Advocacy Leadership Network (ALN) 2021
A Virtual Conference for the Global Autism Community

Day One - April 27, 2021 – WHO Caregiver Skills Training Program (CST)
Advocacy Leadership Network

• Members are respected local leaders with records of innovation and facilitating change
  ✓ Self-advocates, caregivers, professionals, policy-makers, friends and family
  ✓ promote greater autism awareness
  ✓ improve the wellbeing of individuals and families affected by autism

• Biennial meetings to facilitate the exchange of ideas and collaboration
  • 2012 – New York City
  • 2016 Washington, DC
  • 2018 Xiamen
  • 2020 Addis Ababa, Ethiopia (regional)

• Link to recorded presentations
Advocacy Leadership Network
WHO Caregiver Skills Training Program

• Empowers caregivers with skills they can use in daily routines to promote social communication
• Implemented in more than 30 countries
• Adaptable and acceptable (i.e. culturally competent)
• Designed to be adapted and integrated into existing services or systems of care

mhGAP
CST Characteristics

• Caregivers of children 2-9 years of age with a developmental delay or developmental disorder. **A diagnosis is not required.**

• 9 Group sessions at community level (centers, schools, clinics or remotely)

• 2 -2.5 hours each, weekly or biweekly AND

• 3 Individual sessions in caregivers’ homes, (90 minutes each)

• Delivered by non-specialist with support
CST Group Sessions & Home Visits

- **Getting and Keeping Children Engaged**
  - Play and Home Routines
  - Communication
  - Behaviour
  - Skills
  - Caregiver Well-being & Problem Solving

- **Group session**
- **Home visit**

Home visit 2 can be done between Session 3 and Session 4 or 5.

Checkpoints:
1. **phone**
2. **phone**
3. **phone**
Final Notes ~ Day 1

• Many thanks to Caregivers, Translators, RTFPs & MTs, Panelists, Planning Committee, AS staff (special thanks to Adrienne!)
• More to come:
  ✓ CST site survey
  ✓ Quarterly MT meetings beginning in June
  ✓ Online MT/Fac training
• Check out recorded presentations
• Check out CST Quick Tip videos on AS YouTube channel
• Reach out FMI: pamela.dixon@autismspeaks.org
• See you tomorrow for discussion on the WHO-UNICEF World Report and Community Data Collection (NEW Nigerian Autism Screening Ques)
• Join us for networking by clicking the link for the new meeting
WHO Caregiver Skills Training (CST) Global Update

Autism Speaks Advocacy Leadership Network (ALN) 2021
4th Biennial Conference
April 27th, 2021
Overview

• Impact of COVID-19: challenges and opportunities

• New team members, project sites and opportunities

• Project updates:
  – CST materials revision and feedback
  – eCST for caregivers
  – CST 0-3
  – Project surveys
  – Opportunities for collaboration
Impact of COVID-19

Kids with disabilities face health risks and marginalization under COVID-19: expert

Growing Up in a Pandemic: How Covid is Affecting Children's Development

Pediatricians are noting developmental delays as well as potential for long-term health conditions, particularly for children from low-income households.

The potential impact of the COVID-19 pandemic on child growth and development: a systematic review

Liubiana Arantes de Araújo, a, * Cássio Frederico Veloso, b Matheus de Campos Souza, c João Marcos Coelho de Azevedo, c and Giulio Tarro, d, e, f, g

Including Children with Developmental Disabilities in the Equation During this COVID-19 Pandemic

Ramkumar Aishworya and Ying Qi Kang
Impact of COVID-19 on CST: challenges and opportunities

- Projects disrupted/delayed
- Innovations in web-based training and delivery are being made
- Increased opportunities for collaboration between CST teams
CST Innovations

• Development of web-based training of master trainers

• Remote delivery of CST including home visits

• CST Master Trainer Network Meetings (coming soon!)

• Opportunities to learn from teams doing remote training and delivery
Regional Focal Points

- New leadership and training role

- Training of Regional Focal Points in Egypt in Feb 2020 & Montreal in March 2020

- Our Team so far:
  - Janet S.P. Lau (Hong Kong)
  - Alaa Ibrahim (Canada)
  - Sebastián Cukier (Argentina)
  - Pierina Landolfi (Argentina)
  - Rehana Sheriff (Ethiopia)
  - Tigist Zerihun (Ethiopia)
  - Mehdi Ghanadzade (Iran)
New CST Project Teams

- Turkey
- Jordan
- Peru
- Nepal
- Mexico
- Kazakhstan
- Georgia
- US (Detroit, Michigan)
New Projects:
Finalization of CST package

- CST pre-release created based on feedback from pilot testing
- Improvements in materials and adaptation guidance
- Reduces the need for adaptation
- Teams will be invited to review and finished package (Version 4.0) will be released on WHO website
New Projects: eCST for caregivers
New Projects: CST 0-3

- Similar format and outline of topics as CST 2-9
- Tips, Key Messages and Session Outlines will be developed into full group sessions
- Materials will go through several rounds of feedback and revision
- There will be opportunities for you to review

- “Get face-to-face so your child can see you, hear you, move freely and touch you”
- “Choose clean, safe and colourful objects for your child to play with that cannot be swallowed or choked on.”
- “Copy your child’s sounds, gestures, smiles and facial expressions. Look for your child trying to copy you in return”
CST Project Surveys

- CST Progress and Innovation
- Lessons learned
- Feedback

We are grateful for everyone’s participation!
Next Steps

• Upcoming invitations
  – Feedback on CST pre-release
  – Project Surveys
  – Master Trainer Network Meeting
  – e-training and delivery collaboration
  – CST 0-3

• Have a great meeting!

With support from Autism Speaks
WHO Caregiver Skills Training (CST) e-Learning course
for Families of Children with Developmental Disorders or Delays

Autism Speaks Advocacy Leadership Network (ALN) 2021
4th Biennial Conference
April 27th, 2021
CST

• provide caregivers with strategies to support their children’s development
• by engaging children in everyday activities
• by applying strategies to support the development of the child’s communication skills and reduce challenging behaviour

→ The original design of WHO’s CST is a group-based intervention with 9 group sessions for caregivers and 3 home visits delivered by trained non-specialist providers
Online approaches have the potential to

- make interventions more widely available
- be more cost-effective
- overcome barriers to uptake of services such as geographical isolation and stigma concerns
- provide more flexible and user-based utilization options
Content of eCST

• Module 1: Getting children engaged
• Module 2: Keeping children engaged
• Module 3: Keeping children engaged in interaction
• Module 4: Helping children share engagement in play and home routines
• Module 5: Understanding communication
• Module 6: Promoting communication

• Module 7: Preventing challenging behaviour, helping children stay engaged and regulated
• Module 8: Teaching alternatives to challenging behaviour

• Module 9: Teaching new skills in small steps and levels of help
• Module 10: Problem-solving and self-care

Programme Overview for You and Your Child
A caregiver skills training for children with developmental disorders and delays.

Course 1: Getting Children Engaged and Communication
In this course, you will learn how to get children engaged through everyday activities and games.

Course 2: Preventing and Teaching Alternatives to Challenging Behaviour to Help Children Stay Engaged
In this course, you will learn how to respond to challenging behaviors and help your child stay calm and engaged.

Course 3: Teaching New Skills, Problem Solving, and Self-Care
In this course, you will learn how to teach your child new skills for everyday life using small steps. You will also learn how to cope with stress through beneficial self-care practices.
Adaptations to learning strategies

Key Message 2: Find out how your child likes to play and show them new play routines

- Children can practise communication skills and other new skills during play.
- Your child may need your help to learn how to play with the objects first.

• Simplified language and terminology for target audience
• Key messages and tips highlighted and repeated
• Very visual (text supported by many images)
Adaptations to learning strategies

- Interactive approach (quizzes, scenarios, text fields, etc)
- Demonstrations through videos
- Use of journal (personal goals, activities, etc.)
Feedback and field testing

• First round of feedback collected from target users (caregivers of children with developmental delay or disability, including ASD) as well as international experts and those familiar with the regular CST

• Field-testing in multiple countries to test:
  – Feasibility and usability
  – Acceptability
  – Comprehensibility
  – Relevance
Future possibilities for discussion

- Voice over / recordings to facilitate e-learning
- Hybrid approaches (fully online vs guided through phone calls?)
- Use by regular CST workforce (remote support?)
CST within a broader approach to Early Identification and Intervention for Children with Developmental Delays and Disabilities
TWIN TRACK APPROACH

Challenge | Programme activities | Goal
---|---|---

**Main stream**
Include children with disabilities in all aspects of development

**Disability Specific**
Specific initiatives to identify and empower children with disability

**Equality** of rights and opportunities for children with disabilities
Inclusion in Mainstream ECD Programs

Community based, family centered intervention for all children with developmental delay
Monitor and Support Child’s Development
Caregiver education, skill training and empowerment

Vision Screening
Hearing Screening

Developmental Monitoring/Screening (timing based on the tool selected)

Specific Vision EI
Specific Hearing EI
Specific EI for Motor Delays / high risk CP
Specific EI for Behavior, Communication, Intel Delays / High Risk for ASD
Medication Epilepsy

V/H Assessment
Motor Assessment
Developmental Assessment
Seizure Assessment

Vision/Hearing Assessment

Specific Assessments & Intervention based on screening and monitoring

Tier 3
Tier 2
Tier 1

Inclusion in Mainstream ECD Programs

0 mo 3 mo 6 mo 9 mo 12 mo 15 mo 18 mo 21 mo 24 mo 30 mo 36 mo
• Piloting this model in 3 countries: Bulgaria, Peru, Uganda

• Technical support from and collaboration with Autism Speaks and WHO on training national master trainers in these 3 countries
Future collaboration on:

Application of AI/ML on early identification and early intervention on children with developmental delays and disabilities
“Everyone has a mountain to climb and autism has not been my mountain, it has been my opportunity for victory.”

- Rachel Barcellona

https://www.autismspeaks.org/life-spectrum/10-inspiring-quotes-people-autism
THANK YOU.

Dr. Raoul Bermejo III
rbermejo@unicef.org
CST PANEL

Argentina- Ministry of Health
City of Buenos Aires-

TEAM:
Nora Granana- MD Team Leader
Delfina Suaya- CST MT
Veronica Mondaca- FMT
Melisa Pertica- BOSCC PhD student

April 27th, 2021.
1 CST: HV + GROUP SESSIONS - VIRTUAL MODE

- Participants: 10 families from Day Care Centers, whose child presented risks in communication and personal social skills (ASQ-3).
- None of them were receiving intervention due to Covid-19 restrictions and Health Services limitations.
- ECHO AUTISM/ ZOOM Platform: 2hs meetings. Delivered weekly. 10 weeks.

2 TOT VIRTUAL MODE

- Participants: Therapists (Psychologist-Language-Physical-Educational). Working as permanent staff in Primary Health Centers. Authorized to use one journey per week in the CST Program.
- ECHO AUTISM/ ZOOM Platform: 3hs meetings with facilitators. 6/8 weeks + CST with caregivers delivered jointly with MT. 10 weeks.

OUR COMMUNITY-SOCIODEMOGRAPHIC CHARACTERISTICS

- 57% of the families Lower or Middle Lower class.
- Head of household: unregistered workers or unemployed.
- Maternal educational attainment: Elementary Level.
- Household income: Irregular/Minimum wage/social plans.
- House living conditions: Inadequate.

Graffar - Social Economic status
Figure I
**SUCCESSES**

**TOT:**
- All facilitators are available to assign permanent work hours to CST allowing scalability.
- Facilitators highly motivated to include in their work schedules the CST Program.
- Contents are easy for non specialists in ASD, to learn.

**CST:**
- All families described improvements in their child’s development regarding engagement, communication, management of challenging behavior and learning new skills. (Figure 1-2)
- Boscc pre and post assessment: evidenced a global improvement and specific in sociocommunicational skills (Figure 3).
- Almost all of the caregivers could complete the whole program (9/10).
- High attendance to the group sessions 99.8%
- All caregivers managed to enhance their own self care.
- Their children received early intervention while waiting availability for other treatments.

**BOSCC PRE - POST CST (f3)**
**BARRIERS**

**TOT:**
- Facilitators had limited opportunities to practice the interaction with children.
- Access to facilitators out of local area. MT with no funds available outside Buenos Aires City.

**POSSIBLE SOLUTIONS**
- Reviewing and coding other facilitators interactions.
- Grants for scalability outside Buenos Aires City.

**CST:**
- Most families in our community have difficulties with the internet connection. No access to bad services and/or devices.
- Not able to do the facilitator and child interaction in order to model the use of strategies with their children during the virtual mode home visits.

**POSSIBLE SOLUTIONS:**
- Ease connectivity- E.g. Allowing caregivers to attend to Day Care Centers to connect.
- Use video demonstrations.
THANK YOU!!
Panel Discussion: Adapting CST for Telehealth in Argentina
Presented by: Pierina Landolfi & Sebastian Cukier
Project characteristics
Virtual/ remote facilitator training

[Argentina]
Field-testing stage 1: Planning and Adaptation
Project characteristics
Virtual/remote facilitator training

- Site(s): **Buenos Aires & Pilar, Argentina** – Community Centers & Community Rehabilitation Centre

- Stakeholders involved, including government ministries and academic institutions: **Ministry of Social Development of Buenos Aires City & PANAACEA**

- Participants: Master Trainers from PANAACEA (Pierina Landolfi & Sebastián Cukier); facilitators from CPIs & Rehab center (2020)
Adaptation process to virtual/remote delivery during pandemic – **Facilitator training**

- **Platform used:**
  - Zoom: instructions for caregivers & facilitators
Adaptation process to virtual / remote delivery during pandemic – **Facilitator training**

- **Materials:**
  - Adaptation of original training presentations to virtual
    - *Addition of more visual material (e.g. photos of manuals)*
    - *Use of Zoom virtual blackboard*
  - Video - recording of live demonstrations for the sessions
  - Tablets for families
Adaptation process to virtual / remote delivery during pandemic – *Facilitator training*

**Format (training pre-program):**

- 1st part: Review of selected parts of manual content with trainees
- Active learning: trainees *presentations of activities, tips & key messages from sessions* as if to caregivers (recordings and live)
- **Videos of children to practice function of behaviors** (sessions 6&7)
- Practice of self-care activities
- Goal setting practice using vignettes
Adaptation process to virtual / remote delivery during pandemic – *Facilitator training*

**Format (virtual group sessions & virtual HV):**

- **Time:**
  - Sessions lasted **90 minutes** (average vs 120-180 for the in-person)
  - HV lasted **60 minutes** (average)

<table>
<thead>
<tr>
<th>Minutes</th>
<th>Description</th>
</tr>
</thead>
</table>
| 30      | Discussion with caregiver/review of information:  
Visit 1: Take history on child’s problem and contact with support services and assess the child’s development, behaviour and functioning  
Visit 2 and 3: Review key messages, strategies and home practice and plan the guided practice |
| 15      | Observe caregiver interacting with child and video record for 10 minutes  
Comment on what the caregiver does well and provide suggestions |
| 15      | Interact with the child and demonstrate strategies  
Visit 2 and 3: Demonstrate and coach the caregiver on those strategies |
| 10      | Discussion with caregiver about goals:  
Visit 1: Identify expectations and goals  
Visit 2 and 3: Discuss and review the practice session and goals |
| 10      | Planning for the future:  
Visit 1 and 2: Invite family to the next session and discuss possible barriers and solutions  
Visit 3: Discuss plans for continuing practicing strategies in the future. |

*Time = 90 minutes*
Adaptation process to virtual / remote delivery during pandemic – Facilitator training

Format (virtual groups sessions & virtual HV):

HV:

- Explaining to CG position of camera and setting for virtual mode
- Option of recording home practice with children - when live practice of routines during “HV” were difficult (because of camera position, distraction of child, etc.)

In between sessions:

- Sharing with CG videos for modelling and/or explaining tips & strategies via WhatsApp
- Follow up of possible barriers via WhatsApp
Adaptation process to virtual / remote delivery during pandemic – *Facilitator training*

**Format (virtual groups sessions & virtual HV):**

- **In group sessions**
  - Peer practice: *Break rooms* - more conversation about planning of routines (vs actual practice)
  - Inclusion of images of CG manual in the screen during sessions (e.g. readings stories from screen) to increase attention
  - Use of pre-recorded video demonstrations
  - Revision of home practice: inclusion of videos of practice from home
Facilitator Training online Scheduling:

- **Part 1:** Review of Group sessions 1-4 & HV1 (5 weekly meetings of 2 hours) + Learning activities for sessions 1-4 and HV 1 (5 weekly meetings of 2 hours)

- **Parte 2:** Review of Group sessions 5-9 & HV2&3 (5 weekly meetings of 2 hours) + Learning activities for sessions 5-9 & HV2&3 (5 weekly meetings of 2 hours)

**The revision and learning activities were done all together before the implementation because we had thought that we would have the chance of doing the implementation in-person. But isolation went on...**
Adaptation process to virtual / remote delivery during pandemic – MT training
Adaptation process to virtual / remote delivery during pandemic – *MT training*

**Platform used:**
- TEAMs + Zoom

**Materials:**
- Adaptation of original training presentations to virtual
  - Addition of more visual material (e.g. photos of manuals)
- Video - recording of live demonstrations for the sessions

**Format (training pre-program):**
- Review of manual content
- Active learning: trainees presentations of activities, tips & key messages from sessions as if to caregivers (recordings and live)
- Videos of children to practice function of behaviors (sessions 6&7)
- Practice of self care activities
- Goal setting practice using vignettes
- *Review of recorded practice with children*
  - Use of Peer feedback form for live analysis of practice with children
MT Training online Scheduling:

7 DAYS – 7 HOURS EACH DAY
MEETING WITH TRAINERS

7 DAYS
Reading & practice by themselves

Implementation monitoring: Test-run

[Argentina]
Adaptation to virtual / remote
### MT Training online Scheduling:

| Training Day 1: | 9-11am: Presentation of schedule of activities. General presentation of CST. Review main points sessions 1A - 1B  
|                | 11:30-1pm: Review key points from session 2 and session 3  
|                | 2pm-3:30PM: Review session 4 key points  
|                | 3:30 – 6: Preparation of presentations of selected parts of sessions 1-4 to present on Monday  
| Saturday       | Reading & Practice by themselves  
| Sunday         |  
| Training Day 2: | 9-11am: Presentation from trainees 1 and 2: parts of sessions 1-4 as if they were in front of caregivers  
|                | 11:30-1pm: Presentation from trainees 3 and 4: parts of sessions 1-4 as if they were in front of the caregivers  
|                | 2-3:30PM: Review home visit guide 1 and goal-setting  
|                | 3:30 – 5: Preparation for the 1st practice with child and family  
| Tuesday        | Practice with children 1: Throughout the day trainees do the practice with 2 different children each, and video record them. Send un-edited videos to trainers  
| free           |  
| Training Day 3: | 9 to 16hs: review of videos of practice with children. Receiving feedback from other trainees and trainers Using adult-child interaction forms  
|                |  
| Training Day 4: | 9-11am: Review key points from session 5-6  
|                | 11:30-1pm: Review session points 7-8  
|                | 3:30 – 6: Preparation of presentations of selected parts of sessions 5-8 to present on Monday  

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[Argentina]  
Adaptation to virtual / remote
<table>
<thead>
<tr>
<th>Day</th>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>M</td>
<td>9-11am</td>
<td>Presentation from trainees 1 &amp; 2: parts of <strong>sessions 5-9</strong> as if in front of caregivers</td>
</tr>
<tr>
<td></td>
<td>11:30-1pm</td>
<td>Presentation of MTs in formation 3 and 4 parts of sessions 5-9 as if they were in front of the caregivers</td>
</tr>
<tr>
<td></td>
<td>2-3:30PM</td>
<td>Review <strong>home visit guide 1-3</strong> and goal-setting</td>
</tr>
<tr>
<td></td>
<td>3:30 – 5</td>
<td>Preparation for the 2nd practice with child and family</td>
</tr>
<tr>
<td>T</td>
<td>Practice with children 2: Throughout the day, trainees do the practice with 2 different children each (if possible, same children from previous practice) and video record them. Send un-edited videos to coaches</td>
<td></td>
</tr>
<tr>
<td>W</td>
<td>9 to 16hs</td>
<td>Review of videos of practice with children. Receiving feedback from other trainees and trainers Using adult-child interaction forms</td>
</tr>
<tr>
<td>T</td>
<td>9-11 am</td>
<td><strong>Practice of goal-setting</strong>: live with videos and vignettes</td>
</tr>
<tr>
<td></td>
<td>11:30-1pm</td>
<td><strong>measurements, scales and facilitator fidelity</strong></td>
</tr>
<tr>
<td></td>
<td>2-5PM</td>
<td>Q&amp;A and <strong>preparation for remote monitoring</strong></td>
</tr>
</tbody>
</table>
Lessons learned: *challenges* of virtual delivery

### General
- **Connectivity** problems: availability of devices and access to Wi-Fi
- Impression and distribution of printed manuals (some have only cell-pone & no laptop) mainly because of pandemic

### Training
- Practice with children could not be done because of pandemic restrictions (facilitators)
- No possibility of adjustments during practice with children, only in between practices

### Implementation
- Peer and groups practices were mainly planning and conversation (instead of role playing / live practice of strategies)
- **Group sessions:** Presence of children were sometimes distracting or parents needed to interrupt to manage children
- **HV:** coaching was more challenging through the screen – sometimes children would get out of camera or get distracted by device
- Limited access to environment for suggestions related to environment setting
Lessons learned: **advantages/ opportunities** of virtual delivery

- General
  - FTs & MTs from **different cities** could be trained simultaneously
  - MT Training could be more **accessible for distant sites** (e.g. less hotel and travel expenses)
  - FT training: Allowed for implementation with CG from different neighborhoods
  - FT training: More **accessible for caregivers** (less traveling time & cost)
  - CG that can’t **leave their children** to go somewhere else could participate
  - **Video sharing** became more acceptable and accessible
  - Some families were not so comfortable with **in-person home visits**
Focus group: CG, FT & MT quotes

- MT: “Compared to ‘in-person’ version I found them similar” (July, from Peru, had the chance to participate in both trainings)

- MT: “The video-demonstrations and training videos showing the strategies were very useful, and also recording ourselves showing the tips or role-playing with volunteer children and later discussion”

- MT: ”It is easier to get distracted with the Zoom, particularly when we are reviewing the theory. It got better when we started reading the manuals in between meetings and then present in the meeting the main concepts and tips”

- FT: “...virtual delivery was fine, I thought it would be harder, it ended it up being very comfortable and easier for CGs”

- CG: “Virtual HV made it easier because (son) wouldn’t have participated, he is very shy, and with you giving feedback through the screen he wasn’t aware of your presence”

- CG: “Virtual delivery was useful because my son was more at ease”
Impact of remote delivery: **CG quotes**

- “It helped him coming out of the tremendous darkness he was into” “I noticed I could understand my daughter better, communicate better with her, she is not about to explode all the time”
- “Now I automatically place myself in front of her, at her level to talk to her”
- “Facing a tantrum, I used to think ‘I don’t know what to do’, now I learnt to observe where it came from, check my response during the tantrum, how to sooth her... this is a very important knowledge that helps me not to desperate because your desperation alters your daughter”
- ”Teaching everyday routines comes naturally now”
- “I see an impressive change, he has less tantrums now, he understands “later”, he learnt things that he used to do as if a 2 year-old”
- “Now he can dress himself, clean himself, with simple words he got a lot better. He almost never hits anymore, that change was spectacular. Following the suggestions and practicing the routines. I realize when he starts to clinch his fists and teeth and we can solve it. We have a happier child”
- “She used to shout & hit the doors and I would go after her, and she would do it more to call my attention... Now I do the breathing exercises not to get angry ... they helped me to keep regulated and to regulate her.”
WHO Caregiver Skills Training Program:

Argentina

Advocacy Leadership Network 4th Biennial Conference

Thank you!

pierinalandolfi@panaacea.org  sebastiancukier@panaacea.org
A NOVEL REMOTE TRAINING OF THE WHO/AS CAREGIVER SKILLS
TRAINING PROGRAM IN RESPONSE TO THE COVID-19 PANDEMIC:
CANADIAN CONTEXT

Alaa Ibrahim
M.Sc. Student, Integrated Program in Neuroscience
McGill University, Montreal Neurological Institute-Hospital
Montreal, Canada

April 27th, 2021
Autism Speaks Advocacy Leadership Network
CANADIAN ADAPTATION

PRE-PANDEMIC
WHO/AS original training model:

1. Didactic Training
   - Week 1 (5-day course)
     - Introduction
     - Key Messages
     - Review caregiver resources

DURING PANDEMIC
Novel remote training:

2. Scoring Reliability Practice
   - Weeks 2-7 (community practice)
     - Video coding of caregiver-child interactions
     - Self-record
     - Review/Feedback

3. Scoring Reliability Assessment
   - Weeks 8-11 (independent practice)
     - Video coding of caregiver-child interactions
     - Feedback on fidelity
COVID-19 PIVOT FOR MT TRAINING

Novel remote training focus:
- MTs are rated on their ability to recognize CST skills in an adult-child video interaction

Original training focus:
- MTs are rated on their ability to implement CST skills directly to children

Scoring Reliability

Implementation Fidelity
TRAINING MODULES

Module 2: Scoring reliability practice (7 weeks)

- **Individual video coding/scoring:**
  - 7 weekly videos
  - MTs watched an assigned 7-12-minute video of either a play or a home routine and submitted their scores on the Fidelity Rating Checklist

- **MT group sessions (2 hours):**
  - Weekly group review of CST sessions and discussion of video coding

Module 3: Scoring reliability assessment (4 weeks)

- **Individual video coding/scoring:**
  - 10 reliability videos; 2 sets of 5 videos with discussions after each set
  - MTs watched an assigned 7-12-minute video of either a play or a home routine and submitted their scores on the Fidelity Rating Checklist

- **MT group sessions (2 hours):**
  - 2 Group discussions of video coding
SETTING: PLATFORMS

- **Online meetings**
- **Secured training website**
  (online learning management tool)
- **Research data collection**
- **Research data collection**
LESSONS LEARNED

Future Improvements:

- Repository of selected videos for training
  - Standardized instructions for the recorded videos
  - Videos quality (length and technical quality)

Opportunities/Advantages:

- Increase of MTs’ scoring reliability
  - Module 2: significant increase from baseline (V1) to end of module (V7)
  - Module 3: majority of MTs were able to achieve a moderate scoring reliability

- Increase of MTs’ level of confidence on CST knowledge
  - Significant increase from Timepoint 1 (pre-Module 1) and Timepoint 3 (Post Module 3)
THANK YOU!

Montreal Neurological Institute–Hospital
Azrieli Centre for Autism Research

Réseau pour transformer les soins en autisme
Transforming Autism Care Consortium

Public Health Agency of Canada
Agence de la santé publique du Canada

autism speaks®

World Health Organization
Autism Speaks Advocacy Leadership Network (ALN) 2021
4th Biennial Conference
A Virtual Conference for the Global Autism Advocacy Community

Janet SP Lau, PsyD. (Clin Psy)
Regional Technical Focal Point, WHO-CST
Principal Master Trainer, WHO-CST-HK
Project Manager, JCAC Family Support Team

April 27, 2021
Milestones of WHO-CST in Hong Kong

1. November 6, 2018
   - 1st Adaptation Mtg

2. 2018 Nov
   - International Technical Meeting

3. 2019 Jan
   - Expert Seminar

4. 2019 Apr
   - 1st Facilitator Training

5. 2019 Aug
   - JCAC Family Support Team was setup

6. 2020 Jan
   - 1st Facilitator Training

7. 2020 Apr
   - Focus Group with Professionals

8. 2020 Aug
   - Study on Different Delivery Modes

9. 2020 Apr

Adaptations

- 1st Pre-Pilot Run
- 1st Pilot Run (Online)

Implementation

- MT Training
- 2nd Adaptation Mtg
- 3rd Adaptation Mtg
- 1st Pilot Run (Online)
- Study on Different Delivery Modes
As part of the data collection, home visits were moved to HKU setting. Naturalistic home settings might not be observed. To overcome this shortfall, the participants were asked to send a photo of parent-child play area for facilitators’ comments.

Home Visit @HKU
- As part of the data collection, home visits were moved to HKU setting
- Naturalistic home settings might not be observed. To overcome this shortfall, the participants were asked to send a photo of parent-child play area for facilitators’ comments.

Demonstrations
Replaced by pre-taped demonstration videos

Session Format
- Sessions were run via zoom on a weekly basis
- Participants could save time to attend classes without the limitation of distance
- They could attend even right after off-work, travelling back home, or having dinner.

Discussion & Role play
- Discussions were conducted via breakout rooms, more facilitators were invited to help
- Skills practice were done via parent-child play on live. They might be too shy.
CST in Different Modes

<table>
<thead>
<tr>
<th>Features</th>
<th>E-Learning</th>
<th>Video-Conferencing</th>
<th>Adapted In-Person</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 100% Self-learning</td>
<td>• Flow adapted from CST online module</td>
<td>• 100% via Zoom for both home visits &amp; sessions</td>
<td>• As traditional CST</td>
</tr>
<tr>
<td>• Flow adapted from CST online module</td>
<td>• No facilitator intervention</td>
<td>• Flexible for distant families</td>
<td>• But Home visits are taken place at facility setting</td>
</tr>
<tr>
<td>• More flexible</td>
<td>• Live coaching</td>
<td>• Flexible for busy caregivers or working parents</td>
<td>• Ax is possible, &amp; children play with a stranger can be observed</td>
</tr>
<tr>
<td>• Benefit working parents &amp; those FTMs who take care children in day time</td>
<td>• Rapport building</td>
<td>• Less travelling</td>
<td>• Live coaching</td>
</tr>
<tr>
<td>• Less travelling</td>
<td>• Experiential learning</td>
<td>• Peer supports</td>
<td>• Rapport building</td>
</tr>
<tr>
<td>• More focused</td>
<td>• Peer supports</td>
<td>• More focused</td>
<td>• Experiential learning</td>
</tr>
<tr>
<td>• Challenge</td>
<td>• Well-being is doubted</td>
<td>• More focused</td>
<td>• Peer supports</td>
</tr>
<tr>
<td>• Lack of learning motivation</td>
<td>• Not fully acquire skills w/o facilitation</td>
<td>• Availability &amp; instability of hardware &amp; internet</td>
<td>• More focused</td>
</tr>
<tr>
<td>• Not fully acquire skills w/o facilitation</td>
<td>• Lacking peer supports</td>
<td>• Unable to give advice on environment</td>
<td>• Availability &amp; instability of hardware &amp; internet</td>
</tr>
<tr>
<td>• Lacking peer supports</td>
<td>• Well-being is doubted</td>
<td>• Lack of Joint engagement</td>
<td>• Unable to give advice on environment</td>
</tr>
<tr>
<td>• Well-being is doubted</td>
<td>• Joint engagement</td>
<td>• Ax is impossible</td>
<td>• Lack of Joint engagement</td>
</tr>
</tbody>
</table>

Follow-up study

Background
In addition to the general busy working schedules of the Hong Kong caregivers, we have been under few waves of pandemic attacks and unstable social movements in the past two years that made physical or face-to-face intervention impossible, particularly at the times of social distancing or lockdown. So, video-conferencing CST with further adaptations was recommended, while e-learning mode can be an alternative to busy working couples, comparing to traditional mode of CST.

Methodology
34 participants were randomly assigned into the four studied modes, self-e-learning, video-conferencing, in-person modes, and the waitlist control groups. 9 e-learning participants were given the links to self-study the session materials at their schedule on a weekly basis, while 7 video-conferencing participants attended sessions online weekly. As for the in-person group, 9 caregivers were facilitated via video-conferencing with the 4th wave of pandemic attack but they were asked to join three additional skill drilling sessions at 3rd, 6th & 9th sessions. Regarding home visits, IP caregivers were invited to HKU for in-person advices, whereas VC participants were done via video-conferencing. EL and wait-control group, assimilating non-interfering conditions, were asked to send their home visit videos.

Regarding home visits, IP caregivers were invited to HKU for in-person advices, whereas VC participants were done via video-conferencing. EL and wait-control group, assimilating non-interfering conditions, were asked to send their home visit videos.
Challenges of the Professionals

Although online mental health services might not be new to some practitioners, technology-know-how on conducting online training, workshop and program continued to be a challenge.

The professionals reported that they spent significant efforts to produce guidelines in protecting services users’ privacy, to equip themselves with necessary skills in executing privacy-protection measures, and to keep exploring various safer software and resources.
Feedbacks from Participants as Learnings

In-person mode vs Video-conferencing mode

**In-person Mode**
- Human interactions with facilitators & peers are indispensable, e.g. mingling time at tea breaks & before or after the workshops
- They valued the time in the classroom that they could completely enjoy and focus in the workshops
- They all valued the in-person coaching and demo that they could grasp the skills better.

**Both agree**
- In-person facilitation is essential in helping them to attain the knowledge & skills
- Preferred to have in-person home visits
- CST skills are systematic and highly recommended it to other parents, even for non-ASD or non-SEN children

**Video-conferencing Mode**
- Time of workshop became more flexible to them. They saved time for travelling while they might be occupied at taking care of their children, attending classes when they were just off other duties
Acceptability & Feasibility of CST delivered in various modes

Nov 2020 – Mar 2021

Conclusions
Different modes of CST were found effective. The degree of intervention can be a positive factor in the degree of effectiveness. This serves a direction how CST can be implemented in Hong Kong, when considering the effectiveness and constraints in different settings.

Methodology
34 participants were randomly assigned into the four studied modes, self-e-learning, video-conferencing, in-person modes, and the waitlist control groups. 9 e-learning participants were given the links to self-study the session materials at their schedule on a weekly basis, while 7 video-conferencing participants attended sessions online weekly. As for the in-person group, 9 caregivers were facilitated via video-conferencing with the 4th wave of pandemic attack but they were asked to join three additional skill drilling sessions at 3rd, 6th & 9th sessions. Regarding home visits, IP caregivers were invited to HKU for in-person advices, whereas VC participants were done via video-conferencing. EL and wait-control group, assimilating non-interfering conditions, were asked to send their home visit videos.

Results
From the brief analysis, there were improvements recorded in both caregivers’ Quality of Life (QOL) & children’s behaviours (Strength & Difficulties Questionnaire) from T0 to T2. Improvement from Video-conferencing group had the greatest improvement, then in-person group, and followed by e-Learning mode, comparing to the wait-list control group.

Objective
To compare the effectiveness of WHO-CST via e-Learning, Video-conferencing, and In-Person modes

Background
In addition to the general busy working schedules of the Hong Kong caregivers, we have been under few waves of pandemic attacks and unstable social movements in the past two years that made physical or face-to-face intervention impossible, particularly at the times of social distancing or lockdown. So, video-conferencing CST with further adaptations was recommended, while e-learning mode can be an alternative to busy working couples, comparing to traditional mode of CST.
ToT Bulgaria Schedule
(Phase 1 – Didactic Training)

Day 1

Session 1 & 2
Review of S1&2 Session 3
Home visit & Video reviews
Fidelity Practice & Goal setting

Day 2

Review Session 4 & 5
Recap key msgs & skills Video reviews

Day 3

Review Session 6 & 7
Recap key msgs & skills Video reviews

Day 4

Review Session 8 & 9
Recap key msgs & skills Video reviews

Day 5
ToT Bulgaria Learnings & Challenges (Phase 1 – Didactic Training)

Constraints
- Time difference
- Language barrier
- Distant
- Lockdown

Adaptations
- Agreed time fits both trainer & trainees
- Simultaneous Interpretation
- Instead of intensive on-site coaching, acquired skills will be coached via self-practice videos weekly

Challenges
- Interaction not be effective (w/ language barrier & online facilitation)
- Cannot differentiate parents & child’s speech through SI
- Not experiential learning & no live practice
- No instant coaching / comments
- Technical failures

Learnings
- More time is needed between training dates for self-practice than original 7 consecutive days
- Trainees get familiar with the sessions quickly
- Know the progress via their review & presentation
Thank you

For more details, please feel free to contact:
Dr Janet Lau at drjanet@hku.hk or drjanetlau@gmail.com
Virtual Training of Facilitators & Delivery of WHO-CST to Caregivers: *Experiences from a LMIC*

Koyeli Sengupta
Disha Sangvi
Sanchita Mahadik,
Mumbai, India.
### Presumptions versus Reality

<table>
<thead>
<tr>
<th>PRESUMPTIONS</th>
<th>REALITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internet penetration high- most households have smart-phones</td>
<td>Connectivity issues</td>
</tr>
<tr>
<td>Caregivers will be willing and ready for online services</td>
<td>Resistance and scepticism</td>
</tr>
<tr>
<td>What works for one organization works for all</td>
<td>Contexts different</td>
</tr>
<tr>
<td>No home-based visits possible- center-based coaching in lieu</td>
<td>Parents refused to bring children to center</td>
</tr>
</tbody>
</table>
### COMMON ADAPTATIONS DURING VIRTUAL FACILITATOR TRAINING:

- **Platform Used**: Zoom
- **Scheduling & Format**: May – Nov 2020
  Online 16 days (2 modules: 10 + 6) , 2 hours each
  Orientation Session
- **Materials**: Facilitator manuals shared over Whatsapp daily, MTs created PowerPoints with key teaching elements, Demonstration videos, Teams created practice videos –used for group reflection
- Synchronous delivery to facilitate peer discussion

### SITE-SPECIFIC ADAPTATIONS DURING CG TRAINING

- **Fidelity**:
  - MTs joined practice sessions, 2 per facilitator (synchronous)
  - Reviewed clips of video-recordings (asynchronous)

- **Delivery of CST to parents by Facilitators**:
  - A “publicity cum demonstration-session”
  - Key word: **Flexibility**
  - Online/ Hybrid/ Center-based

- **Observation and Supervision by MTs**:
  - Synchronous
  - Asynchronous
Campaigns to develop interest in virtual CST
Practice Video by Facilitators used during training
Virtual Delivery to Care-Givers

FACILITATOR COACHING A CAREGIVER ONLINE

FACILITATOR CONDUCTING ONLINE GROUP SESSION
# Virtual Training & Delivery to Care-Givers

<table>
<thead>
<tr>
<th>ADVANTAGES</th>
<th>DISADVANTAGES</th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ Wider geographic reach</td>
<td>▪ Logistically- Required more organisation</td>
</tr>
<tr>
<td>▪ Saved travel and time</td>
<td>▪ Supporting acquisition of fidelity harder</td>
</tr>
<tr>
<td>▪ Increased numbers</td>
<td>▪ Online delivery from Facilitator to Families still a challenge</td>
</tr>
<tr>
<td>▪ Evaluation and Data Collection challenging</td>
<td></td>
</tr>
</tbody>
</table>
Thank You
TELEHEALTH DELIVERY OF THE CST
PROGRAM IN NEW YORK CITY

CST-NYC Project Team
Pauline Theresa Sikat, MS, MPH
Angela M. Chan, MD, MPH
Jennifer D. Lau, MPH
Naumi Feldman, DrPH, MPH

Charles B. Wang Community Health Center, New York, NY
April 27, 2021
Disclosure & Disclaimer

The authors have no conflicts of interest in relation to this presentation or program.

Please do not cite the information or data presented today without written permission of the authors.
Adaptation to Telehealth

Training of Master Trainers (TOT)

- Online Trainer Orientation

- 5 half-days of didactic training
  - Shared screened power point via Zoom
  - Master Trainer fidelity videos & case studies
  - Mock virtual group sessions & tips on facilitating telehealth group sessions

- Online post-session feedback by trainees
  - Remote guest appearance of current Master Trainers (MT) & Facilitators (FAC) for Q&A
Adaptation to Telehealth

Fidelity Process

- Trainees (MTs and FACs) attended 4 weekly remote sessions (1.5 hrs. each)
  - Reviewed CST Key Messages & Tips (2 modules per session)
  - Reviewed & discussed MT live practice videos
  - Submitted a 18-20 minute fidelity video each week
  - Shared 2-3 minute excerpts for group feedback

- Focus was on MTs ability to explain and demonstrate the CST TIPS virtually

- CST Skills Practice Feedback Form was used to rate videos “adequate” or “well-done” to pass

- Fidelity process completed by 6 MTs in 4 weeks
Adaptation to Telehealth

Group Sessions

▪ Teams used Zoom/Skype to conduct group sessions and home visits. Trainers corresponded to caregivers using emails, phone, text messages, WeChat in between sessions.

▪ Group Session approaches:
  o Share screen of Participant Booklets or power points developed by trainer
  o Videos from CBWCHC staff and Autism Speaks
  o Live role plays between a trainer (acting as a child) and caregivers to practice CST skills

▪ Post-session feedback forms were completed online using SurveyMonkey®
Adaptation To Telehealth

Home Visits

- Guidelines from the Home Visit Guide and Master Trainer/Facilitator Goal Setting worksheet adapted by the Missouri CST site were followed specifically for remote home visits.

- Video conferencing made individual coaching with caregivers and follow-up more feasible.

- Trainers turned off their video camera and a caregiver used an earpiece so the trainers can coach without distracting the child and caregiver.
## Lessons Learned

### Training of Master Trainers & Facilitators

<table>
<thead>
<tr>
<th>CHALLENGES</th>
<th>OPPORTUNITIES/ADVANTAGES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not enough MT live practice videos</td>
<td>Remote training of trainers allowed more flexibility</td>
</tr>
<tr>
<td>Have not assessed how effective a trainer is at coaching a caregiver</td>
<td>Create resources and scripts to promote coaching skills</td>
</tr>
</tbody>
</table>
## Lessons Learned

### Group Sessions & Home Visits

<table>
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<tr>
<th>CHALLENGES</th>
<th>OPPORTUNITIES/ADVANTAGES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rapport &amp; building relationship with caregiver was not the same as in-person.</td>
<td>Master Trainers/Facilitators coached via online; caregivers became empowered to manage their child’s challenging behavior.</td>
</tr>
<tr>
<td>Limited camera view of caregiver-child interaction during home visits. Caregiver had trouble adjusting camera while interacting with child</td>
<td>Pre-visit planning for home visits include instructions for caregivers how to set up the environment, including positioning of camera for optimum viewing.</td>
</tr>
</tbody>
</table>
Acknowledgements

Thank you to all who supported our pilot.

Organizations

Autism Speaks, CARES, Inc., Center for All Abilities, Chinese-American Planning Council (CPC-Queens), Easter Seals Midwest/CST Missouri Site, World Health Organization (WHO)

CBWCHC

Dr. Loretta Au, Dr. Perry Pong, Kenneth Shieh, Manna Chan, Social Work, Health Education and IT Departments

The CST Pilot 2 was supported by a grant from the Mother Cabrini Health Foundation.

Contact: ptsikat@cbwchc.org
Virtual CST & Facilitator Training
Missouri Site

Location of MT or Facilitator

69, 704 square miles
CST Virtual
CST: Virtual

**Platform:**
- All home visits and sessions were conducted via **Zoom**
- Families signed in on a computer/laptop or phone. One family called in.
- All home visits were recorded via Zoom for scoring purposes. One family pre-recorded sessions and sent them in.
- Some groups preferred viewing screenshots of materials via powerpoint on the screen. Other groups preferred no screen sharing.
- Screen sharing was paused for all group discussion.
CST: Virtual

**Scheduling:**
- Held one additional home visit after session 1 to review goal setting sheet with family
- All sessions were held weekly for 1.5 hours

**Materials:**
- Families were mailed paper packets of session materials several weeks at a time prior to the appointments.
- Short video examples of Master Trainers working with children were used in place of demonstrations
- Reformatted all session materials to match new content
CST: Virtual

Lessons Learned:

• Group dynamics varied – some groups formed relationships right away, others were more quiet

• Compared to in-person, bonds may have formed more slowly due to no breaks or option for 1:1 time

• Virtual made it easier for other Master Trainers to fill in if needed

• In rural Missouri, virtual allowed us to reach families who lived a significant distance from a training site

• Multiple time offerings (lunchtime and 2 evening groups) allowed families to choose their group regardless of physical location
CST Facilitator Training
CST: Master Training

- Initial Missouri Master Training occurred in a weeklong format in person
- Follow-up visits were conducted in a virtual ECHO Autism format
  - Master Trainers submitted weekly 10-minute clips applying CST strategies with a child
  - Videos were reviewed and scored using the Caregiver-Child Interaction Form
  - On weekly calls, videos were shared and discussed for strengths and areas for improvement
CST: Facilitator Training

**Scheduling & Content**

- 8 two-hour virtual training sessions over Zoom
  - Reviewed CST sessions and home visits
  - Watched videos of strategies being applied by Master Trainers with real children
  - Facilitators practiced presenting sessions
  - Discussed telehealth format of materials
  - Viewed goal setting sheet
CST: Facilitator Training

• Held 14 **ECHO Autism: CST** calls after training started
  • Master trainers presented a short didactic slide presentation on the upcoming session and/or home visit content
  • Facilitators took turns presenting on case studies on
    • 1) a group session and
    • 2) a home visit
  • The team discussed how to address any challenges that occurred in the group session or how to help the family after viewing the home visit
CST: Facilitator Trainings

**Lessons Learned:**

- Allowed our group from across the region to be together without travel or time away from family.
- Took a few sessions to determine which format for training worked best for the team.
- Lost opportunity to practice implementing the strategies with children due to COVID restrictions at the time.
  - In future could do the didactic training virtual and still allow for in vivo practice with children and families.
Our Missouri Team

• Master Trainers:
  • Missy Killen
  • Rachel Masters
  • Jordan Starr
  • Megan Tregnago

• Facilitators:
  • Carolyn Allen
  • Cindy Eubanks
  • Kayleigh Fogle
  • Courtney Luebbering

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• Jeanne Marshall, ESMW
• Kristin Sohl, ECHO Autism
• Alicia Curran, ECHO Autism
• Melissa Mahurin, ECHO Autism