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

Original Article


Adapting and pre-testing the World Health Organization's Caregiver Skills Training programme for autism and other developmental disorders in a very low-resource setting: Findings from Ethiopia

Bethlehem Tekola¹, Fikirte Girma², Mersha Kinfe², Rehana Abdurahman³, Markos Tesfaye⁴, Zemi Yenus⁵, WHO CST Team⁶, Erica Salomone^{6,7} , Laura Pacione⁶, Abebaw Fekadu^{1,2}, Chiara Servili⁶, Charlotte Hanlon^{1,2}, and Rosa A Hoekstra¹ 

Journal of Autism and Developmental Disorders
<https://doi.org/10.1007/s10803-021-05367-0>

ORIGINAL PAPER


World Health Organisation-Caregiver Skills Training (WHO-CST) Program: Feasibility of Delivery by Non-Specialist Providers in Real-world Urban Settings in India

Koyeli Sengupta¹  · Henal Shah² · Subharati Ghosh³ · Disha Sanghvi¹ · Sanchita Mahadik¹ · Allauki Dani² · Oshin Deshmukh¹ · Laura Pacione^{4,7} · Pamela Dixon⁵ · Erica Salomone^{6,7} · WHO-CST team⁷ · Chiara Servili⁷

Journal of Autism and Developmental Disorders
<https://doi.org/10.1007/s10803-021-05297-x>


ARTICLE

Pilot Randomized Controlled Trial of the WHO Caregiver Skills Training in Public Health Services in Italy

Erica Salomone^{1,2}  · Michele Settanni³ · Helen McConachie⁴ · Katharine Suma⁵ · Federica Ferrara³ · Giulia Foletti³ · Arianna Salandin³ · WHO CST Team · Chiara Servili² · Lauren B. Adamson⁶



Autism
1–13
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updates



Goals for Scaling up CST

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

Near-term	Long-term
<ul style="list-style-type: none">➤ Explore incorporation of CST into US programs and systems (<i>e.g. Head Start, Part C Early Intervention, PTICs, HMOs</i>)	<ul style="list-style-type: none">➤ Broad nation-wide accessibility
<ul style="list-style-type: none">➤ Increase the number of communities and countries implementing CST globally via broad, multistakeholder collaborations	<ul style="list-style-type: none">➤ Facilitate, enhance and sustain global CST accessibility, implementation, and innovation through an online community of practice

 **autism speaks®**
**advocacy leadership
network**





advocacy leadership network



- 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
 - UN/WHA resolutions
 - Caregiver Skills Training (CST)
 - Global Report for Children with Developmental Disabilities





Inaugural meeting (New York City, 2010)





Biennial (Washington DC, 2016)

第四届自闭症倡导领袖联盟双年会

THE 4TH BIENNIAL MEETING OF AUTISM ADVOCACY LEADERSHIP NETWORK

November 10th 11th, 2018
2018年11月10日-11日

Xiamen, China
中国·厦门



ALN/CST Technical Consultation (Xiamen, 2018)



Africa Regional (Addis Ababa, 2020)





Biennial (Long Island City, 2023)



ALN - Near Term Goals



advocacy leadership network



- Advocacy Training Package – by and for Autistic Adults
- Launch African Research Consortium for Neurodevelopmental Disabilities
 - Quarterly webinars
- Biennial Meeting 2025



Thank you!!!

