

Caregiver skills training for families of children with developmental delays or disabilities

Introduction



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Preface

This is the first part of the caregiver skills training package for families of children with developmental delays or disabilities. This five-part course package provides guidance – presented in text form as well as in a set of illustrated parenting strategies – to increase caregivers' ability to promote their children's development and well-being through play and home routines.

Caregivers play a key role in promoting nurturing environments. Psychosocial interventions and parent-mediated interventions can improve the developmental trajectories, functioning and quality of life for children with developmental disabilities. Yet most children with such conditions and their caregivers do not have access to such care.

The caregiver skills training package is designed to be delivered by trained non-specialists. The training adopts a family-centred approach to help care providers support caregivers in defining specific training goals for each family. The training package is for the caregivers of children aged 2–9 years with developmental delays or disabilities and aims to provide them with skills that they can use at home to improve their child's engagement in activities and communication, and to promote positive behaviour and skills for daily living. The course is designed to be integrated within a network of community-based health and social services for children with developmental disabilities and their families. It should be delivered as part of the “stepped care” approach to child health whereby the most effective, yet least resource-intensive, treatment is delivered before “stepping up” to more specialist services.

During field-testing the caregiver skills training package was found to support the feasibility, acceptability and relevance of this training package as an intervention for families while helping to improve the caregivers' parenting skills and supporting their well-being.

We hope that once this training package has been adapted to fit the local context in countries across the world, it will reach many more families and help caregivers and their children with developmental disabilities to enjoy optimal well-being, relationships and quality of life.

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Director

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Acknowledgements

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Background

The five-part *Caregiver skills training for families of children with developmental delays or disabilities* (CST) package was developed to facilitate access to parenting support for caregivers of children with developmental delays or disabilities. The development of the training package materials was based on evidence on parenting and parent-mediated interventions for children with developmental disabilities and, in particular, on evidence on strategies targeting the caregivers of children with delays or impairment in social and communication domains. The training package was developed in consultation with – and informed by feedback from – international experts, service providers, caregivers and family advocates, with extensive field-testing across regions.

Who is the caregiver skills training package for?

The intended audience is caregivers of children aged 2–9 years with developmental delays or disabilities, with a specific focus on caregivers of children with delays or impairments in social and communication domains – although the age range can be adjusted slightly, depending on the needs of the setting. Importantly, a diagnosis is not required to access the training course. The lack of a diagnostic requirement means that the training package can be provided to families once a developmental delay has been identified. This may reduce other potential barriers – including the potential reluctance of caregivers to identify themselves as the parents of children with developmental disabilities and experiences of stigma from attending a course labelled as being exclusively for caregivers of children with developmental conditions. The expectation is that primary health-care providers, community health workers, educational providers or specialists will recommend the caregiver skills training course to families.

Format of the caregiver skills training package

The course is designed to be delivered in nine core group sessions for caregivers and three home visits. The group sessions can be provided at a health facility, school or other community-based facility. Each group session lasts 2.5 to 3 hours, including a break. Sessions can be scheduled either weekly or every two weeks depending on what is most feasible for caregivers in the local context. Home visits are scheduled at the beginning, middle and end of the course – i.e. before group session 1, between sessions 5 and 6, and after the final group session. Home visits are typically conducted in caregivers' homes and last 1.5 to 2 hours each, although they can be offered in a community setting if home visits are not feasible due to geographical distance, safety concerns or other challenges. Typically, two caregivers per household are invited to participate in the group sessions. The core 9-session course has also been adapted for virtual delivery through videoconferencing for group sessions and home visits.

Additional group sessions and home visits can be offered to allow more time to acquire strategies related to caregiver well-being and strategies tailored to the needs of caregivers of children who have little or no spoken language.

Caregiver skills training implementation tools

In addition to this introduction, there are four subsequent parts of the caregiver skills training package while two additional parts are being developed:

- Adaptation and implementation guide;
- Facilitators' guide: group sessions 1–9;
- Participants' guide: group sessions 1–9;
- Home visit guide for facilitators;
- Caregivers of children who have little or no spoken language: facilitators and participants' guides (forthcoming);
- Caregiver well-being: facilitators' and participants' guides (forthcoming).

Group session structure and goals

A general group session structure should be followed for sessions 2 through 9, and includes:

- a brief wellness activity (calm breathing);
- review of key messages and tips from the previous session;
- discussion of home practice experiences;
- presentation of a caregiver story that is illustrated in the participant guide (caregiver stories are used to deliver educational messages, provide examples of how the strategies can be implemented at home and explore common caregiver experiences), followed by guided questions for learning and discussion;
- group teaching and activities, including presentation of key messages and tips for the session;
- a break;
- facilitator demonstration of skills and strategies using role-play, followed by guided questions for learning and group discussion;
- planning for home practice and practice of skills through role-plays with facilitators, coaching and feedback;
- review of the session and closing.

This caregiver skills training course is a caregiver-mediated intervention that integrates these strategies into everyday life. Group session goals include building the caregivers' knowledge and skills while supporting them in practising the caregiver skills training strategies at home with their child. Home practice between group sessions is considered essential and caregivers are asked to practise the skills with their child daily.

Home visit structure and goals

Goals of the home visits include building rapport with the family, including those family members who do not attend group sessions, learning about the child's developmental competencies and behaviour, and the home environment; helping the caregiver to set target goals for their child; coaching the caregiver to do the strategies learned in group sessions; troubleshooting caregiver challenges; promoting attendance at group sessions; and identifying any additional needs of the family and referring to additional services as needed.

Each home visit has specific tasks and goals that are detailed in the home visit facilitation guide.

The general home visit structure includes:

- Greeting the family and child.
- Discussing with the caregiver issues that are specific to that visit. Visit 1 includes taking a history of the family's contact with support services and assessment of the child's communication, behaviour and functioning. Visits 2 and 3 include review of key message strategies and home practice.
- Observing the caregiver interacting with the child and the interaction between the facilitator and the child.
- Demonstration of the caregiver skills training skills and strategies (tips) by the facilitator, and coaching of the caregiver on those strategies.
- Goal-setting that is based on observation and interview with the caregiver. Goals are identified in Visit 1 and discussed and reviewed in Visit 2 and Visit 3.
- Planning for the future. Visits 1 and 2 include inviting the family to the next session and discussing possible barriers and solutions, and Visit 3 includes creating a plan for ongoing practice of caregiver skills training strategies.

Each home visit includes an assessment of the families' needs. Facilitators are to be aware of signs that additional supports are needed – including child health or caregiver health, mental health challenges, potential child maltreatment or material deprivation.

Content of the caregiver skills training package

The course's theoretical foundation and methodology are informed by principles of applied behavior analysis, developmental science, social communication interventions, positive parenting and self-care methods. Specifically, the caregiver skills training package is based on naturalistic-developmental-behavioural approaches for promoting shared engagement and communication including JASPER (Joint Attention Symbolic Play Engagement Regulation) and PRT (Pivotal Response Treatment); positive parenting approaches for promoting positive child behaviour and management of challenging behaviour; problem solving and promotion of caregiver well-being.¹

The first two group sessions focus on getting children engaged in activities (both daily home activities and play) and keeping them engaged. Group session 3 focuses on the development of play and home routines as a means of encouraging engagement, communication, positive behaviour and skills for daily living. Sessions 4 and 5 focus on recognizing a child's communication abilities and creating opportunities to promote communication. Group session 6 is focused on teaching skills for everyday living in small steps using different levels of help. Sessions 7 and 8 focus on promoting positive behaviour and reducing challenging behaviours. Session 9 focuses on caregiver well-being, problem-solving and setting goals for ongoing practice.

¹ For further details, see the following:

Kasari C, Lawton K, Shih W, Barker TV, Landa R, Lord C et al. (). Caregiver-mediated intervention for low-resourced preschoolers with autism: an RCT. *Pediatrics*. 2014;134:e72–e79.

Kaale A, Smith L, Sponheim E. A randomized controlled trial of preschool-based joint attention intervention for children with autism. *J Child Psychol Psychiatry*. 2012;53:97–105.

Kasari C, Gulsrud A, Paparella T, Hellemann G, Berry K. Randomized comparative efficacy study of parent-mediated interventions for toddlers with autism. *J Consult Clin Psychol*. 2015;83:554–63.

Educational methods

The caregiver skills training course draws on educational methods that are relevant to adult learning, including personal goal-setting, active learning through questions (guided questions for learning) and discussions. The expertise and experiences of participants are brought into group sessions through discussions and when home practice is discussed; participants have the opportunity to benefit from the ideas, experiences and suggestions of others. Active learning is promoted by teaching strategies through modelling (facilitator demonstration) and by having participants practise in the session with feedback and coaching from facilitators. Key to the facilitation of the caregiver skills training course is the creation of a safe and positive learning environment in which participants feel comfortable asking and answering questions, and sharing their ideas and experiences with other caregivers.

Who can provide the caregiver skills training course?

Facilitators should be trained and supervised non-specialists (community health workers, social service workers, nurses, early childhood education facilitators, teachers, experienced caregivers etc.). The selection of facilitators should take account of the potential for sustainability and scalability in the local context. Facilitators must have adequate time – ideally within their regular work schedules – to provide the caregiver skills training group sessions and home visits. Travel time should also be taken into account. Facilitators will preferably have completed high school education or equivalent, while experience of providing care for children with developmental disabilities and facilitating groups will be an asset. Facilitators should be approachable and capable of working well with other adults maintaining a supportive environment in group sessions and providing feedback and coaching in a supportive manner. Facilitators will need to be equipped with training on caregiver skills training skills and strategies both for the facilitation of group sessions and for home visits. Facilitators should receive continuing support and supervision from a trained supervisor.

Who can train and supervise the facilitators?

The facilitators should be trained and supervised by local master trainers and supervisors. Master trainers and supervisors may be non-specialist primary health-care providers, such as general physicians or nurses, or specialized health-care providers such as paediatricians, psychiatrists, psychologists or mental health nurses who have been trained to deliver the caregiver skills training package. Additional selection criteria for master trainers and supervisors include a suggested minimum education of formal training in child development or mental health training at the post-secondary level or equivalent. Clinical or significant past personal experience with children with developmental disabilities is important. Supervisors should be trained in the use of the caregiver skills training package and should have personal experience of delivering group sessions and home visits. Training and supervisory experience is an asset.

Facilitators' training

A suggested strategy for the training of facilitators is as follows:

- A three-day classroom-based training course (Initial course, part 1) provided by local master trainers and covering key content and strategies for group sessions 1 to 5, group facilitation and home visit skills.
- Field experience involving joint delivery of group sessions 1 to 5 and home visits 1 and 2 to a group of caregiver participants with a master trainer or supervisor. Scheduled sessions for trainers for debriefing and guidance with master trainers or supervisors after each group session and home visit (20–30 minutes each).
- A second three-day classroom-based training course (initial course, part 2) provided by local master trainers, giving an overview of key content and strategies for group sessions 6 to 9, group facilitation and home visit skills.
- Further field experience provided by joint delivery of group sessions 6 to 9 and home visit 3 to a group of caregiver participants with a master trainer or supervisor, with scheduled debriefing and guidance after each group session and home visit.
- Further two-day training focuses on advanced skills, group facilitation, troubleshooting, problem-solving skills and coaching of caregivers.
- Additional practice, training or co-facilitation experience at the discretion of the master trainers or supervisors.
- More field experience to follow with the joint delivery of a full caregiver skills training course of nine core group sessions and three home visits to a group of caregiver participants with another facilitator trainee and with supervision sessions scheduled after each group session and home visit.
- Ongoing supervision involving the provision of the caregiver skills training course paired with another facilitator; this should include, at a minimum, a formal check after each home visit. Debrief with master trainers or supervisors after each group session is recommended, although this can be phased out over time as facilitators gain experience. Nevertheless, master trainers or supervisors should be available for questions or concerns.

Supervision

The supervision of facilitators is essential and should be provided at a minimum after each home visit. Supervision can be provided in person or online, and can be conducted in a group. Once there is an experienced group of facilitators, peer supervision can be implemented. However, a master trainer or supervisor should always be available for troubleshooting and guidance. One-on-one supervision (e.g. in response to a participant's urgent concern about a child) should also be available as needed as part of a group supervision model.

Supervision involves:

- discussion of the child's developmental competencies in terms of level of play, communication skills, behaviour and skills for daily living (aided by making a videorecording of the first home visit);
- determination of the child's target skills on the basis of her/his developmental competencies;
- the choice of suitable caregiver goals for the child;

- discussion of any additional family needs related to child health, caregiver mental health, suspected child maltreatment, etc;
- discussion of home visits, coaching, any difficulties experienced, or identified barriers to attendance;
- discussion of challenges concerning group dynamics;
- discussion of positive experiences and caregivers' successes with their children;
- role-playing on how to manage difficulties or practise skills (to improve facilitators' skills in group management, coaching etc.);
- ongoing evaluation of the facilitator's workload;
- attention to the facilitator's self-care.

How to use the facilitators' guides

Facilitators should have the manual with them in the sessions and should refer to it often in order to know what to do and to read the suggested questions, prompts or scripts (included *in italics*).

Practical things to consider

Number of facilitators

- The caregiver skills training course should be provided by facilitators working in pairs. Group sessions require two facilitators.
Home visits can be conducted by facilitators individually.

Number of caregivers per group

- Groups can range in size from 6 to 12 participants.
- Two caregivers from each family should be invited to participate.

How to manage the group sessions

The following are necessary skills for the management of the caregiver skills training group sessions.

Keeping to time without cutting short valuable group discussion

- It is helpful to remind participants about time schedules throughout the intervention.
- Break times can be used to return to the group discussions that you have needed to cut short.
- Sometimes you might decide that it is very important to continue with a group discussion and so you decide to shorten another section of the session (see the example below). If you decide to do this, think about how you can make up time to cover the topic you have skipped (e.g. ask the group to stay longer, ask the group to arrive earlier next time, make the breaks shorter etc.). Always talk with your supervisor about these decisions to make sure that you have not skipped important information.
 - For example, a discussion about how one participant is applying a strategy at home is going on for longer than expected. You decide to continue this discussion because you can see that other participants are also learning about the strategy and how they can apply it to their own practices.

Managing participants who speak a lot or very little in the group sessions

- Some participants may talk a lot in discussions in a way that interferes with others' participation. They may interrupt, talk over others or disagree with other participants' experiences or opinions. In this situation, facilitators should use their skills to manage these persons during the group sessions.
 - For example: *"Thank you (name). What you are saying is helpful, but we would also like to hear from others in the group. Would anyone else be willing to share their experience with the home practice?"*
 - If this difficulty persists, consider speaking to your supervisor.
- For very quiet participants, consider talking individually to participants to help them participate in the group.
 - For example: *"I have noticed you are very quiet in the group. Is there anything I can do to help you engage more in the discussions?"*

Managing group discussions that go off-topic or identifying unhelpful strategies or strategies outside of the caregiver skills training course

- Facilitators are advised to be firm when redirecting group discussions. Facilitators can make use of basic helping skills. For example: *"I can see this is an interesting discussion, but we have moved away from the focus of this session. Let's come back and we can discuss this topic during the break."*
 - For example: *"This strategy sounds like it was helpful for you, but we need now to continue with this session's activities. We will have an opportunity to discuss this more during the home visit/other group session."*

Responding to incorrect or partially correct answers

- Guided questions for learning are part of the group sessions. These are designed to help caregivers think about and discuss the material. Their purpose is not to test caregiver knowledge.
- It is important to respond to incorrect or partially correct answers in a supportive way that promotes a safe learning environment in which caregivers are comfortable taking risks, sharing their ideas and asking and answering questions.
 - For example (for an incorrect answer): *"Actually, the demonstration was supposed to illustrate [a specific caregiver skills training strategy]. Does that make sense?"*
 - For example (for a partially correct answer): *"Yes, and the caregiver in the demonstration used other strategies as well. Would someone else like to share another strategy they noticed?"*

Promoting attendance and reducing drop-out

- Facilitator should proactively identify barriers to attendance at the first home visit and use problem-solving.
- Facilitators are advised to speak with participants who are regularly missing sessions, who report not doing the home practice, who are regularly showing up late or leaving early etc. Facilitators should show curiosity, emphasize the effort they are already putting into the course and help them problem-solve if appropriate.
- If a participant drops out, they may need a different type of help or service. Facilitators are advised to discuss strategies to help participants who have dropped out with their supervisors.
- Facilitators should talk with your supervisor if they are concerned that a participant is disrupting the group.

Caregivers and children at risk of harm or experiencing harm

- During the course of home visits or group sessions, facilitators may become concerned about the well-being of a caregiver or child.
- Facilitators may discover that a participant is experiencing abuse (e.g. gender-based violence perpetrated by a partner) or has a mental health condition (see the home visit guide for details).
- Facilitators may learn that a child is being neglected or harmed by harsh physical punishment or is harming her/himself or being physically violent with other members of the family.
- Facilitators may learn about these things during a group session or home visit, or another caregiver could tell you that it is happening to someone in the group.
- If a facilitator learns from others that a caregiver or child is at risk or is being harmed, she/he should ask the participant privately about this.
- If a caregiver is fearful for her/his own or someone else's safety in the home, including their children, facilitators should contact their supervisors immediately so that appropriate action can be taken. This depends on the setting and the national laws but it could involve reporting abuse to the police, a specific protection agency or informal network or local authorities. It is important that facilitators inform the participant of the actions that they will take to keep the caregiver and/or others in the participant's home safe.
- Facilitators are advised to talk always to their supervisors about caregivers, children or other family members they are concerned about.

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