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

Adaptation and implementation guide
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Introduction

This adaptation and implementation guide is part of a package of materials for delivery of WHO’s Caregiver Skills Training for Families of Children with Developmental Delays or Disabilities (CST).

Background

This caregiver skills training package was developed to facilitate access to parenting skills and strategies for caregivers of children with developmental delays or disabilities.

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 and impairments in social and communication domains. However, a child does not need to have a diagnosis for the training package to be used, and the age range can be adjusted slightly depending on the needs of the setting.

Overview of the course structure

The caregiver skills training course is designed to be delivered in 9 group sessions and 3 home visits by trained and supervised non-specialist facilitators. Additional group sessions and home visits can be offered to allow more time for strategies on caregiver well-being and for strategies tailored to the needs of caregivers of children who have little or no spoken language.

The caregiver skills training materials include the following:

- Introduction;
- 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).

Adaptation

The caregiver skills training package has been carefully developed and informed by both clinicians and caregiver-mediated interventions implemented in high-income and low- and middle-income countries that have research evidence supporting their influence on children’s behaviour and caregivers’ skills. The package was informed by experiences in different regions and sociocultural contexts. Many issues are the same everywhere; however, there is a need to examine the unique characteristics of the local context carefully to ensure that the package reflects the needs of the course beneficiaries as well as possible.

Adaptation is the process of deciding on and producing the changes needed in the training strategies and training materials to fit a country’s circumstances.

Certain adaptations may be needed to make the package suitable for use in different cultures and contexts. There is evidence in psychotherapy that suggests that cultural adaptations improve the effectiveness of interventions. However, there is always a balance between maintaining fidelity to an evidence-based intervention versus ensuring cultural and contextual “fit”.


The goals of adaptation are to ensure that: 1) the content of the training package is comprehensible, culturally acceptable and relevant to local participants; 2) the package is responsive to the local socioeconomic, political and cultural context; and 3) the training course is delivered in a way that meets participants’ needs. The adaptation process should aim to maximize accessibility, feasibility and acceptability, and to reduce foreseeable barriers to participation.

In general, it is recommended that the core strategies and components of the training course should be maintained while minor changes to other components – such as names of characters in stories and demonstrations, certain illustrations and examples of everyday activities, toys and games – should be made to improve acceptability, comprehensibility and relevance of the package.

Adaptations can be made to two elements of the training course: the training materials (i.e. the content of the facilitators and participants’ guides) and the training process (e.g. the frequency and setting of group sessions, provision of additional services, supervision and training models etc.).

Recommended adaptations to the training materials include: 1) translation into the local language, ensuring that language use (vocabulary, phrasing, verbal style etc.) is culturally appropriate, the literacy level is consistent with that of the intended participants, and technical terms are explained in culturally and linguistically appropriate terms; 2) changing aspects of content, including the names and types of characters in stories and role-plays so that they are familiar to the participants, adding local activities, toys, games, stories or examples and modifying other aspects of the package as needed (e.g. writing activities). For the convenience of the adaptation team, an adaptation ready version of the facilitators’ guide, in which the first instances of character names are highlighted in yellow, is available. Any changes made to the facilitators’ guide should also be made in the corresponding section of the participants’ guide.

Recommended adaptations to the training process include adaptations that improve feasibility and acceptability – such as choosing an appropriate group session schedule (e.g. weekly, biweekly, daytime, after hours), providing childcare, refreshments, or using culturally-appropriate additional activities such as welcome and closing rituals.

It is expected that most adaptations will take account of the context in which the course is to be delivered. Some changes based on culture are also expected, especially to ensure that terminology for behaviours, relationships etc. is locally appropriate and understandable. It is recommended that only changes that are deemed essential to implementation of the caregiver skills training package should be made at first and that additional changes should be made after pilot-testing and collecting feedback from caregivers and facilitators.

If an adaptation team wishes to make significant changes to the structure of the course (e.g. conducting it as an individual course rather than a group course, removing sections of content, changing the number of sessions), it is recommended that this be done only after careful consultation, that changes are well documented, and that the course is evaluated to assess for effectiveness in the modified format.

In summary:

- Make only recommended adaptations and those deemed essential.
- Discuss and document the rationale for any changes.
- Sometimes it may be better to test a particular intervention or way of delivery. If required, changes can be made in the subsequent revision.
What has already been done to facilitate the adaptation process?

- Developers have tried to reduce the need for cultural adaptation by:
  - utilizing universal examples, themes and phrasing;
  - using plain language as much as possible;
  - avoiding Western biases (e.g. individualism, consumerism);
  - aiming to ensure that the package is consistent with the situation of participants in low-resource settings;
  - avoiding barriers to implementation.

- Developers have identified and highlighted items and areas in the training materials for which adaptation may be necessary and have developed an adaptation-ready version of the training materials.
  The adaptation documentation form included in Annex 2 lists suggested and optional items for adaptation or consideration for adaptation. The adaptation-ready version of the materials is an electronic copy of the facilitators and participants’ guides with minor items to be considered for cultural adaptation marked by “[consider need for adaptation]” in the text. Character names in stories and role-plays are highlighted in yellow so they can be easily identified and evaluated for cultural appropriateness. The adaptation-ready version of the materials can be obtained upon request.

- Developers have identified the key active elements thought to contribute to caregiver skills training package’s effectiveness.
  In each session key messages and tips capture essential information and strategies that are perceived as instrumental for improving caregivers’ skills. These should not be changed except in consultation with experts, and only when considered essential to the package’s acceptability.

How to use this guide

This guide provides information on how to adapt caregiver skills training materials and delivery strategies to the local context. It includes guidance on development and implementation of contextual and cultural adaptation plans. It provides important considerations to guide the course implementation, including for making available additional group sessions and home visits and other significant modifications to the caregiver skills training delivery strategy. In addition, core components of the package are described. These are the key elements or characteristics that are thought to be essential to the effectiveness of the caregiver skills training intervention and should be modified only after careful consideration.

At each step of the adaptation process, proposed and agreed adaptations should be recorded systematically on the adaptation documentation form (see Annex 2). The adaptation documentation form is an integral part of the adaptation process. This form is based on the Bernal framework which is a method for coding adaptation of interventions (1). This framework allows for documenting several significant elements of intervention adaptation, namely: language; persons; metaphors; content; concepts; goals; methods and context.
Part 1: Contextual and cultural adaptation plan

This section outlines steps to be carried out at the national/local level. Figure 1 shows an outline of the recommended process.

Figure 1. Overview of the adaptation plan for the caregiver skills training package

- Establish local adaptation team.
- Map local services and available resources and complete the “Services and Resources for Families” section in the participants’ guides.
- Translate materials.

- Adaptation team meeting 1.
  - Optional: Focus group discussions and interviews with caregivers and care providers.
  - Stakeholder consultation.

- Adaptation team meeting 2.
  - Pre-pilot field-test of adapted materials.
  - Adaptation team meeting 3.

Notes about the timing of activities

- Teams that include bilingual master trainers may want to do the training of master trainers before the materials are translated and before the adaptation team meeting 1. This ensures that the bilingual master trainers have a clear understanding of the concepts in the package before being involved in the adaptation process.
- Teams that include bilingual master trainers may want to hold the adaptation team meeting 1 before the materials are translated. This can allow these team members to facilitate the translation by identifying challenging terms and concepts and proposing translations and additional explanations.

1) Establish an adaptation team

Rationale:

This step ensures that adequate expertise is available to support the adaptation and enhances local engagement of key stakeholders.

Methods:

- Prior to any adaptation, a project manager will be appointed to oversee the process. The person selected should have appropriate knowledge of caregiver skills training interventions and the cultural adaptation process. This task may be shared by more than one person if necessary.
- In most cases, the project manager will select an adaptation advisory group.
- The adaptation advisory group should consist of approximately 12-18 people and can include:
  - a core local adaptation team (see below);
  - a researcher in charge of the evaluation (if applicable);
  - translators;
representatives from local health departments;
- potential end-users of the training course;
- potential future facilitators of the training course;
- other local experts and service providers;
- other local agency representatives and policy-makers;
- other community experts (e.g. religious leaders, elders, community group leaders).

- The core local adaptation team should have a target size of 5–6 people. This group should
  comprise health research workers or health professionals, selected for their knowledge of mental
  health, child development, and familiarity with the local language, community, culture and the
  intended participants’ socioeconomic, political and cultural context. Bilingual specialists in mental
  health, child development, and public health are extremely valuable.
- The core local adaptation team members should expect to commit to reviewing all the training
  materials personally and attending the adaptation workshops.
- Two members of the core local adaptation team will need to deliver the intervention to
  participants in the pre-pilot acceptability trial and at least one team member will be needed to
  observe the intervention.
- The roles of the other members of the adaptation advisory group are explained in further detail
  below.
- In selecting and coordinating this group, issues of language should be considered. Future steps
  (in terms of languages used and translation processes) should be planned accordingly.

Risks of not completing this step:
Risks could include: 1) inadequate cultural and or contextual knowledge to inform the adaptation; and
2) inadequate engagement from key stakeholders who will be vital in enabling implementation of the
adapted intervention.

2) Map local services and available resources

Rationale:
It is important for each member of the adaptation advisory group to be aware of the context in which the
intervention will be conducted. In addition, a list of local resources for children and families will need to
be compiled, added to the participants’ guides (see Annex 1) and made available to facilitators and
trainers.

The project manager is responsible for conducting a preliminary situational analysis of mental health, family
and child development services in the target community/country.

Where possible, the caregiver skills training intervention should be embedded into existing services.

Methods:
The project manager should do the following:

- Review any relevant local legal frameworks that may relate to the caregiver skills training course,
  and their limitations (e.g. child protection legislation regarding the reporting of suspected child
  maltreatment).
- Compile a list of available services that may be relevant to the participants in this training course
  (e.g. health services, clinics, NGOs, food banks, housing services, respite services, charities).
- Clarify within the current health system the range of available personnel, level of competence,
  available referrals and interventions.
Part 1: Contextual and cultural adaptation plan

- Consider where the caregiver skills training course could be embedded into existing services.
- Develop a provisional plan for including optional modules in the course. See Part 5 of this document.
- Compile a comprehensive summary document for the adaptation team.

Risks of not completing this step:
Risks could include: 1) Inadequate understanding of the context in which the course is to be delivered; and 2) inability to provide caregivers with information on available options for additional support if needed.

3) Translate materials to the selected local languages

Rationale:
Translation into local languages is a critical aspect of adaptation. Back-translation is recommended to assess the adequacy of translation and to ensure that relevant concepts are captured well. However, if the adaptation team includes bilingual specialists who are familiar with the concepts and terminology of the package, they may be able to validate the accuracy of the translation, thus eliminating the need for a full back-translation. However, back-translation of at least the key messages and tips (skills and strategies) is recommended.

Methods:
- An electronic adaptation-ready copy of the facilitators and participants' guides is available upon request. Items or areas that are likely to require cultural adaptation are marked by colour highlights within the text. Table 1 provides an overview of specific terms and concepts that are likely to require additional attention in the translation and adaptation process.
- Translation and back-translation will be completed. At minimum, back translation of the key messages and tips (skills and strategies) is recommended.
- The translation will be completed by one or two (where resources allow) professional translators. Ideally, these should be selected on the basis of their knowledge/experience in translating materials relating to child development, mental health, and/or family interventions. They should be native speakers of the target language, and fluent in the source language (i.e. English; as per ISPOR adaptation guidelines) (2).
- The back-translation will be completed by a professional translator who is ideally a native speaker of the source language (i.e. English), and fluent in the target language (as per ISPOR guidelines) (3). The translator should be selected on the basis of knowledge/experience in translating materials relating to child development, mental health and/or family interventions. She/he should have no prior knowledge of the materials and should not see the source materials before or during the translation process. The back-translation will be literal rather than conceptual, allowing for identification of areas lacking clarity (3).
- The translators should document any necessary changes to the literal translation that are made to ensure comprehensibility using the adaptation documentation form (see Annex 2 at the end of this document).
- The translators should mark with a colour highlight any terminology or concepts that are likely to require the creation of an explanatory note within the text. This should be recorded into the adaptation documentation form.
- The decision to translate optional modules at this stage will be based on the provisional plan for optional modules. At a minimum, a summary of each of the optional modules will be translated.
**Table 1. Specific terms and concepts that are likely to require additional attention in the translation and adaptation process, organized by where the term or word is introduced in the ca.**

<table>
<thead>
<tr>
<th>Term/Concept</th>
<th>Definition</th>
<th>Example of how it is used in the package</th>
<th>Session where it is introduced</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delay</td>
<td>Children with a developmental delay achieve developmental milestones (e.g. speaking, walking, social behaviour) later than expected for their age (or corrected age if they were born prematurely) (4).</td>
<td>Caregiver skills training is designed to benefit families of children with developmental delays or disabilities.</td>
<td>1</td>
</tr>
<tr>
<td>Development</td>
<td>The increase in a child’s mental, social, emotional and physical skills and abilities over time (4).</td>
<td>The doctor explained to Mary and her husband, “I have checked your child’s development.”</td>
<td>1</td>
</tr>
<tr>
<td>Disability</td>
<td>Disability is due to the interaction between health conditions and environmental and personal factors. Disability can occur at three levels: impairment in body function or structure (such as cerebral palsy), a limitation in activity (such as an inability to communicate), and a restriction in participation (such as exclusion from school) (4).</td>
<td>Caregivers can help children with developmental delays and disabilities learn.</td>
<td>1</td>
</tr>
<tr>
<td>Engagement; engaged</td>
<td>Being interested in doing or sharing an activity with another person.</td>
<td>Getting children engaged in interaction is one of the goals of the package.</td>
<td>1</td>
</tr>
<tr>
<td>Shared engagement</td>
<td>Noticing another person and your shared activity. In shared engagement, the adult and the child should be doing an activity together. Both should have a role and be focused on each other and the activity.</td>
<td>Shared engagement is best for learning.</td>
<td>1</td>
</tr>
<tr>
<td>Gesture</td>
<td>A movement of part of the body, especially a hand or the head, to express an idea or meaning.</td>
<td>The gestures we focus on in the package are point, show and give.</td>
<td>1</td>
</tr>
<tr>
<td>Improvement</td>
<td>Change in a positive way. (In some languages, the word for “change” or “positive change” may be more suitable than “improvement”.)</td>
<td>Caregivers can learn new skills to help their children participate in everyday activities and improve their behaviour.</td>
<td>1</td>
</tr>
<tr>
<td>Term/Concept</td>
<td>Definition</td>
<td>Example of how it is used in the package</td>
<td>Session where it is introduced</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>Regulated</td>
<td>Calm and ready to learn. Also referred to as “cool” and “green” on the behaviour thermometer.</td>
<td>Caregivers can help children stay engaged and regulated.</td>
<td>1</td>
</tr>
<tr>
<td>Dysregulated or not regulated</td>
<td>Very upset, angry or overexcited. A child who is dysregulated needs help to calm down. The signs you may notice are: Crying, screaming, whining, tantrum or meltdown behaviour, running away, rolling on the floor, overexcitement or running around.</td>
<td>A child who is showing “red” or “hot” behaviour on the behaviour thermometer is dysregulated.</td>
<td>1</td>
</tr>
<tr>
<td>Green/cool</td>
<td>Calm, alert and ready to learn, which is also called “regulated”. Some signs you may notice are: Smiling and laughing, the child's body is still and relaxed and the child is making sounds or talking.</td>
<td>Children may show green or cool behaviour.</td>
<td>1</td>
</tr>
<tr>
<td>Warm/yellow</td>
<td>Showing the first signs of frustration, distress or upset. The signs you may notice are: making repetitive sounds, whining, fussing, fidgeting, moving around, looking around, not taking turns or participating in the routine, or becoming not engaged. Warm or yellow behaviour may be a warning sign for red or hot behaviour.</td>
<td>Children may show warm or yellow behaviour. (</td>
<td>1</td>
</tr>
<tr>
<td>Hot/red</td>
<td>Very upset, angry or overexcited. A child who is hot/red needs help to calm down. The signs you may notice are: Crying, screaming, whining, tantrum or meltdown behaviour, running away, rolling on the floor, overexcitement or running around.</td>
<td>Children sometimes show hot or red behaviour. (See behaviour thermometer)</td>
<td>1</td>
</tr>
<tr>
<td>Transition</td>
<td>A change from one activity to another activity. Difficult transitions often happen when a child is asked to change from an activity they like (e.g. playing) to one that they don’t like (e.g. going to bed).</td>
<td>A child may become dysregulated because of a difficult transition.</td>
<td>1</td>
</tr>
<tr>
<td>Attention</td>
<td>Taking special notice or care of someone or something.</td>
<td>Notice when your child is behaving well or doing something well, and respond with attention, smiles and kind words.</td>
<td>1</td>
</tr>
<tr>
<td>Term/Concept</td>
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<td>Session where it is introduced</td>
</tr>
<tr>
<td>----------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>Attention</td>
<td>Being focused on something while ignoring other things in the environment.</td>
<td>Shared engagement is when the child is paying attention to two things: you and the activity that you are doing together.</td>
<td>2</td>
</tr>
<tr>
<td>Stigma</td>
<td>Negative attitudes and beliefs, and a strong feeling of disapproval that some people in a society have towards certain groups – usually unfairly. Stigma can lead to judgement, negative actions and discrimination.</td>
<td>Some caregivers of children with developmental delays and disabilities experience stigma in their communities</td>
<td>2</td>
</tr>
<tr>
<td>People games</td>
<td>A way to play when children are not playing with toys or objects but rather play by interacting with people (e.g. clapping, singing, swinging and chase games).</td>
<td>Children of all ages enjoy people games.</td>
<td>2</td>
</tr>
<tr>
<td>Simple play with objects</td>
<td>A way to play when children first start to play with toys or objects and they do single actions with them (e.g. rolling a ball, pushing a toy along the ground, shaking or dropping objects).</td>
<td>Children who like to drop, bang and shake objects are doing simple play.</td>
<td>2</td>
</tr>
<tr>
<td>Put together play</td>
<td>A way to play that typically comes after simple play. Children play at this level by stacking, putting objects inside containers and building (e.g. putting rocks in a box, stacking cups on top of each other, building a tower out of objects).</td>
<td>Children who like to stack, build and put items into containers are doing put together play.</td>
<td>2</td>
</tr>
<tr>
<td>Early pretend play</td>
<td>The next way to play after put together play. Children start to use toys in an imaginary way to do common activities (e.g. playing with toy animals by putting them together in a farm; pretend to pour a drink into cups, pretending to feed a baby).</td>
<td>Children who like to do simple things with toy animals and dolls are doing early pretend play.</td>
<td>2</td>
</tr>
<tr>
<td>Advanced pretend play</td>
<td>The next way to play after early pretend play that involves more imagination and creativity (e.g. the child pretends to be a mother cooking a meal for the family, the child pretends that dolls and animals are alive and walking, talking, eating or sleeping).</td>
<td>Children who like to pretend dolls and animals are alive are doing advanced pretend play.</td>
<td>2</td>
</tr>
<tr>
<td>Routine</td>
<td>A routine is an activity that has a set of clear small steps that make sense and make up a story. Routines can be restarted and repeated. Both the child and the adult have an active role and are partners in the routine. Over time, you can add new steps to the routine. (See examples in the facilitators’ guide.)</td>
<td>You can help your child engage in play and home routines.</td>
<td>3</td>
</tr>
<tr>
<td>Term/Concept</td>
<td>Definition</td>
<td>Example of how it is used in the package</td>
<td>Session where it is introduced</td>
</tr>
<tr>
<td>--------------</td>
<td>------------</td>
<td>------------------------------------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>Share</td>
<td>Communication to share means sharing your interest with another person. When you are communicating to share, you are trying to get the other person to notice something interesting or unexpected. Communication to share is not the same thing as sharing toys (letting someone else use your toys) or sharing food (giving someone some of your food).</td>
<td>There are two main reasons why we communicate: we communicate to request and communicate to share our interest with someone.</td>
<td>5</td>
</tr>
</tbody>
</table>

**Risks of not completing this step:**
Inadequate translation will significantly affect local implementation. The back-translation is a key step in ensuring the accuracy of the initial translation.

**Note:**
Where a country may wish to provide a version of the package in an official national language as well as a dialect, the translation and adaptation steps may proceed in tandem where appropriate.

**4) Adaptation team meeting 1: workshop with adaptation team to make minimal linguistic and cultural adaptations and decide on adaptations to reduce barriers to attendance**

**Rationale:**
The core local adaptation team should review results from the translation process and the comments marked by translators. The team should make minor recommended changes and simple linguistic changes, as well as simple cultural references.

**Methods:**

- This process will aim only to adapt minor aspects thought to be necessary at this early stage (e.g. names of characters in stories and role-plays, specific terms, language use, objects, toys, settings etc.).
- Aspects of the materials that should be considered for adaptation in phase 1 are specified in the adaptation documentation form (under “linguistic and cultural considerations”) and flagged in the translated adaptation-ready copy of the facilitators and participants’ guides.
- The adaptation team will also be asked to consider local legal frameworks and their limitations in suggesting changes (e.g. frameworks regarding child maltreatment, education access etc.).
- If not already determined, the adaptation team should also decide
  - the location of group sessions;
  - the frequency of group sessions (weekly or every two weeks);
  - whether childcare will be provided at group sessions (this may be essential to enable caregiver participation); and
  - whether economically disadvantaged caregivers will receive transportation costs to attend group sessions.
Independent review

- Each member of the adaptation team will independently review the translated and/or back-translated materials and will point out any segments where translation has not been adequate, or has not captured vital elements of the package adequately, and will suggest changes.
- Team members should also note linguistic and cultural elements for consideration in the cultural adaptation process, making note of both minimal adaptations and any excerpts they may wish to review with stakeholders in the cultural acceptability/feasibility workshop.
- In their review of the materials, team members should also note contextual and methodological considerations (See adaptation documentation form “Contextual and methodological considerations”). They may wish to discuss these considerations in the cultural acceptability/feasibility workshop with stakeholders in preparation for adaptation phase 2.
- Team members should also review the provisional plan for the inclusion of optional modules and the optional modules summaries. If the team wishes to include optional modules that have not already been translated, translation of these modules can be requested at this time.

Adaptation workshop

A variety of methods are possible to contextualize/adapt the caregiver skills training package. Organizing a workshop is an effective method since it provides an opportunity for the core local adaptation team members to discuss the issues face-to-face and reach a consensus in an efficient manner.

- The core local adaptation team should hold a one-day or half-day workshop to review the translated materials and agree on and make minimal cultural adaptations.
- The length of the workshop depends on the available resources and the available time of the participants.
- Participants who are involved from a distance should be invited to attend via telephone or Internet.
- Workshop participants should be encouraged to prepare their comments as described above before coming for the workshop.
- It is helpful to have facilitator(s) to plan and run the workshop to ensure adequate use of time. This person should be familiar with the training package and the adaptation process. The project manager could be a facilitator.
- At the beginning of the workshop there should be a brief presentation on the aims and methodology of the adaptation process and workshop. This should include clarification of what changes are to be made at this stage and which are to be made at a later stage.
- At the beginning of the workshop there should be a brief presentation on the aims and methodology of the adaptation process and workshop. This should include clarification of what changes are to be made at this stage and which are to be made at a later stage.
- The facilitator will lead the participants in discussing their proposed adaptations for each session, ensuring that approximately equal time is spent on each session of the course. Facilitators can plan the best approach based on their preference but taking a step-wise approach to go through each session can be helpful. Where changes are made to language in an earlier session, these changes can often be carried forward to future sessions.
- Changes will be proposed by individual members and decided on by consensus within the team.
- For each decision, team members will have the option to abstain if they do not agree with a proposed change but do not wish to block a decision from being made.
• In cases where consensus cannot be reached, the decision can be deferred until the stakeholder workshop (Step 5).

• The team will follow the specified process for documenting adaptation efforts (see adaptation documentation form in Annex 2).

• The draft list of adaptations should be finalized by the end of the workshop through discussion among the participants.

• The team will keep in mind that only essential changes should be made at this stage.

• Adaptations that affect core package components thought to be essential for the efficacy of the course should not be made at this phase. These should only be made in conjunction with experts and, if deemed absolutely necessary, by the adaptation team following the stakeholder workshop (Step 5).

Materials to be available before/during the workshop include:
- the adaptation documentation form (one hard copy for each participant);
- one hard copy of the facilitators and participants’ guides;
- a laptop and projector for discussions.

Adaptations that are recommended to ensure minimal acceptability and relevance

Table 2 provides an overview of adaptations that are likely to be required to ensure acceptability and relevance of caregiver skills training materials in the local context.

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Consideration</th>
<th>Adaptation options</th>
<th>Session where introduced</th>
</tr>
</thead>
<tbody>
<tr>
<td>Names of characters in stories and role-plays.</td>
<td>Names should be familiar to caregivers who are receiving the course.</td>
<td>Suggest names be changed as needed, while still maintaining diversity (consider common names for different ethnic and minority groups within countries/regions to ensure they are also represented).</td>
<td>All</td>
</tr>
<tr>
<td>How to refer to father and mother in the role-plays. In the package the parents’ first names are used.</td>
<td>It is not appropriate in all cultures to refer to parents/caregivers by name.</td>
<td>Remove the caregivers' names from the role-play and refer to them by appropriate terms.</td>
<td>1–8</td>
</tr>
<tr>
<td>A nurse provides information in Rosa's story in session 9.</td>
<td>This is not the role of a nurse in all settings. In some settings this would be another health-care provider.</td>
<td>Change the professional’s title from “nurse” to something more appropriate. Consider the need to change illustrations to be consistent with this change.</td>
<td>9</td>
</tr>
<tr>
<td>Aspect</td>
<td>Consideration</td>
<td>Adaptation options</td>
<td>Session where introduced</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>Types of play materials and toys used in the demonstrations.</td>
<td>Play materials used should be locally available and consistent with what families would typically use.</td>
<td>Suggested materials are common household items, but these can be changed depending on the context. In some settings it may be appropriate to make low-cost toys. Guidance is available for this activity (5).</td>
<td>2</td>
</tr>
<tr>
<td>Any aspect of the facilitators’ guides marked with [Consider need for adaptation].</td>
<td>These aspects include writing activities, which may be inappropriate in some settings, beliefs (e.g. myths) about developmental disabilities and delays), and other aspects that relate to schooling and well-being activities.</td>
<td>Replace, modify or remove these aspects.</td>
<td>1</td>
</tr>
</tbody>
</table>

**Risks of not completing this step:**

Risks may include minor difficulties in translation and cultural relevance may not be addressed prior to a workshop with stakeholders. Time with the stakeholders should be used to address broader contextual and cultural issues that require expert input rather than minor issues that could have been addressed by the core local adaptation team.

**Optional: focus group discussions and/or in-depth interviews with caregivers and community-based care providers**

Whenever possible, it would be useful to use qualitative methods to assess the specific needs of caregivers of children with developmental disabilities or delays in the local context. Focus group discussions and/or in-depth interview with caregivers could provide useful information on: their needs and preferences concerning the parenting package; possible barriers to attending the training course and potential opportunities to link the training course to other community services or support group’s activities; and the feasibility and acceptability of the caregiver skills training package’s content and strategies. Focus group discussions and/or in-depth interviews with community-based care providers (potential course facilitators) would provide useful information on the availability of care providers, their interest in the course and their perceived gaps in knowledge and skills.
5) Stakeholders’ consultation

Rationale:

The input from local stakeholders is key to ensuring that the intervention is acceptable, feasible and relevant, and to ensure that the community engagement is adequate to facilitate initial and sustained implementation.

Methods:

- This workshop should be organized by the project manager, with the core local adaptation team members assisting where required.
- The workshop will be held at the target site, and will involve a facilitator(s) leading a small group of people through a discussion to better understand community values, beliefs and norms to ensure cultural competence and responsiveness to the needs of participants (e.g. reading level of the target population, values and norms, attractiveness of the intervention) community concerns, resources etc.
- The facilitator(s) should be familiar with the training package and the adaptation process. The project manager could be a facilitator.
- Participants will be approximately 8–12 key stakeholders from the broader adaptation advisory group. This group can include representatives from local health departments, potential end-users of the training course, potential future facilitators of the course, other local experts and service providers, other local agency representatives and policy-makers, and community experts who have in-depth cultural knowledge and experience with the target population, and are able to provide input into the adaptation process (e.g. local community leaders, religious leaders and elders)
- At the beginning of the workshop there should be a brief presentation on the aims and methodology of the adaptation process and workshop.
- A prepared presentation can be given on the adaptation team’s understanding of the national situation, to provide information and encourage discussion on the health system and human resources organization, services and resources.
- Some countries might have already gone through the adaptation process. At the beginning the facilitator(s) can discuss the process followed in those countries as well as the outcomes.
- Participants will view excerpts from the package to guide their responses about the training materials. Suggested excerpts for review will be indicated in the adaptation-ready training materials and can be chosen by the adaptation team.
- The facilitator will lead the participants to discuss each question, ensuring that approximately equal time is spent on each question. Facilitators can plan the best approach based on their preference. The length of the workshop will depend on availability of stakeholders and facilitators.
- There should be adequate record-keeping. Depending on available resources, this could involve detailed note-taking by a dedicated person, or audio recordings which are later transcribed.
Materials to be available before/during the workshop include:

- a laptop and projector for discussions;
- caregiver skills training materials (one hard copy of relevant excerpts for each participant);
- reference documents (it is sufficient to have just one copy available in the room) such as
  - the national health and mental health policies, legislations and plans, and
  - a WHO AIMS report and any other relevant mappings of the national mental health system (e.g. Atlas country profiles for mental health).

Risks of not completing this step:

Risks may include inadequate input and engagement from key stakeholders, resulting in a finished product that cannot be implemented in a sustainable way or does not meet local needs.
6) Adaptation team meeting 2

Rationale:
The members of the core local adaptation team now have information from their review of translated materials, their own knowledge of the culture and context, and input from key stakeholders. The next step is to ensure that this knowledge is effectively utilized to inform adaptations to materials.

Methods:

- Again, organizing a workshop to contextualize/adapt the caregiver skills training package is an effective method since it provides an opportunity for the core local adaptation team members to discuss issues face-to-face and reach a consensus efficiently. However, it may be possible for countries to implement this process without a face-to-face workshop (e.g. by corresponding via email, telephone, Internet calls).
- The core local adaptation team should hold a one-day or half-day workshop to review the results from the workshop with stakeholders and decide on any adaptations to be made.
- The length of the workshop depends on the available resources and the available time of the participants. Participants who are involved from a distance should be invited to attend via telephone or Internet.
- It is helpful to have facilitator(s) to plan and run the workshop to ensure adequate use of time. This person should be familiar with the caregiver skills training package and the adaptation process. The project manager could be a facilitator.
- There should be a brief presentation at the beginning of the workshop on the aims and methodology of the adaptation process and workshop. This can include clarification of what changes are to be made at this stage.
- At this stage, the adaptation team will consider linguistic and cultural considerations as well as contextual and methodological considerations (see adaptation documentation form for suggested and optional adaptations).
- The adaptation team will again be asked to consider local legal frameworks and their limitations in suggesting changes.
- The facilitator will lead the participants to discuss their proposed adaptations for each session. Facilitators can plan the best approach based on their preference but taking a step-wise approach to go through each session can be helpful.
- Changes will be proposed by individual members and will be decided on by consensus within the team.
- For each decision, team members will have the option to abstain if they do not agree with a proposed change but do not wish to block a decision from being made.
- The team will follow the specified process for documenting adaptation efforts (see the adaptation documentation form).
- The draft list of adaptations needs to be finalized by the end of the workshop through discussion among the participants.
- The team will keep in mind that only essential changes should be made.
The adaptation team will aim to ensure that materials are: 1) comprehensible (can they be understood by the target audience?); 2) acceptable (might some people be made to feel uncomfortable or offended?); 3) relevant (are they relevant to the lived experience of the target population?); and 4) based on a well-documented and systematic approach to translation of materials (6).

Any indicated adaptations that will affect the identified core intervention components (key messages, tips, guided practice during home visits) but are thought to be essential for acceptability or feasibility of the course should be carefully considered. Ideally, the adapted package will be piloted and evaluated prior to broader implementation.

If the adaptation team feels that it is necessary to make significant structural changes to the course (e.g. changing number and/or length of sessions or home visits, changing format from group to individual), this should be done only if a comprehensive plan is developed for documenting these changes and evaluating and reporting back to the effectiveness of the course.

Materials to be available before/during the workshop include:

- the adaptation documentation form (one hard copy for each participant);
- one hard copy of the facilitators and participants’ guides;
- a laptop and projector for discussions;
- reference documents (it is sufficient to have just one copy available in the room) such as:
  - the national health policy, legislation and plan,
  - the national mental health policy, legislation and plan, and
  - a WHO AIMS report and any other relevant mappings of the national mental health system (e.g. Atlas country profiles for mental health).

Risks of not completing this step:

Risks may include lack of consensus. Changes should be made by consensus within the team, which allows for input from a variety of people with differing expertise. It is expected that this will reduce the likelihood of unnecessary changes or changes that affect core course components or strategies from being made.
7) Pre-pilot field-test of adapted materials

Rationale:

Prior to implementation in trials and/or in the broader populations, the adapted materials should be field-tested in a small-scale exercise, with qualitative and quantitative information gathered on the acceptability, comprehensibility, and relevance of the materials to the target population.

Methods:

Pilot

- During this phase, the adaptation team will test the materials with the target population (i.e. caregivers of children with developmental delays or disabilities).
- A target group size of eight caregivers (minimum six) will be recruited to participate.
- The target group will receive the adapted intervention, delivered in its intended format by two members of the adaptation team who will facilitate the training course. At least one of these facilitators should be a master trainer. One additional member of the adaptation team will also attend each session as an observer.
- The course will be delivered as intended based on the adaptations so far.

Process evaluation

- The observer should record any questions or comments raised by the caregivers that could potentially indicate a lack of comprehensibility, acceptability, or relevance. The observer will also be asked to note any issues with regard to instructional pacing, time allotted for activities, the physical teaching environment, etc.
- Feedback will be collected from participants and facilitators to assess for:
  - comprehensibility of instructions and messages;
  - acceptability and relevance of materials to the target audience;
  - any issues with the teaching process, flow, pacing and length of activities;
  - the need for further adaptation or modification, etc.
- Methods should include where feasible:
  - post-session and post-course feedback forms completed by participants, facilitators and observer;
  - post-course focus groups for participants;
  - post-course discussion groups with facilitators and observer;
  - collection of clinical outcome measures on selected key target variables as a trial of local planned evaluation and monitoring methods (or in preparation for a research trial when conducted in the context of research).
- Post-session feedback forms (available by request) should be completed either: 1) as paper forms by respondents with guidance from the facilitators; or 2) verbally by an assistant/facilitator. Information will be gathered using questions, rather than statements asking for a degree of agreement, in order to avoid cultural response styles where participants tend to agree with statements. Questions will inquire about session comprehensibility, relevance and congruence with the personal values of participants.
- Post-course feedback forms (available by request) should be completed at the end of the final group session. These will be completed either: 1) as paper forms by respondents with guidance from the facilitator; or 2) verbally by an assistant/facilitator. Questions will inquire about the comprehensibility, relevance and congruence of the package with the personal, family, community and religious values.
Quantitative data will be collected on:
- the number of sessions attended by each participant (based on the attendance record);
- treatment fidelity based on session checklists completed by facilitators and the observer.

**Qualitative evaluation**
- Post-course focus groups should be conducted soon after the intervention finishes.
- One group should be conducted with caregivers; and one with facilitators and the observer.
- The groups should be conducted by a facilitator(s) who should ideally be familiar with the caregiver skills training package and the adaptation process. The project manager could be a facilitator.
- Depending on cultural norms, these groups should be somewhat informal in nature and should last no longer than 2 hours.
- An example draft interview guide is available by request, but this can be adapted by the core local adaptation team as considered necessary.
- Caregivers who have dropped out of the course could be contacted and invited to participate in a telephone interview using adaptations of the same questions.
- There should be adequate record-keeping during these focus groups/interviews. Depending on available resources, this could involve detailed note-taking by a dedicated person, or audio recordings which are later transcribed.
- The project manager and/or other members of the core local adaptation team should review the qualitative data to search for common themes in the data relating to:
  - comprehensibility of instructions and messages;
  - acceptability and relevance of materials by the target audience;
  - any issues with the teaching process, flow, pacing and length of activities;
  - barriers and facilitators of participation (compare the qualitative approach of inductive thematic analysis) (7).
- Depending on the languages spoken by the project manager and the members of the core local adaptation team assisting with this task, the transcripts may need to be translated prior to analysis.
- The information on themes should be compiled into summary sheets and distributed to the core local adaptation team for consideration of further proposed changes to the package.

**Risks of not completing this step:**
Risks may include information from initial testing not being collected and further changes not being made to improve the materials.
8) Adaptation team meeting 3: workshop with adaptation team to make further changes

**Rationale:**

The core local adaptation team now has information from all previous stages as well as from field-testing the intervention with intended participants. It is vital at this stage to see if any further revisions are needed. During this phase, all materials will be finalized, including facilitators' training materials.

**Methods:**

- As in previous adaptation phases, organizing a workshop is an effective method. However, it may be possible for countries to implement this process without a face-to-face workshop (e.g. through correspondence via email, telephone, Internet calls).
- It is recommended that the workshop should begin with a presentation of the results and findings of the pre-pilot field-test. The methods and processes should be similar to those of previous workshops.
- During the workshop, the adaptation team will review results from the pre-pilot field-test and decide on any further adaptations to be made. The team will consider linguistic and cultural issues as well as contextual and methodological concerns (See the adaptation documentation form for suggested and optional adaptations).
- The facilitator will lead the participants in discussing their proposed adaptations to the package, ensuring that adequate time is allocated to review each of the themes arising from the pilot-testing. Facilitators can plan the best approach based on their preference but taking a step-wise approach to go through each theme can be helpful.
- Again, the adaptation team will follow the specified process for documenting adaptation efforts (see the adaptation documentation form), and the draft list of adaptations should be finalized by the end of the workshop through discussion among the participants.
- The adaptation team will again aim to ensure that the materials are comprehensible, acceptable and relevant. The team will also aim to ensure that the course is feasible in the given context and will consider adaptations that reduce barriers to participation.
- Any indicated adaptations that will affect the identified core package components but are thought to be essential for acceptability or feasibility should be carefully considered. Ideally, the adapted package will be piloted and evaluated prior to broader implementation.
- If the adaptation team feels that it is necessary to make significant structural changes, these should be made only if a comprehensive plan is developed for documenting these changes and a plan made for evaluating and reporting on the effectiveness of the package.

**Materials to be available before/during the workshop include:**

- the adaptation documentation form (one hard copy for each participant);
- one hard copy of the facilitators and participants’ guides;
- a laptop and projector for discussions;
- any other reference document as relevant (the national health and mental health policies, legislations and plans; WHO AIMS reports; Atlas country profiles for mental health and any other relevant mappings of the national mental health system).
**Risks of not completing this step:**

Changes should be made by consensus within the team, allowing for input from a variety of people with differing expertise. It is expected that this will reduce the likelihood of unnecessary changes or changes that affect core course components or aims. Further, information from the pre-pilot testing is vital for determining the utility of the adapted package with the target population and should therefore be incorporated into decisions about further adaptations.
Part 2: Implementation considerations

Below are some key implementation considerations.

Reducing barriers to attendance
Some options for consideration for implementation (dependent on resources available) include:
- reimbursement of transport costs to attend sessions;
- provision of childcare where possible (this may be essential in some settings to allow caregivers to participate);
- provision of a small snack or meal;
- provision of a small gift (such as soap, a children’s book).

Involvement of all caregivers
- It should be standard practice to invite any two caregivers per family to attend the group sessions. This does not necessarily have to be a relative of the child but could be any important person in the child’s life who provides regular care (e.g. a formal carer, friend). Minors should not be invited to attend the training course as main caregivers (except for minors who are parents of a child with a developmental disability or delay).
- It is not recommended to invite only one parent/caregiver from each family (e.g. only mothers, or only fathers) because of the resultant structural discrimination.
- However, a decision to only invite one parent/caregiver is justifiable if the adaptation team concludes that extending an invitation to a second caregiver is likely to disempower the primary caregiver and affect that caregiver’s participation and learning (i.e. in situations where there is a large power differential which puts the primary caregiver at a disadvantage). Other caregivers will be offered the opportunity to take part in home encounters with the facilitators and in specific sessions.

Methods to encourage family involvement
- Consider providing two copies of the participants’ guide per family if appropriate.
- This would give caregivers who attend alone an opportunity to share the training materials with another important person in their child’s life who may not live in the same home.
- This also reduces the burden on the primary caregiver and sends an important message to the family that their contribution is both wanted and needed.

Scheduling
- It will be important for country teams to consider the scheduling of groups carefully.
- Any additional burden on caregivers should be considered.
- The inclusion of all caregivers may be enhanced by scheduling groups outside of working hours.

Addition of a booster session to maintain participant progress
- Depending on local resources, the adaptation and implementation team may wish to schedule one or more “booster” session(s) for participants to meet together and share their experiences.
- This can be a less formal group session. It may take the form of a peer support group, rather than a facilitator-led group. Preferably it would be provided as an optional session, rather than being compulsory. Timing is optional, but one to two months after conclusion of the training course could be considered.
Delivering brief training courses by delivering only some components

- The adaptation and implementation team may feel strongly that the training course can be delivered only in a briefer format.
- If this is the case, the team could consider delivering only certain training sessions.
- In almost all cases, sessions 1 and 2 – which introduce the course and foundational skills – should be delivered. Session 3 forms a standalone module on building routines using play and home activities; sessions 4 and 5 form a module on communication; session 6 is a module on teaching adaptive behaviour (dressing and hand-washing) and skills and sessions 7 and 8 form a module on managing behaviour. Session 9 also forms a module on caregiver well-being and problem-solving. Additionally, session 9 provides a review of the course, so ideally would be delivered in most instances.

Community awareness and reduction of stigma

- In certain settings it may be appropriate for the local caregiver skills training team to conduct community awareness, stigma reduction and disability advocacy activities prior to conducting the caregiver skills training course.
- This must be conducted with an understanding of cultural beliefs, norms and practices.
Part 3: Core components of the training package

Core components are the key elements or characteristics that are thought to be essential to the effectiveness of the caregiver skills training package. Given their importance, changes to these elements of the package are not recommended because they may have a negative impact on the ability of the caregiver skills training course to meet its goals (2).

At times there might be conflict between ensuring cultural acceptability and maintaining fidelity to the core components of the intervention. For instance, the cultural adaptation team may wish to remove or de-emphasize certain components of the package for cultural reasons (e.g. non-violent discipline, social rewards). In circumstances where the local adaptation team wishes to make substantial changes to core components of the package, this can be done only after careful consultation and where there is a strong rationale for these adaptations to improve the effectiveness of the caregiver skills training course at country level. Such adaptations must be well documented and backed by evaluation data from either field-testing by the local adaptation team or a research trial.

Core content and conceptual components – the knowledge, skills, attitudes and values taught in the course

Examples of changes that should not be made without consultation with experts:
- changes to or removal of key messages or tips;
- removal of group session activities (demonstrations, role-plays, case stories, discussion);
- removal of a session;
- removal of home visits;
- removal of guided practice during home visits;
- removal of goal-setting (setting individualized goals for the family);
- removal of home practice.

Core instructional components – the teaching methods used in the course

Examples of changes that should not be made without consultation with experts:
- making adaptations or changes to teaching methods and activities such as group discussions, work in pairs, the amount or intensity of home practice, etc;
- eliminating learning activities or altering the delivery instructions for facilitators (e.g. reading the description of a demonstration rather than performing the demonstration).

Core implementation components – the logistics that make for a good learning experience

Examples of changes that should not be made without consultation with experts:
- changing the facilitator-to-participant ratio;
- changing the sequence of group sessions;
- expanding or restricting the definition of the target population for the course.
Part 4: Choosing to make optional modules available

Additional caregiver skills training facilitators’ guides will be available for implementation to address the following:

1) Strategies and supports for children who have little or no spoken language.
2) Caregiver well-being.

These are considered as optional modules.

Local teams may decide, on the basis of local needs and available resources, whether and what optional modules will be part of the intervention. Local teams will also decide whether optional modules will be delivered whenever the intervention is provided or will be delivered only to groups of caregivers that would – on the basis of the facilitators’ assessment – benefit most from them.

- **The adaptation team should develop a provisional plan for optional modules**
  This plan will show which modules the adaptation team intends to make available and will train facilitators to deliver. This will best be done in phase 1 after the review of available local services.

  The provisional plan should be based on the perceived or documented needs of intended participants, feasibility considerations (economic and human resources, including resources for training and supervising facilitators) and perceived acceptability to participants (considering length of the training course and participant retention).

  If the team wishes to collect more information before making a plan, stakeholders can be consulted at the cultural acceptability/feasibility workshop. The translated summaries of the modules can be used to aid in this process.

- **Optional modules designated for inclusion should be translated and adapted**
  If the adaptation team’s provisional plan is to include optional modules, these modules should be translated and subjected to the same adaptation process as the other materials.

- **The team should collect feedback on both the provisional plan for including/excluding optional modules and the modules themselves**
  The adaptation team can collect feedback on the plan for including or excluding optional modules during the stakeholder workshop. The comprehensibility, acceptability and relevance of optional modules designated for inclusion can also be evaluated. Further information can be collected from the pre-pilot field-trial.

- **Guidelines for determining whether available optional modules should be offered to a specific group of participants will be included in the training materials**
  The decision to make optional modules available and train facilitators to deliver them at the local level will be made as part of the adaptation process. The decision to offer available optional modules to a given group of participants will be made by facilitators in conjunction with master trainers and supervisors.
Part 5: redesigning the caregiver skills training course from group to individual format and other significant modifications

Sites may wish to redesign the course so that it can be delivered in individual sessions rather than in group sessions. This will be important in areas where there are not enough participants to form a group, when participants cannot participate in groups due to the geographical, economic, political, social or cultural situation, or when there is an existing health intervention that entails regular home visits to families. Given the types of interactive learning activities in the group sessions and the reliance on live demonstrations to teach concepts, the creation of individual sessions would require a substantial redesign of the training package and would be best done in consultation with experts. The plan for how the caregiver skills training package could be redesigned will need to be tailored to the local context and resources.
References


Annex 1: Resource list for caregivers (participants’ guide template)

A list of local resources should be compiled, added to the participants’ guide for each session, and made available to facilitators and trainers. Here below a template to provide a contextualized list of resources for caregivers.

**Services and resources for families**

This information describes local services and resources for you, your child and your family. *[To be completed based on the local context]*

**What can I do if my child is ill?**
The text here will describe a plan of action and list local resources (e.g. addresses, hours and telephone numbers of medical clinics or local hospital) with associated requirements and fees for visits. Information could also include helplines and websites.

**What can I do if I think my child might have been hurt or abused by someone?**
The text here will describe a plan of action and local resources (e.g. addresses, hours and telephone numbers of medical clinics or local hospital) with associated requirements and fees for visits as well as information about social service agencies and how to contact them. Information could also include helplines and websites.

**What can I do if my family needs things that we do not have?**
The text here will describe a plan of action and local resources for food, clothing, diapers etc. (e.g. religious and community organizations and social service agencies and how to contact them). Information could also include helplines and websites.

**What can I do if there are difficulties at home?**
The text here will describe local resources for issues such as intimate partner violence or psychological abuse, problems with alcohol or substance use (e.g. addresses, hours and telephone numbers of medical clinics or local hospital) with associated requirements and fees for visits, as well as religious and community organizations and social service agencies. Information could also include helplines and websites.

**What can I do if my family has other challenges?**
The text here will describe local resources for housing, shelter and legal assistance, resources for immigrant and refugee families etc. (e.g. addresses, hours and telephone numbers of social service and community agencies). Information could also include helplines and websites.

**What can I do if I feel I am not coping well?**
The text here will describe local resources for health and mental health issues (e.g. addresses, hours and telephone numbers of medical clinics or local hospital) with associated requirements and fees for visits, as well as religious and community organizations and social service agencies. Information could also include helplines and websites.

**Other messages could be included here.**
Annex 2: Adaptation documentation form

Many adaptations described below in Table 3 are recommended and can be made in phase 1 of the adaptation process if deemed appropriate by the adaptation team (See the adaptation plan). Items labelled “consider” can be considered for adaptation in phases 2 and 3. Items labelled “optional in certain contexts” can be considered in phases 2 and 3 but are not appropriate for adaptation in the context of multi-centre research studies.

Remember:

1. Make only the most essential cultural adaptations to the content of the training package.
2. Consider adaptations to make the package more suitable for your local context and more responsive to the needs of local participants.

Table B.1. Form for documenting proposed adaptations to the caregiver skills training materials and delivery strategies.

<table>
<thead>
<tr>
<th>Adaptation principle (1)</th>
<th>Implementation (what changed)</th>
<th>Rationale (why it changed)</th>
<th>Evidence base (advice of adaptation team, adaptation workshop, pre-pilot, literature etc.)</th>
<th>Adaptation phase/date of change</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>LINGUISTIC AND CULTURAL CONSIDERATIONS</strong> (Modification of language, content, metaphors, concepts and goals in order to increase comprehensibility, cultural acceptability and relevance for participants)</td>
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<tr>
<td>LANGUAGE (vocabulary, phrasing, verbal style and other aspects of language should be similar to those of the intended participants)</td>
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<tr>
<td>Translation into selected local language</td>
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<tr>
<td>Focus on key terms to ensure the meaning of the term is maintained during the translation (see part 3)</td>
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<tr>
<td>Language use (vocabulary, phrasing, verbal style etc.) is culturally appropriate</td>
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<tr>
<td>Language use and literacy level are consistent with those of the intended participants</td>
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<tr>
<td>Adaptation principle (1)</td>
<td>Implementation (what changed)</td>
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<tr>
<td>Technical terms are replaced by plain language (easy-to-read language) whenever useful</td>
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<tr>
<td>Technical terms are explained by the addition of culturally and linguistically appropriate explanatory notes</td>
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<tr>
<td>CONTENT (cultural knowledge about values, customs and traditions)</td>
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<tr>
<td>Examples, facilitator role plays, stories and videos reflect the reality of the intended participants (i.e. appropriate character names [recommended] and genders, objects, settings, cultural references, local terminology and wording, etc.)</td>
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<tr>
<td>Colour scheme for materials is culturally appropriate</td>
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<tr>
<td>Consider: Incorporation of local practices (e.g. addition of culturally-appropriate welcomes or other rituals to group sessions)</td>
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<tr>
<td>Optional in certain contexts: Addition of relevant content to make the package more appealing to the intended participants (i.e. additional examples, pictures, stories etc.)</td>
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<tr>
<td>METAPHORS (symbols and concepts; sayings, idioms)</td>
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<td>Metaphors used are culturally relevant</td>
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<td>(e.g. “behaviour thermometer” in behaviour sessions)</td>
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<tr>
<td>Consider: Addition of local idioms or sayings to describe caregiver or child emotional states or behaviours</td>
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<tr>
<td>Optional in certain contexts: Addition of relevant explanatory stories and local examples</td>
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</tbody>
</table>
### Concepts (Conceptual Constructs i.e. How a Child’s Difficulties Are Conceptualized and Communicated – Including Availability of Linguistic Terms)

<table>
<thead>
<tr>
<th>Adaptation Principle (1)</th>
<th>Implementation (What Changed)</th>
<th>Rationale (Why It Changed)</th>
<th>Evidence Base (Advice of Adaptation Team, Adaptation Workshop, Pre-Pilot, Literature Etc.)</th>
<th>Adaptation Phase/Date of Change</th>
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<tbody>
<tr>
<td>Complex or ambiguous concepts are explained with additional explanatory notes</td>
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<tr>
<td>Plan to address cultural conceptions of the causes of developmental disabilities (e.g. divine punishment for caregivers’ wrongdoing, curses/hexes etc.) within the package. Possible methods of addressing these conceptions include adding a small component to the package, such as a group discussion, to respectfully acknowledge participants’ conceptual constructs and to identify any associated barriers to participation in the course (e.g. a belief that their child cannot make progress).</td>
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<tr>
<td>Plan to address cultural conceptions of the reasons for a child’s difficult or challenging behaviour (e.g. inherent badness/“bad child”, spirit possession etc.) within the package</td>
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<tr>
<td>Plan to address cultural conceptions of the reasons why the child is not talking (e.g. spirit possession etc.) within the package</td>
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<tr>
<td>Consider: Plan to address religious or other cultural concepts within the package</td>
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</table>

### Goals (Reflecting Cultural Knowledge of Values, Customs and Traditions)

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<tr>
<th>Adaptation Principle (1)</th>
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</tr>
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<tbody>
<tr>
<td>Optional in certain contexts: Adaptations intended to increase emphasis on culturally important secondary goals of the course (e.g. to promote caregiver well-being, human rights, social connectedness etc.)</td>
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<tr>
<td>CONTEXTUAL AND METHODOLOGICAL CONSIDERATIONS (Changes to methods or other aspects of the course in order to adapt the package to the social, economic, political and cultural context in which participants live. Considerations include cultural processes, norms and values, gender roles, availability of social support, and economic and human resources. Goal: to increase accessibility, feasibility and acceptability, and to overcome barriers to participation)</td>
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<td>Ensure that training materials, activities and evaluation methods are consistent with the literacy level of the intended participants in the language of instruction (e.g. additional illustrations could be added to the participant manual, the text could be changed or reduced, post-session evaluation questionnaires could be replaced by interviews etc.)</td>
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<td>Reduce barriers to participation for people with disabilities (e.g. select a location that does not present physical barriers, permit a support person to attend group sessions etc.)</td>
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<tr>
<td>Determine which of the optional modules, if any, will be offered (considering participants' needs, relevance of the content, feasibility, economic and human resources, training and supervision, acceptability etc.)</td>
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<td>Make changes to additional components of the package to fit the local context (e.g. text message reminders should be replaced with alternative methods where mobile telephones are not common, reminders can be sent by other appropriate staff members when facilitators have a high workload)</td>
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<tr>
<td>Optional in certain contexts: Increase general accessibility (e.g. provision of childcare during group sessions, childcare stipends, transportation or transportation subsidies, reminders etc.)</td>
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<tr>
<td>Optional in certain contexts: Increase feasibility (e.g. seek “buy-in” from other family members, especially those who may influence access to the course, by involvement in initial home visit or a course orientation, inclusion/exclusion of other family members in group sessions, choice of location, scheduling of group sessions etc.)</td>
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<td>Optional in certain contexts: Increase engagement and accessibility for male caregivers (e.g. role of family members, outreach and promotion methods, scheduling and timing of sessions and home visits [such as after-hours options, planning well in advance], gender choice for characters in role-plays, stories and examples, additional facilitator training etc.)</td>
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<td>Optional in certain contexts: Increase acceptability for participants (e.g. by providing food, beverages or other adaptations to improve participants’ physical comfort), providing small incentives for participation in group sessions (e.g. soap, children’s books etc.)</td>
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<td>Optional in certain contexts: Increase acceptability at the community level (e.g. develop a plan to promote community engagement and reduce stigma, examine the fit with other interventions and services etc.)</td>
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<td>Optional in certain contexts: Reduce risk of stigma or discrimination (e.g. discuss caregivers’ perceptions or concerns, community liaison activities, methods and means of outreach and promotion etc.)</td>
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<tr>
<td><strong>Optional in certain contexts:</strong> Increase participant engagement and buy-in (e.g. pre-training group orientation session, discussion of caregivers’ concerns that their parenting skills may be judged or criticized, promotion methods and strategies, adaptations to increase social support or group cohesion etc.)</td>
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<td><strong>Optional in certain contexts:</strong> Increase participant retention in the course (e.g. telephone call or in-person “catch-up” when a caregiver misses a session, one-on-one support for caregivers with more complex challenges etc.)</td>
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<tr>
<td><strong>Optional in certain contexts:</strong> Structural adaptations (e.g. choice of delivery location, flexibility in schedule of group sessions or home visits etc.)</td>
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<tr>
<td><strong>Optional in certain contexts:</strong> Tailored supervision structure and tools for facilitators (e.g. customized supervision structure/plan, addition of job aids, etc.)</td>
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<tr>
<td><strong>Optional in certain contexts:</strong> Adaptation of training and supervision methods to match facilitators’ experience levels (e.g. offering additional support or supervision, observation of group sessions by supervisors etc.)</td>
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<td><strong>Consider only with careful evaluation procedures in place:</strong></td>
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<tr>
<td>Significant structural changes to training materials, including reducing the length or number of sessions, or delivery in individual rather than group sessions.</td>
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</table>
### Adaptation principle (1)

<table>
<thead>
<tr>
<th>Implementation (what changed)</th>
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</tr>
</thead>
</table>

### PEOPLE (participant–facilitator relationship; ethnic / racial / gender / cultural similarities and differences)

- Consider facilitator-participant, ethnic, racial, gender, language and cultural/subcultural similarities and differences
  - (Comment on these factors and their importance)

- Consider other participant–facilitator contextual factors (e.g. lived experience, urban-rural background, socioeconomic status etc.)

- Consider cultural competency of facilitator depending on the degree of mismatch described above
  - (Comment on this)
Caregiver skills training
for families of children
with developmental delays
or disabilities

World Health Organization
20 Avenue Appia
CH-1211 Geneva 27
Switzerland