



autism speaks®

**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



自闭症倡导领袖联盟双年会
ANNUAL MEETING OF AUTISM ADVOCACY LEADERSHIP NETWORK

November 10th - 11th 2018 Xiamen, China
2018年11月10日-11日 中国·厦门





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

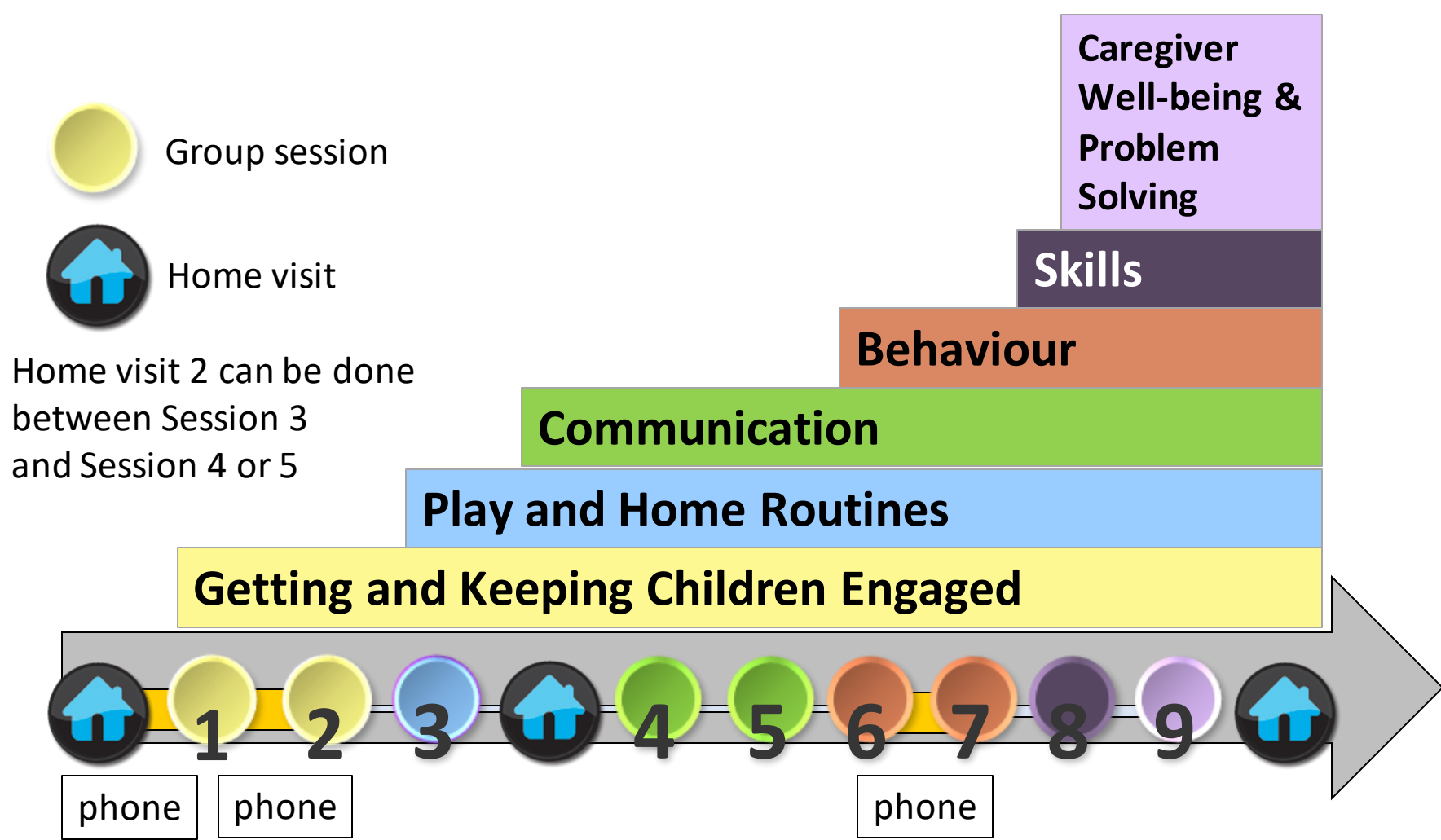


CST Characteristics

- 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



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

Thank You



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

NEWS > COVID-19

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 complications, particularly for children from low-income households.



[J Pediatr \(Rio J\)](#). 2020 Sep 23

PMCID: PMC7510529

doi: [10.1016/j.jped.2020.08.008](https://doi.org/10.1016/j.jped.2020.08.008) [Epub ahead of print]

PMID: [32980318](https://pubmed.ncbi.nlm.nih.gov/32980318/)

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}

[J Autism Dev Disord](#). 2020 Aug 20 : 1–4.

PMCID: PMC7438977

doi: [10.1007/s10803-020-04670-6](https://doi.org/10.1007/s10803-020-04670-6) [Epub ahead of print]

PMID: [32816170](https://pubmed.ncbi.nlm.nih.gov/32816170/)

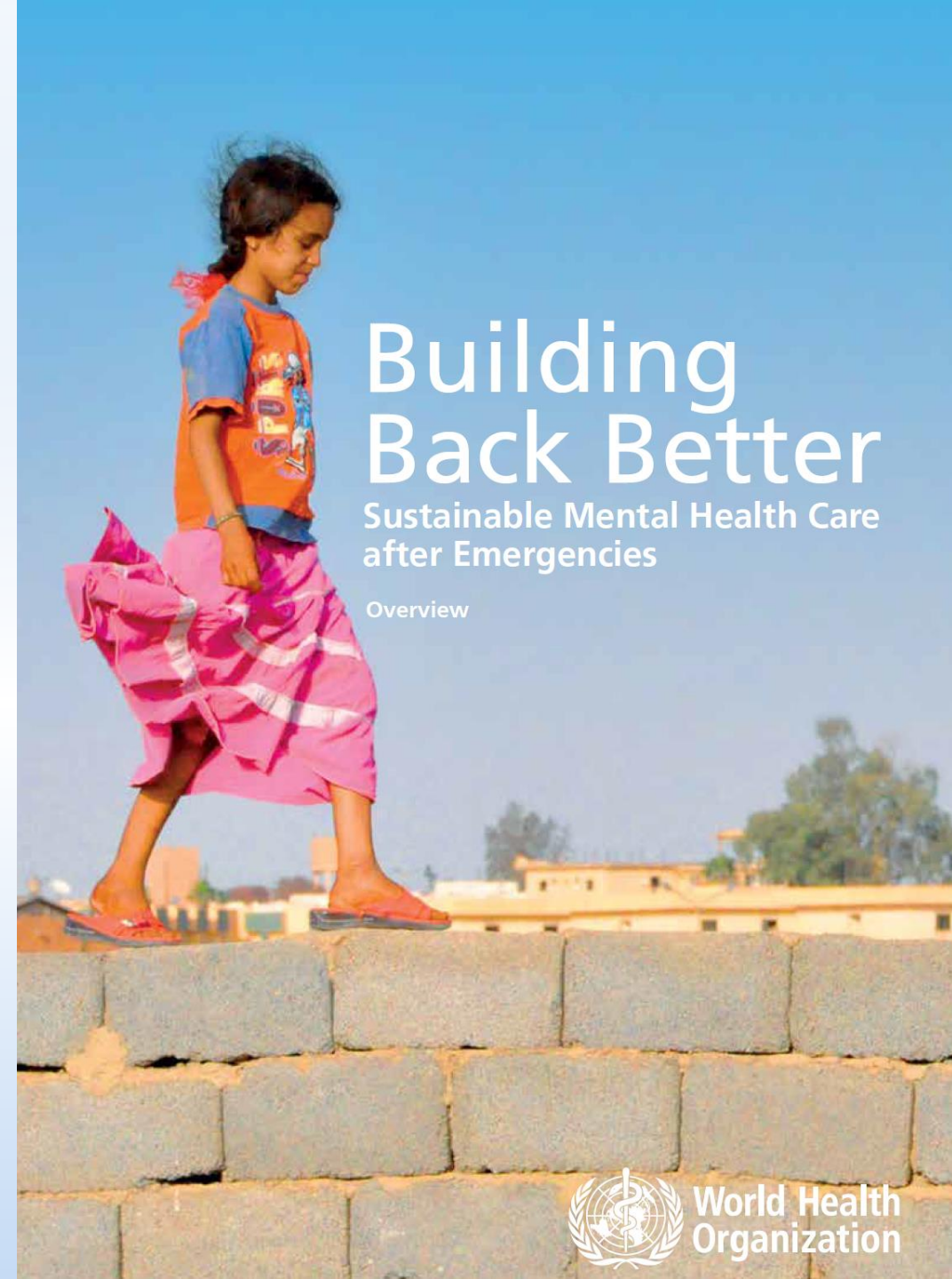
Including Children with Developmental Disabilities in the Equation During this COVID-19 Pandemic

[Ramkumar Aishworiya](#)[✉] 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)

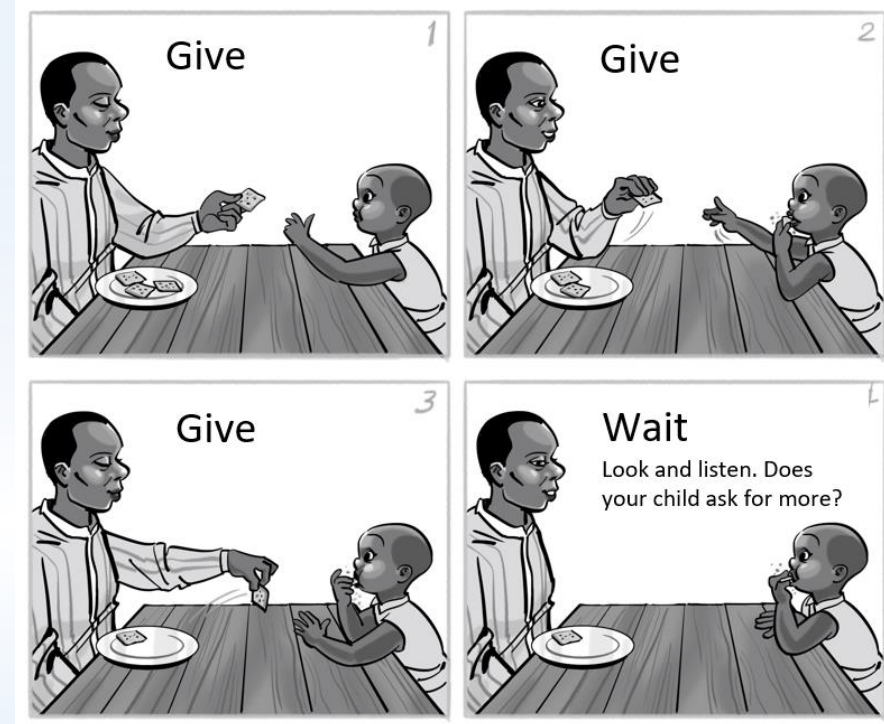




New Projects:

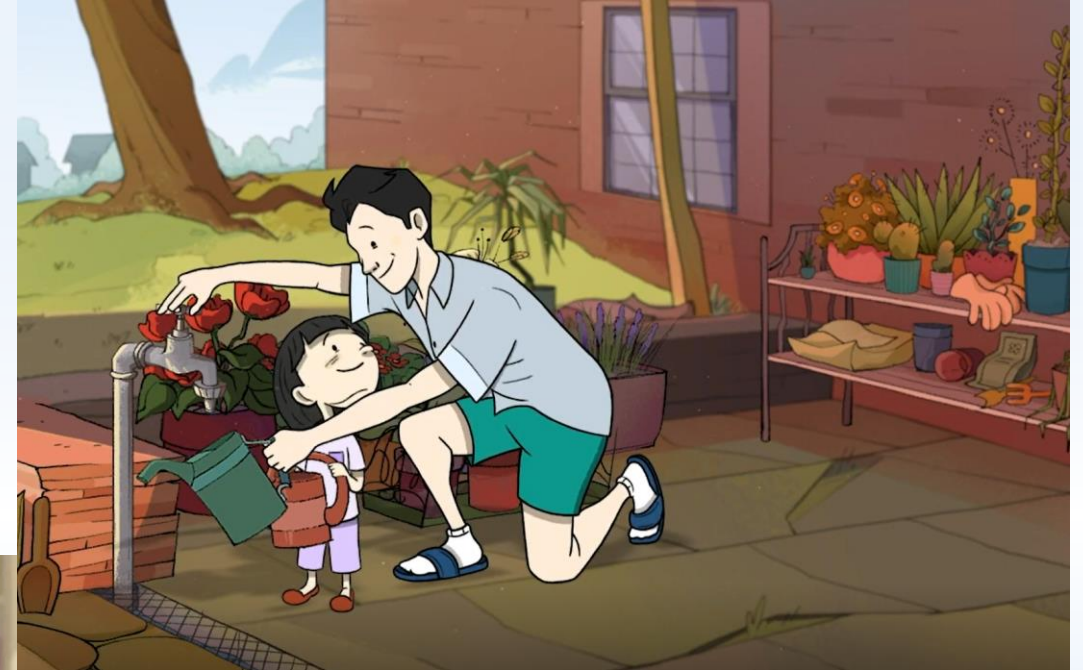
Finalization of CST package

- 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

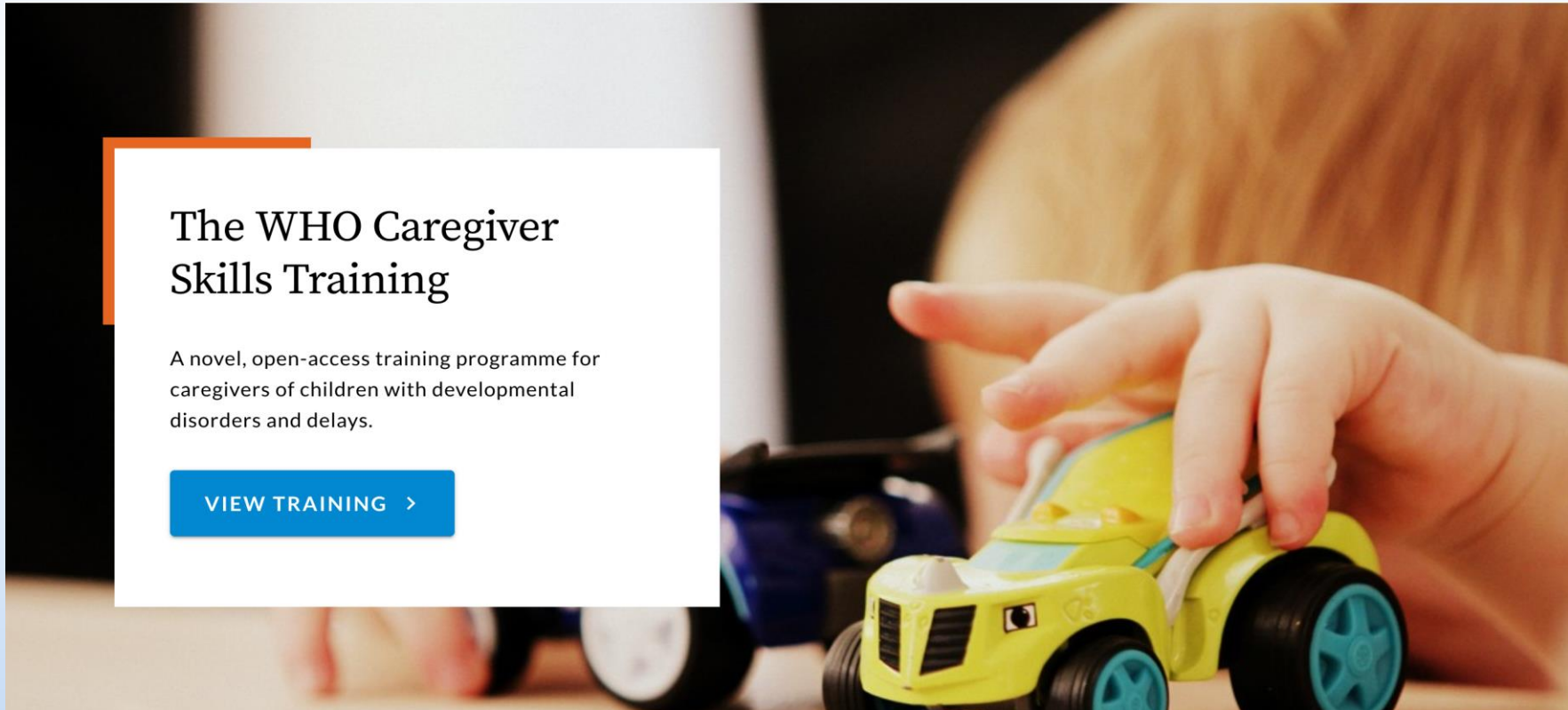
for Families of Children with Developmental Disorders or Delays

Autism Speaks Advocacy Leadership Network (ALN) 2021
4th Biennial Conference
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The WHO Caregiver Skills Training

A novel, open-access training programme for caregivers of children with developmental disorders and delays.

[VIEW TRAINING >](#)





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



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 practises.

- *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



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

Lesson 4: Communication

Lalitha's Story Part 1: Introduction to Communication

Lalitha's daughter Saanvi is four years old and she doesn't have words yet. As you read Lalitha's story, look and listen to how Saanvi is communicating with her mother. When you look and listen, you are using your ears and eyes to detect your child's behaviour.



It's difficult for Saanvi to communicate and tell her mom what she wants. Because Saanvi is sitting next to the water jug, Lalitha thinks that Saanvi is thirsty. She thinks Saanvi is trying to tell her that she wants some water by crying.

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



Lalitha's Story Part 2: Saanvi's Communication



What message is Saanvi sending in the market?

Enter your answer

SUBMIT ANSWER



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



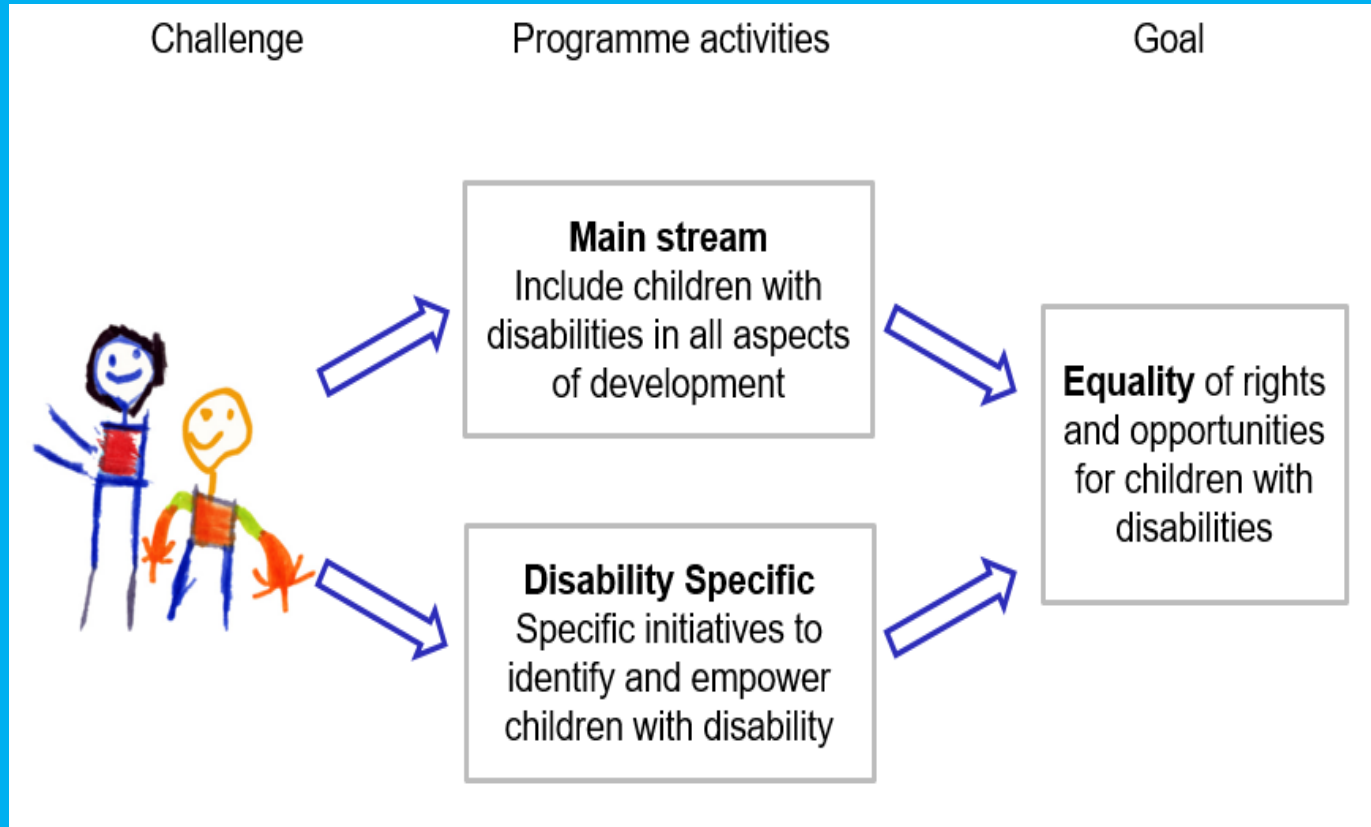
Future possibilities for discussion

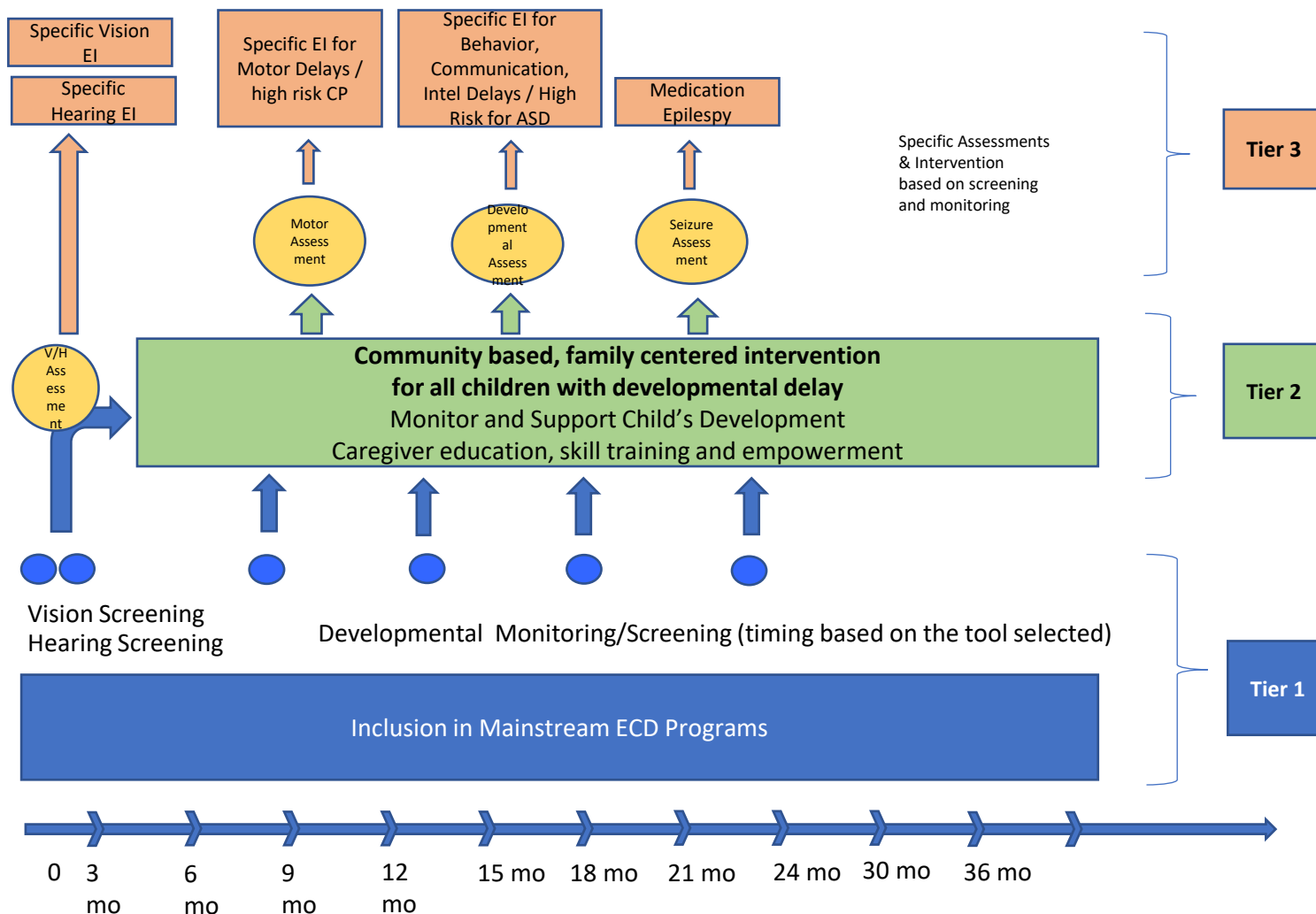
- Voice over / recordings to facilitate e-learning
- Hybrid approaches (fully online vs guided through phone calls?)
- Use by regular CST workforce (remote support?)



CST within a broader approach to Early Identification and Intervention for Children with Developmental Delays and Disabilities

[TWIN TRACK APPROACH]







- 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.



World Health
Organization

A Virtual Conference for the Global Autism Advocacy Community



Advocacy Leadership Network
4th Biennial Conference



Buenos
Aires
Ciudad



Tomemos
distancia



PROTECTEA

Programa Orientación Temprana y Concientización
Trastornos del Desarrollo y Espectro Autista

ACTIVITIES

2 TOT VIRTUAL MODE

- Participants: Therapists (Psychologist-Language-Physical- Educational). Working as permanente 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.

1 CST: HV + GROUP SESSIONS- VIRTUAL MODE

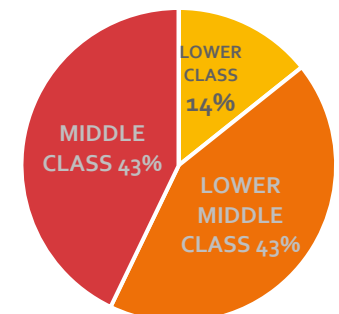
- Participants: 10 families from Day Care Centers, whose child presented risks in communication and personal social skills (ASQ-3).
- None of them where recieving intervention due to Covid19 restrictions and Health Services limitations.
- ECHO AUTISM/ ZOOM Platform: 2hs meetings. Delivered weekly. 10 weeks.

OUR COMMUNITY-SOCIODEMOGRAPHIC CHARACTERISTICS

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

Graffar-Social Economic status

Figure I



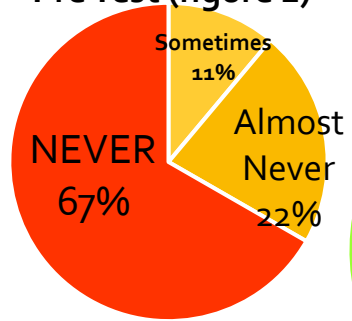
SUCCESSSES

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.

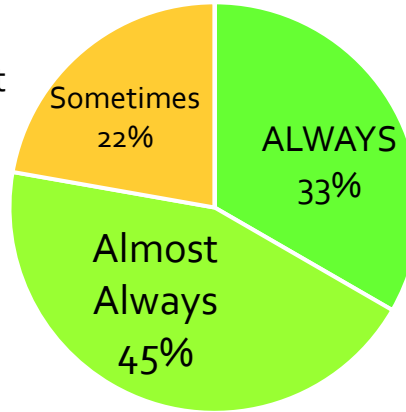
LEARNING NEW SKILLS-

Pre Test (figure 1)



Post Test

(f1)

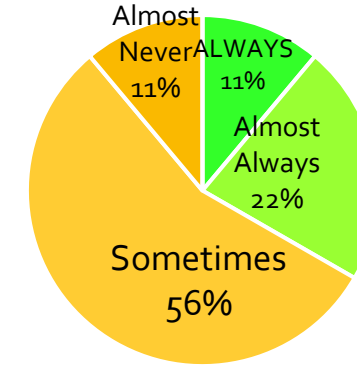


CST:

- All families described improvements in their child's development regarding engagement, communication, management of challenging behavior and learning new skills.(Figure 1-2)
- Bossc 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.

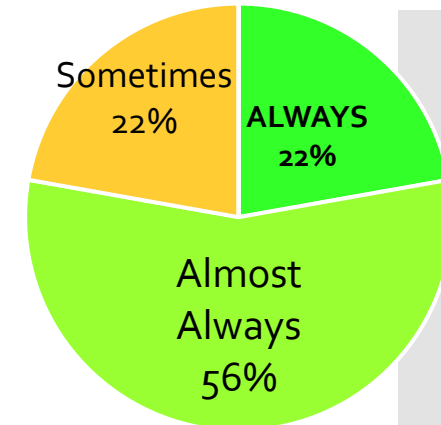
CHALLENGING BEHAVIOUR –

Pre Test (figure 2)

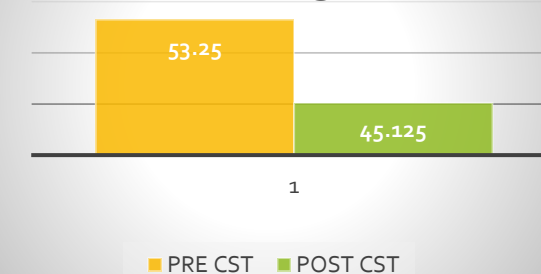


Post Test

(f2)



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.

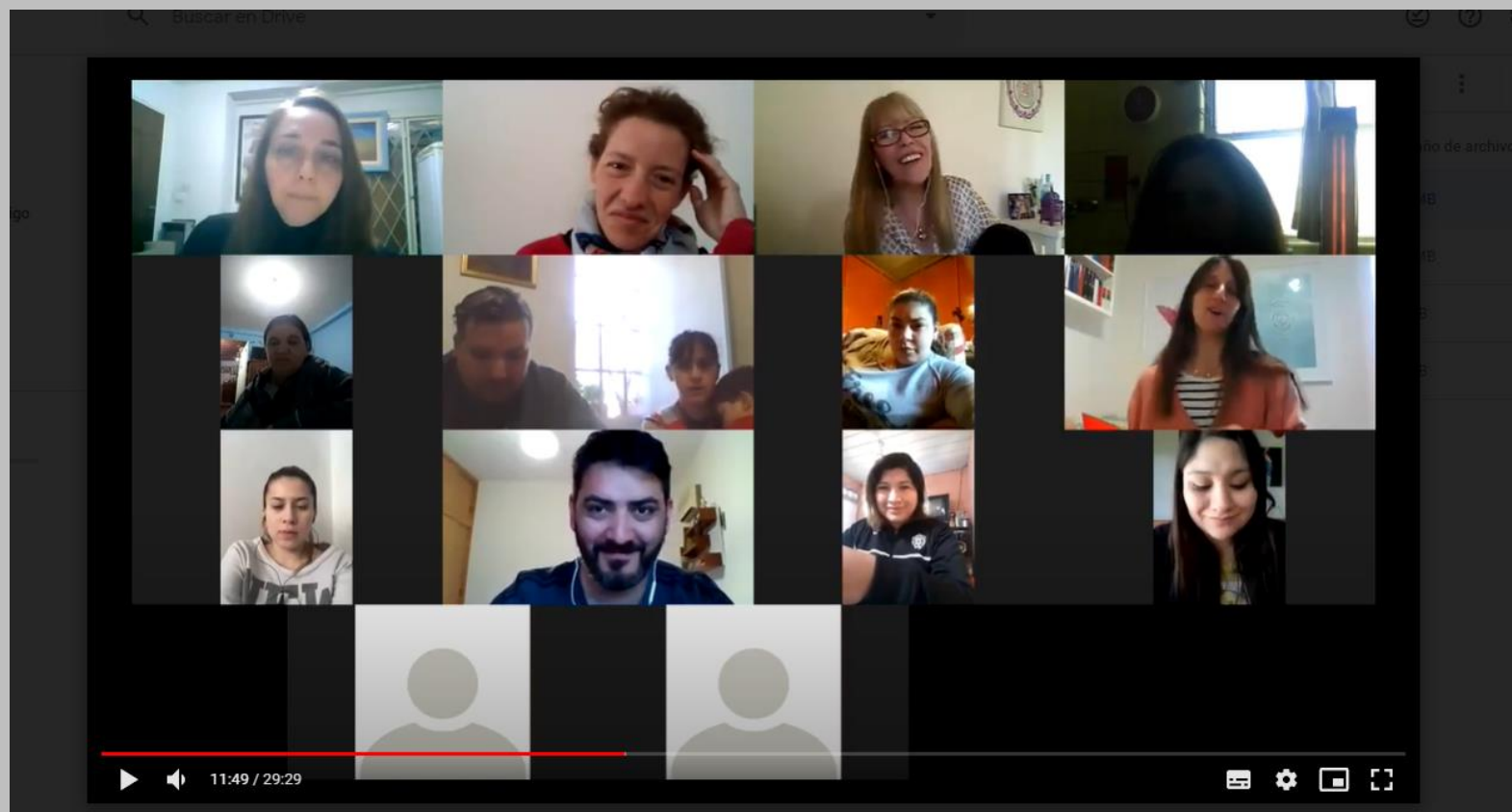
CST:

- Most families in our community have difficulties with the internet connection. No access o 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.

THANKYOU!!



WHO Caregiver Skills Training Program:

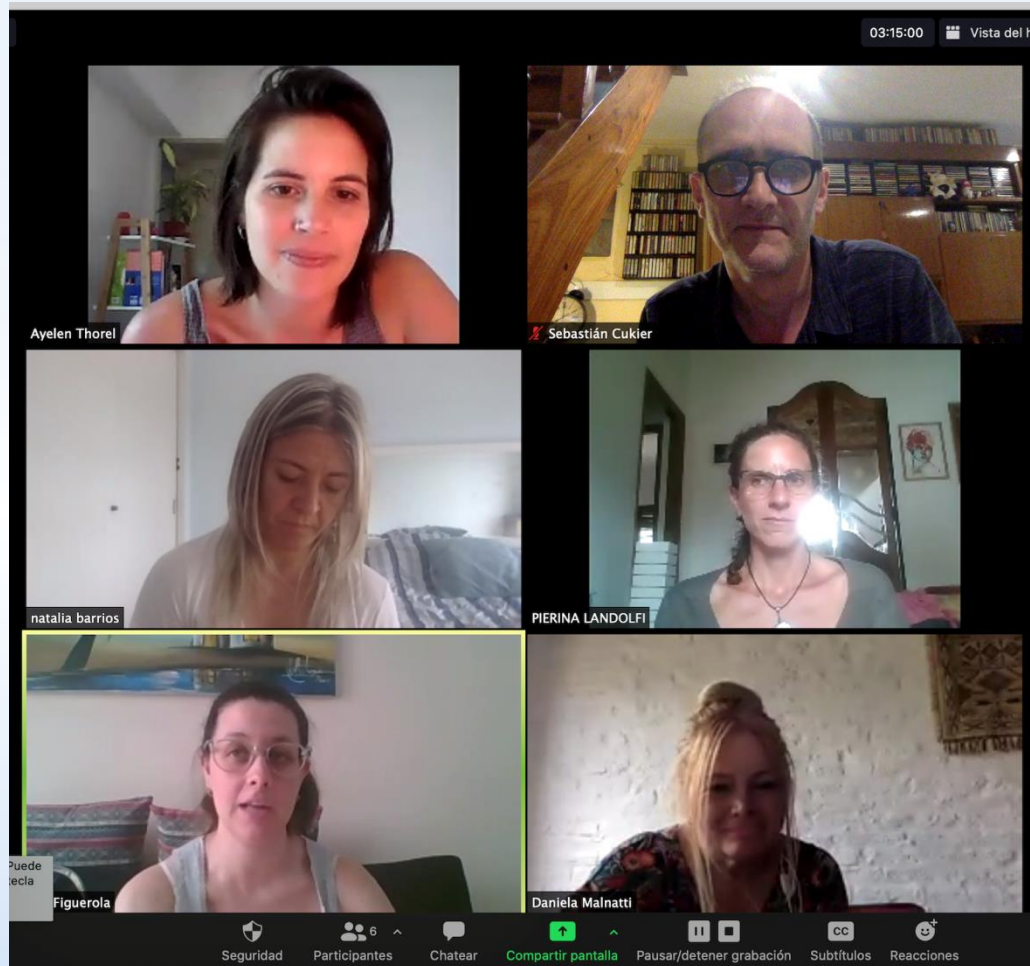
Advocacy Leadership Network 4th Biennial Conference
April 27 - 28, 2021

Panel Discussion: Adapting CST for Telehealth in Argentina
Presented by: Pierina Landolfi & Sebastian Cukier



Project characteristics

Virtual/ remote *facilitator training*



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*

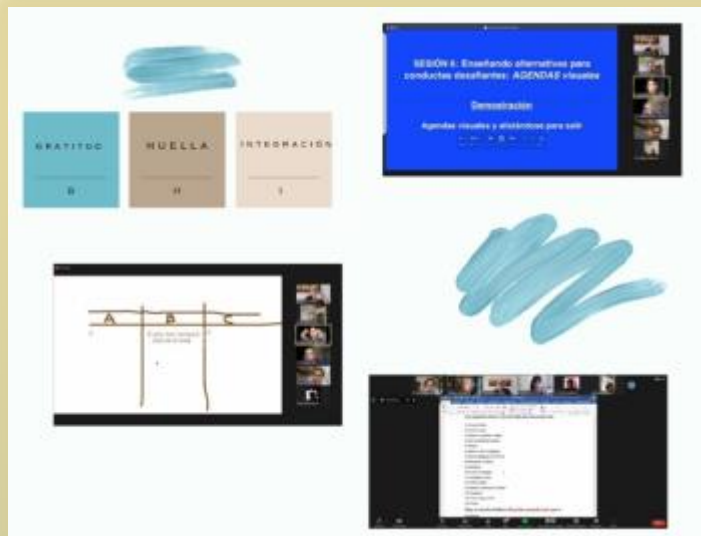
- Platform used:
 - **Zoom:** instructions for caregivers & facilitators



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)



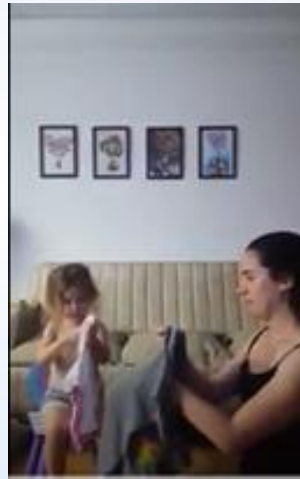
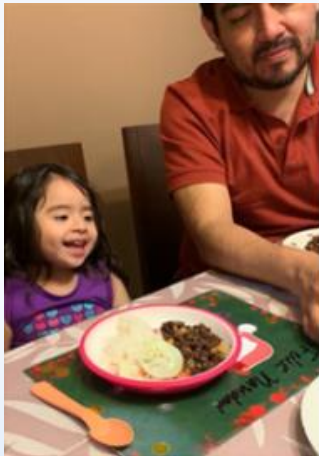
Minutes	
30 Minutes	Discussion with caregiver/review of information: Visit 1: Take history on child's problem and contact with support services and assess the child's development, behaviour and functioning Visit 2 and 3: Review key messages, strategies and home practice and plan the guided practice
15 Minutes	Observe caregiver interacting with child and video record for 10 minutes Comment on what the caregiver does well and provide suggestions
15 Minutes	Interact with the child and demonstrate strategies Visit 2 and 3: Demonstrate and coach the caregiver on those strategies
10 Minutes	Discussion with caregiver about goals: Visit 1: Identify expectations and goals Visit 2 and 3: Discuss and review the practice session and goals
10 Minutes	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*):

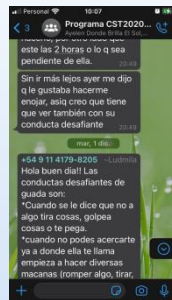
- HV:

- ✧ 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



Peer Practice in breakrooms

Pre-recorded video demonstrations



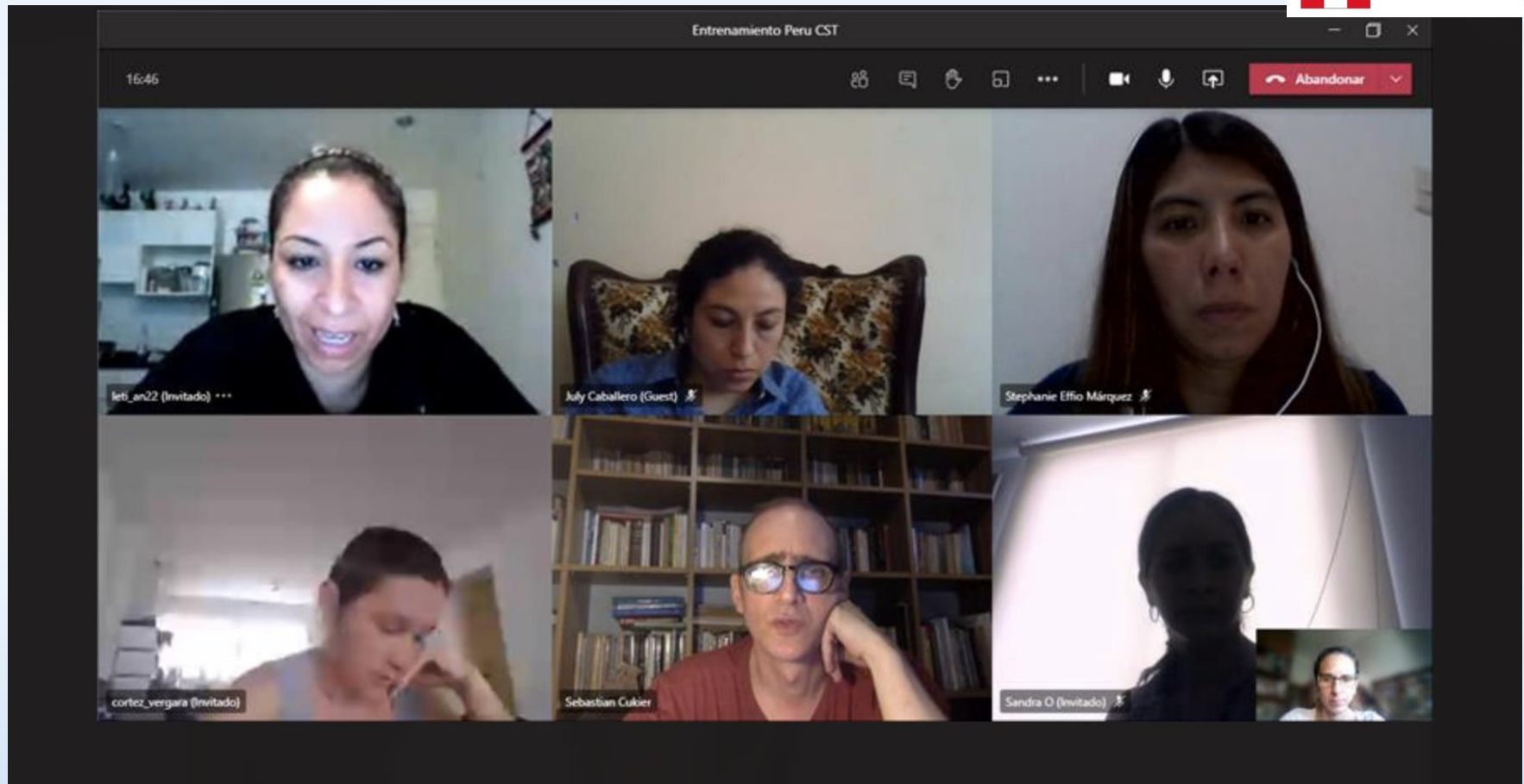
Facilitator Training online Scheduling:



- **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:

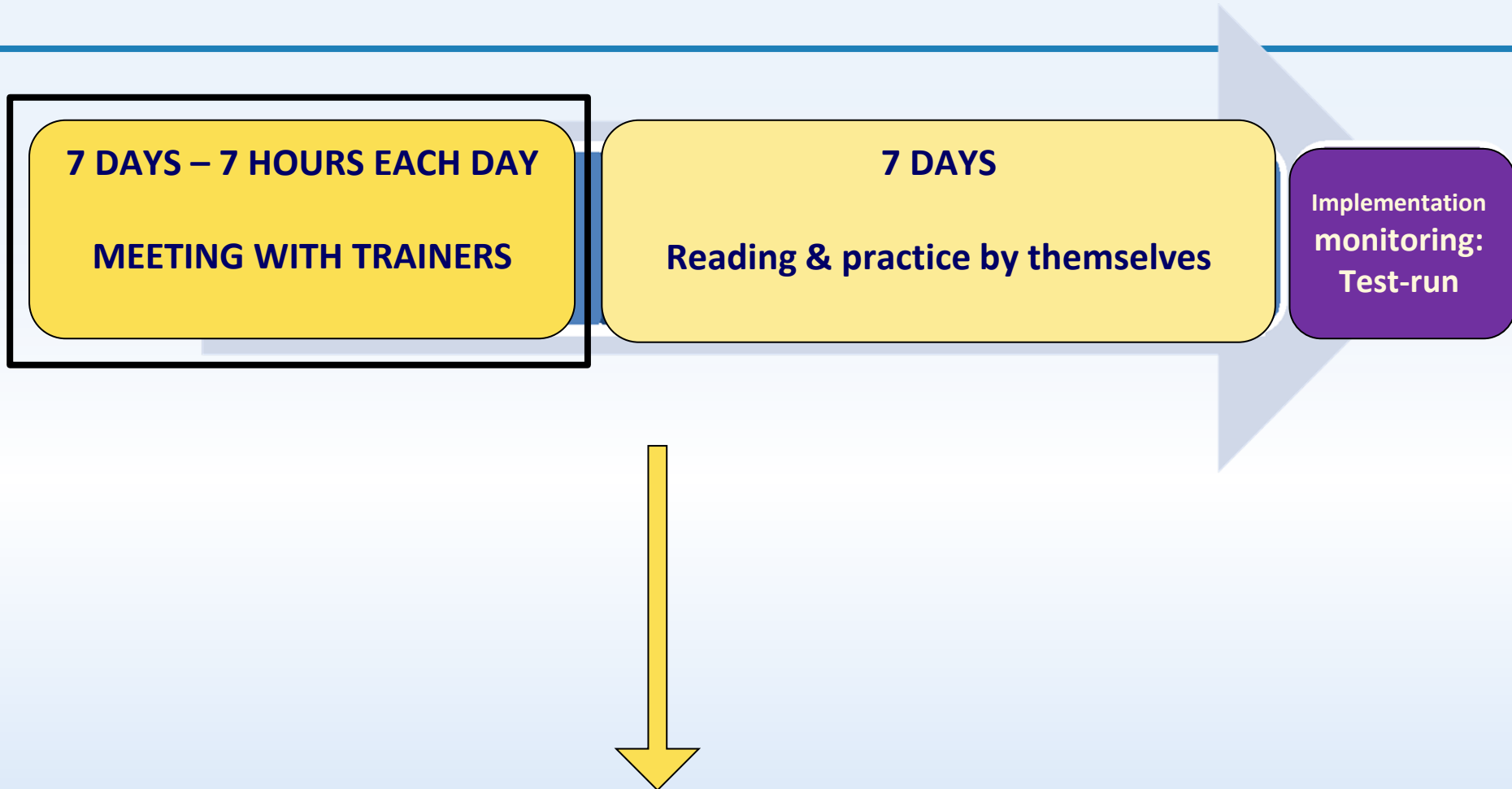
- Adaptation of original training presentations to virtual
 - Addition of more visual material (e.g. photos of manuals)
- Video - recording of live demonstrations for the sessions

- Format (training pre-program):

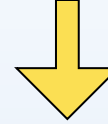
- Review of manual content
- Active learning: trainees presentations of activities, tips & key messages from sessions as if to caregivers (recordings and live)
- Videos of children to practice function of behaviors (sessions 6&7)
- Practice of self care activities
- Goal setting practice using vignettes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



MT Training online Scheduling:



MT Training online Scheduling:



Training Day 1:	F	<p>9-11am: Presentation of schedule of activities. General presentation of CST. Review main points sessions 1A - 1B</p> <p>11:30-1pm: Review key points from session 2 and session 3</p> <p>2pm-3:30PM: Review session 4 key points</p> <p>3:30 – 6: Preparation of presentations of selected parts of sessions 1-4 to present on Monday</p>
Saturday	S	Reading & Practice by themselves
Sunday	S	
Training Day 2:	M	<p>9-11am: Presentation from trainees 1 and 2: parts of sessions 1-4 as if they were in front of caregivers</p> <p>11:30-1pm: Presentation from trainees 3 and 4: parts of sessions 1-4 as if they were in front of the caregivers</p> <p>2-3:30PM: Review home visit guide 1 and goal-setting</p> <p>3:30 – 5: Preparation for the 1st practice with child and family</p>
Tuesday free	T	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
Training Day 3:	W	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:	T	<p>9-11am: Review key points from session 5-6</p> <p>11:30-1pm: Review session points 7-8</p> <p>2pm-3:30PM: Review of Home Visit Guide 2 and 3. Goal-setting practice</p> <p>3:30 – 6: Preparation of presentations of selected parts of sessions 5-8 to present on Monday</p>



MT Training online Scheduling:



Friday free	F	Reading & Practice by themselves
Saturday	S	
Sunday	S	
Training Day 5:	M	<p>9-11am: presentation from trainees 1 & 2: parts of sessions 5-9 as if in front of caregivers</p> <p>11:30-1pm: presentation of MTs in formation 3 and 4 parts of sessions 5-9 as if they were in front of the caregivers</p> <p>2-3:30PM: Review home visit guide 1-3 and goal-setting</p> <p>3:30 – 5: preparation for the 2nd practice with child and family</p>
Tuesday free	T	<p>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</p>
Training Day 6:	W	<p>9 to 16hs: review of videos of practice with children. Receiving feedback from other trainees and trainers Using adult-child interaction forms</p>
Training Day 7:	T	<p>9-11 am: Practice of goal-setting: live with videos and vignettes</p> <p>11:30-1pm: measurements, scales and facilitator fidelity</p> <p>2-5PM: Q&A and preparation for remote monitoring</p>

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-phone & 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

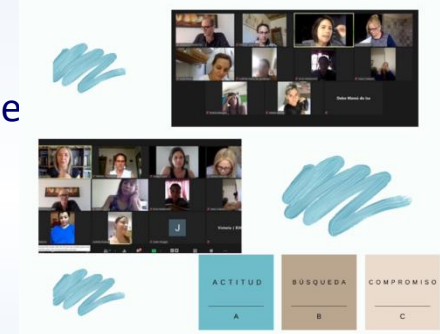
● Implementation

- Peer and groups practices were mainly **planning and conversation** (instead of role playing / live practice of strategies)
- **Group sessions**: Presence of **children** were sometimes distractive 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 clench 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!

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

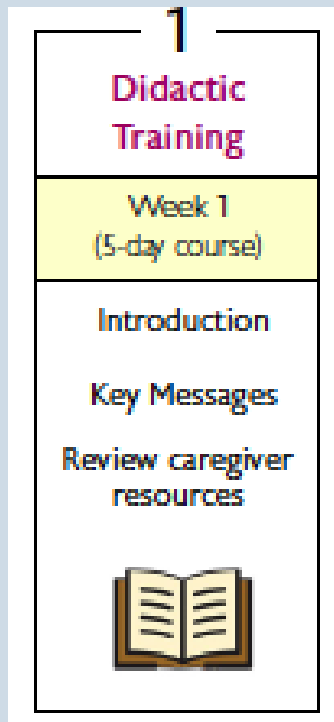
April 27th, 2021

Autism Speaks Advocacy Leadership Network

CANADIAN ADAPTATION

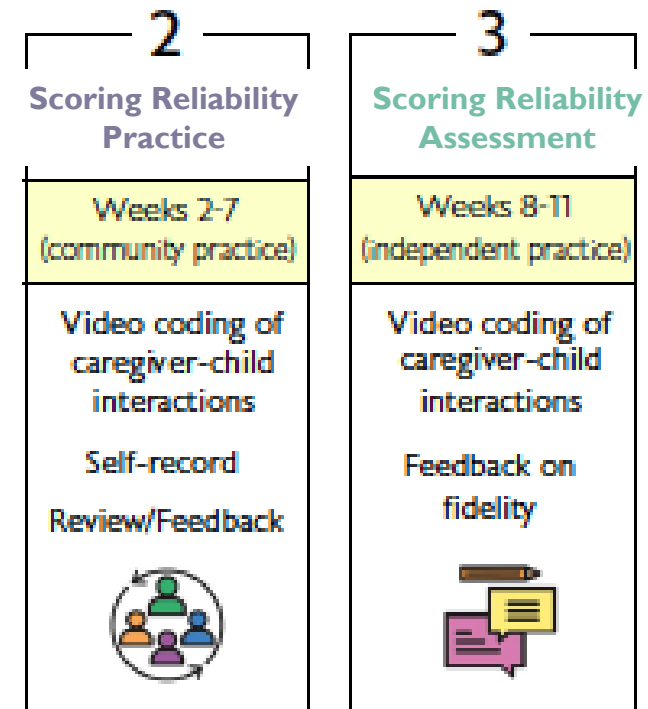
PRE-PANDEMIC

WHO/AS original training model:



DURING PANDEMIC

Novel remote training:



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

Scoring Reliability



Original training focus:

- MTs are rated on their ability to implement CST skills directly to children

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!



Réseau pour transformer
les soins en autisme

Transforming Autism
Care Consortium



Public Health
Agency of Canada

Agence de la santé
publique du Canada



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 Manger, JCAC Family Support Team

April 27, 2021

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同心同步同進 RIDING HIGH TOGETHER

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教育局
Education Bureau



香港大學社會科學學院



香港聖公會福利協會有限公司
HONG KONG SHENG KUNG HUI WELFARE COUNCIL LIMITED



東華三院
Tung Wah Group of Hospitals

Milestones of WHO-CST in Hong Kong



Online Mode

Certain Adaptations had been introduced to ensure the team delivered the skills and strategies effectively

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




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.

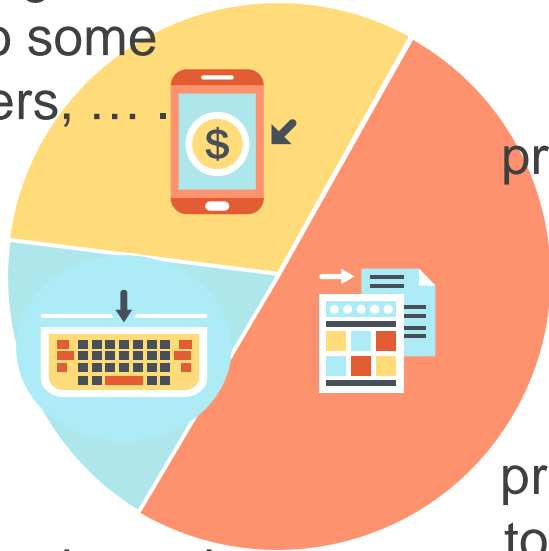
Methodology

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.

	 E-Learning	 Video-Conferencing	 Adapted In-Person
Features	<ul style="list-style-type: none">•100% Self-learning•Flow adapted from CST online module•No facilitator intervention	<ul style="list-style-type: none">•100% via Zoom for both home visits & sessions	<ul style="list-style-type: none">•As traditional CST•But Home visits are taken place at facility setting
Learnings	<ul style="list-style-type: none">•More flexible•Benefit working parents & those FTMs who take care children in day time	<ul style="list-style-type: none">•Flexible for distant families•Flexible for busy caregivers or working parents•Less travelling	<ul style="list-style-type: none">•As is possible, & children play with a stranger can be observed•Live coaching•Rapport building•Experiential learning•Peer supports•More focused
Challenge	<ul style="list-style-type: none">•Lack of learning motivation•Not fully acquire skills w/o facilitation•Lacking peer supports•Well-being is doubted	<ul style="list-style-type: none">•Availability & instability of hardware & internet•Unable to give advice on environment•Lack of Joint engagement•As is impossible	<ul style="list-style-type: none">•Parents hesitate to join in a group under pandemic•Distant parents not join

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

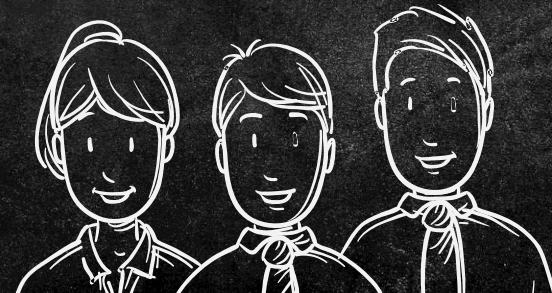
- Human interactions with facilitators & peers are indispensable, e.g. mingling time at tea breaks & before or after the workshops
- They valued the time in the classroom that they could completely enjoy and focus in the workshops
- They all valued the in-person coaching and demo that they could grasp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

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

Methodology

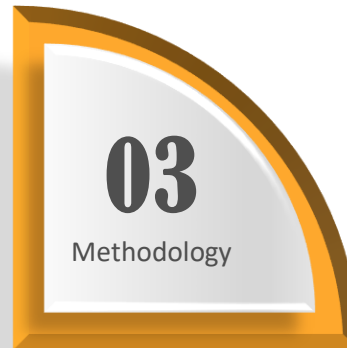
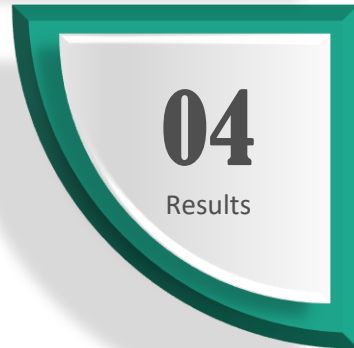


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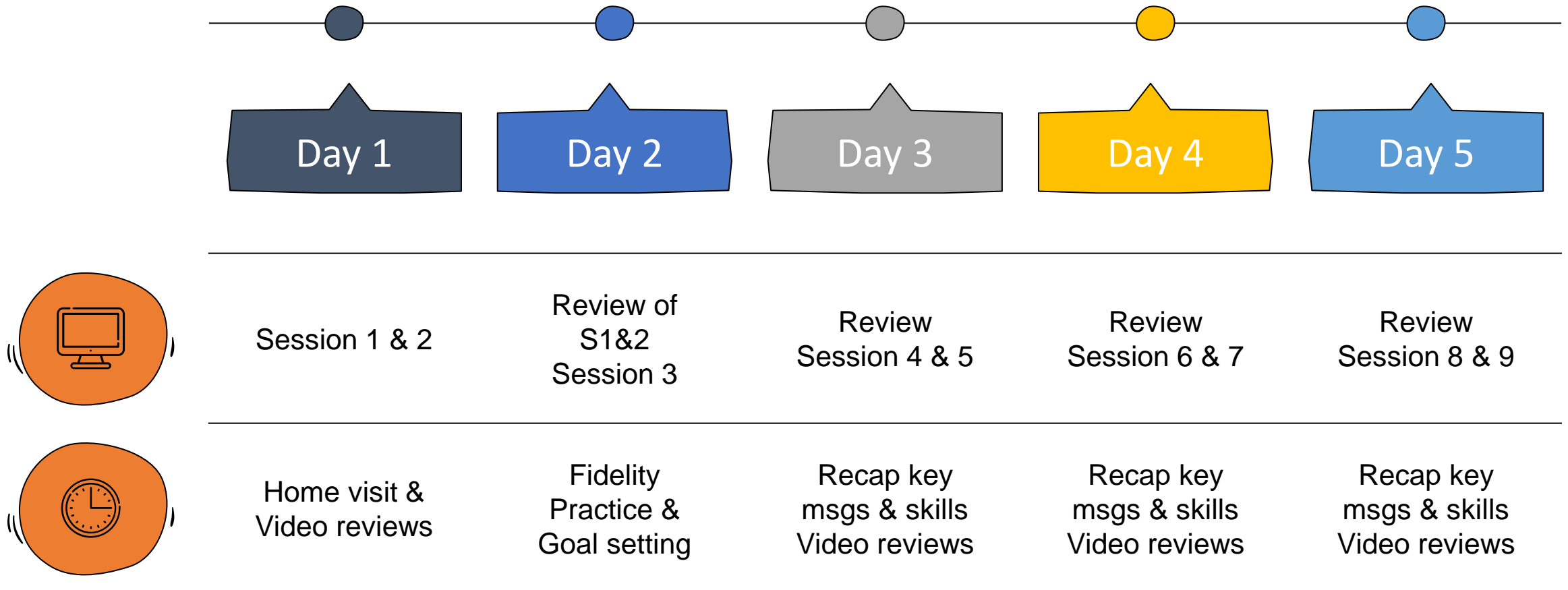
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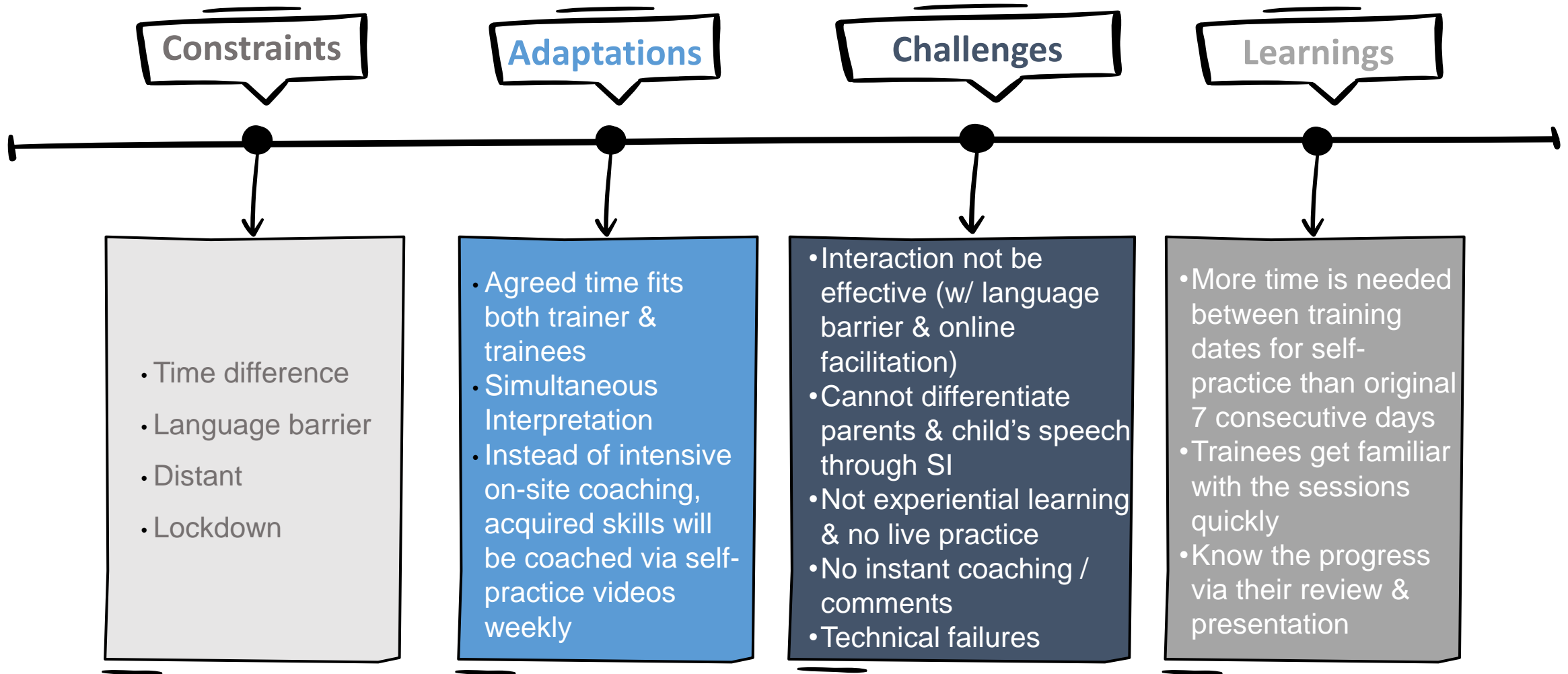


ToT Bulgaria Schedule (Phase 1 – Didactic Training)



ToT Bulgaria Learnings & Challenges

(Phase 1 – Didactic Training)

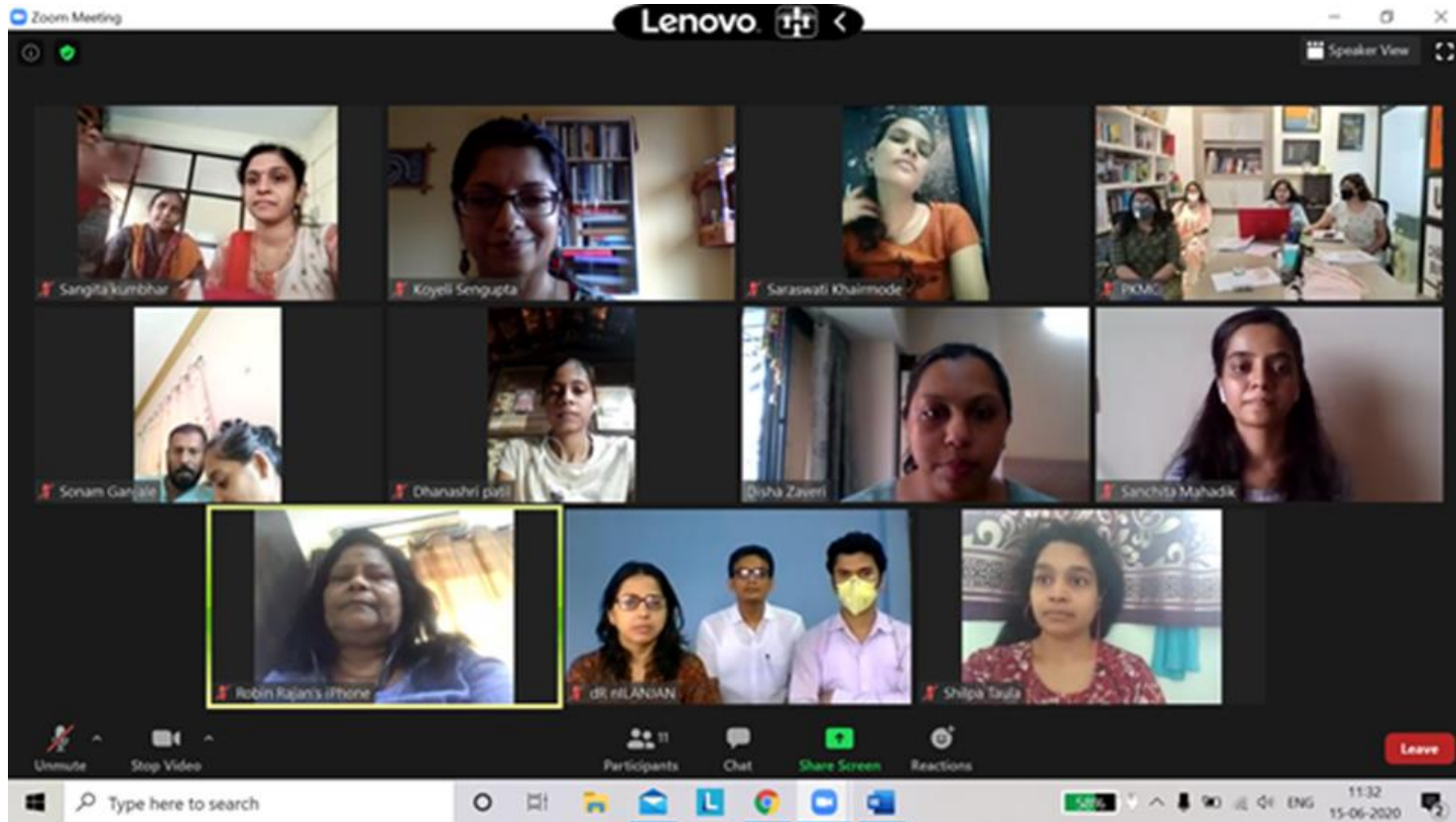




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Dr Janet Lau at drjanet@hku.hk or

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Koyeli Sengupta
Disha Sangvi
Sanchita Mahadik,
Mumbai, India.

Virtual Training of Facilitators & Delivery of WHO-CST to Caregivers: *Experiences from a LMIC*

4 sites, 11 Facilitators, 40 Caregivers, 3 Languages

Presumptions versus Reality

PRESUMPTIONS

Internet penetration high- most households have smart-phones

Caregivers will be willing and ready for online services

What works for one organization works for all

No home-based visits possible- center-based coaching in lieu

REALITY

Connectivity issues

Resistance and scepticism

Contexts different

Parents refused to bring children to center

Adaptations across a Continuum

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



and



**Pushpa Khanna
Memorial Centre**
CELEBRATING DIVERSE ABILITIES
A Rehabilitation Centre for Children with Special Needs

Mumbai Kanpur

Bring an interactive online session for the parents / caregivers

"HOW TO MANAGE SPECIAL NEED CHILDREN DURING LOCKDOWN"

Program Highlights :

1. Intensive session on how to work with your kids at home
2. Practical tips to manage your child at home
3. Information about WHO Caregiver Skill Training Program

Monday,
10th August
2020

3:00 to
4:00 pm
on **zoom**

Speaker :

Sanchita Mahadik,
Senior Autism Intervention Therapist, Ummeed Mumbai


Disha Zaveri,
Senior Autism Intervention Therapist, Ummeed Mumbai

For more details contact
Pushpa Khanna Memorial Centre
3A/161, Azad Nagar, Kanpur • Mob.: 7311133337, 8318899024

🌐 www.pkmcnlk.org 📧 : pkmcdisa@gmail.com



**Pushpa Khanna
Memorial Centre**
CELEBRATING DIVERSE ABILITIES
A Rehabilitation Centre for Children with Special Needs



WHO-CAREGIVER SKILLS TRAINING (CST)

PROGRAM SUPPORTED BY AUTISM SPEAKS

In collaboration with Ummeed Child Development Center, Mumbai
(A training Program for Caregivers / Parents of children aged 2 to 9 yrs.)

There are more than **50 million** children affected by **Developmental Disability**. Despite having such a huge number, it has been seen that not much is done for the same. The reasons being :

- Lack of awareness
- Waiting for the child to learn or acquire skills eventually
- Not accepting of the differences in the child
- Lack of therapists and professionals and designated system in the society

CST would work on the areas like

- Communication
- Play
- Behaviour
- Independence

KEY HIGHLIGHTS OF THE PROGRAM

A 3 month program of 2:30 hours, CST would conduct 9 group sessions and 3 individual sessions. Study material to help and inform all the members of the family. A training to help you help your child with play, communication, independence and behaviour.

For more details contact
Pushpa Khanna Memorial Centre
3A/161, Azad Nagar, Kanpur
Mob.: 7311133337, 8318899024

CST PROGRAM
Every Friday,
4:00 pm for
9 weeks
starting from the last
week of August 2020

🌐 www.pkmcnlk.org

📧 : pkmcdisa@gmail.com

Practice Video by Facilitators used during training

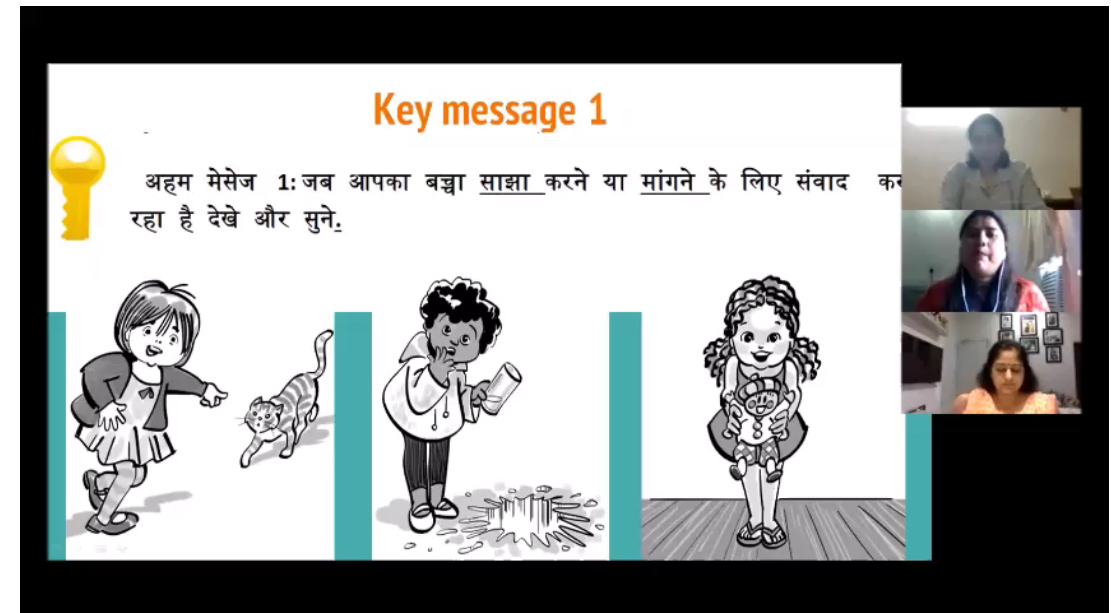


Virtual Delivery to Care-Givers

FACILITATOR COACHING A CAREGIVER ONLINE

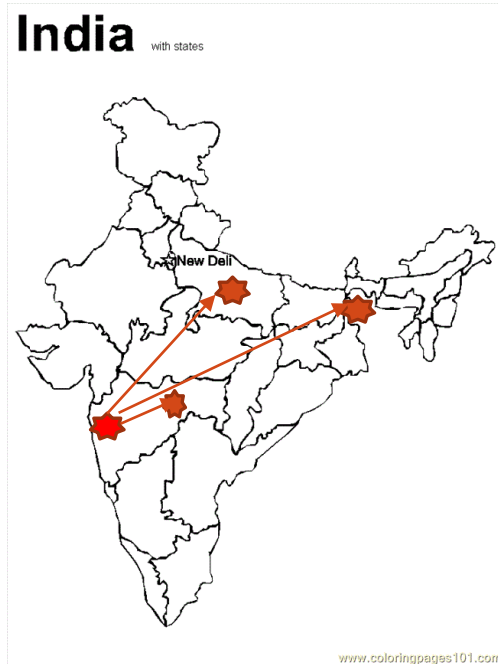


FACILITATOR CONDUCTING ONLINE GROUP SESSION



Virtual Training & Delivery to Care-Givers

ADVANTAGES



- Wider geographic reach
- Saved travel and time
- Increased numbers

DISADVANTAGES

- Logistically- Required more organisation
- Supporting acquisition of fidelity harder
- Online delivery from Facilitator to Families still a challenge
- Evaluation and Data Collection challenging



Thank You

TELEHEALTH DELIVERY OF THE CST PROGRAM IN NEW YORK CITY

CST-NYC Project Team

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Jennifer D. Lau, MPH

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Charles B. Wang Community Health Center, New York, NY

April 27, 2021



CHARLES B. WANG
COMMUNITY HEALTH CENTER
王嘉廉社區醫療中心

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.



CHARLES B. WANG
COMMUNITY HEALTH CENTER
王嘉廉社區醫療中心

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:
 - Share screen of Participant Booklets or power points developed by trainer
 - Videos from CBWCHC staff and Autism Speaks
 - 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

CHALLENGES

- Not enough MT live practice videos
- Have not assessed how effective a trainer is at coaching a caregiver

OPPORTUNITIES/ADVANTAGES

- Remote training of trainers allowed more flexibility
- Create resources and scripts to promote coaching skills



Lessons Learned

Group Sessions & Home Visits

CHALLENGES

- Rapport & building relationship with caregiver was not the same as in-person.
- Limited camera view of caregiver-child interaction during home visits. Caregiver had trouble adjusting camera while interacting with child

OPPORTUNITIES/ADVANTAGES

- Master Trainers/Facilitators coached via online; caregivers became empowered to manage their child's challenging behavior.
- Pre-visit planning for home visits include instructions for caregivers how to set up the environment, including positioning of camera for optimum viewing.



Acknowledgements

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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

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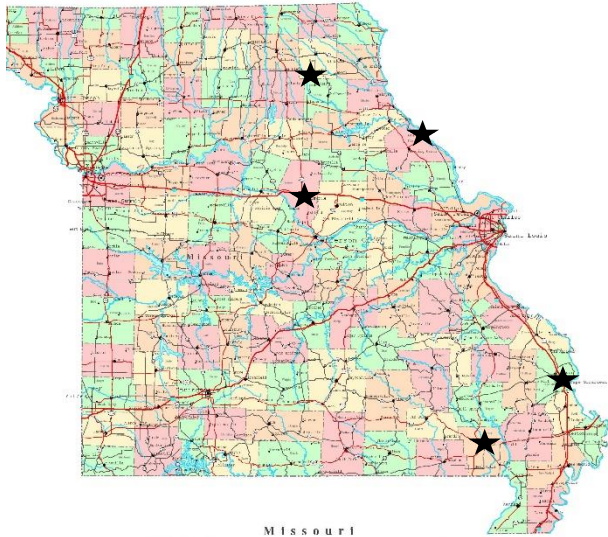
Contact: ptsikat@cbwchc.org



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王嘉廉社區醫療中心

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

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 - Missy Killen
 - Rachel Masters
 - Jordan Starr
 - Megan Tregnago
- Facilitators:
 - Carolyn Allen
 - Cindy Eubanks
 - Kayleigh Fogle
 - Courtney Luebbering

- Pam Dixon, Autism Speaks
- Cecilia Montiel-Nava, UTRGV
- Jeanne Marshall, ESMW
- Kristin Sohl, ECHO Autism
- Alicia Curran, ECHO Autism
- Melissa Mahurin, ECHO Autism

