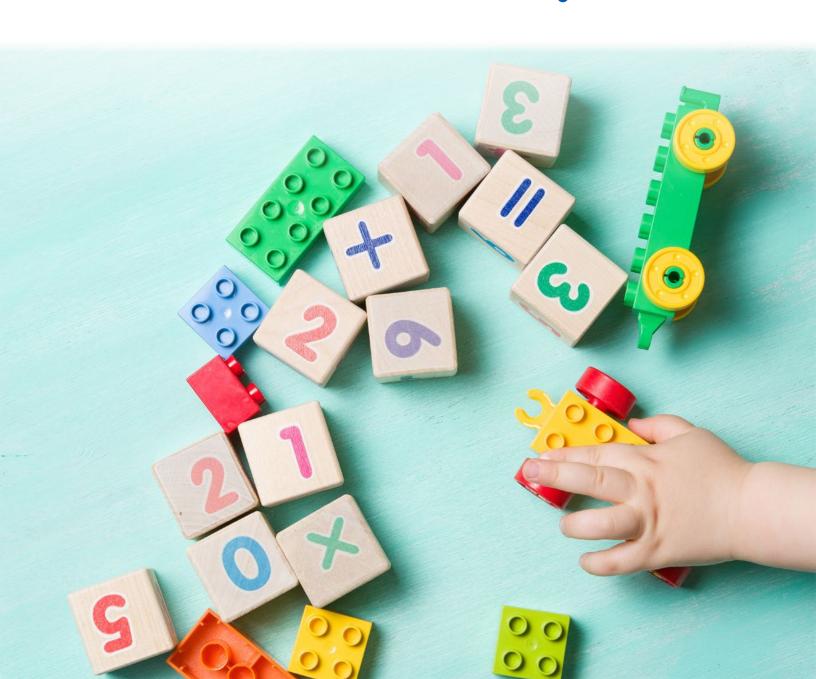


# Study Program Manual for Caregivers



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# Disclaimer

This manual contains recommendations based on recent evidence and clinical experience with constraint and bimanual therapy for children with cerebral palsy.

This manual was developed for caregivers and healthcare providers to use as a guide to provide practical suggestions to implement constraint and bimanual therapy and does not constitute professional clinical advice. Healthcare providers are required to exercise their own clinical judgment in using the manual and application of any information contained in this manual should be based on individual family/client/patient needs, the relevant circumstances, and local context. Caregivers are encouraged to seek professional advice to ensure the suggestions within are appropriate. Neither University of Calgary nor any of the authors and/or contributors of the manual are providing treatment services through the information contained in this manual. Moreover while every effort has been made to ensure the accuracy of the content of the manual at the time of publication, neither University of Calgary, nor any of its agents, appointees, directors, officers, employees, contractors, members, volunteers or related parties: (i) give any guarantee to the completeness or accuracy of the information contained herein; and (ii) TO THE EXTENT PERMITTED BY APPLICABLE LAW, ACCEPT ANY LIABILITY OR RESPONSIBILITY FOR THE USE OR MISUSE OF THE MANUAL BY ANY INDIVIDUAL OR ENTITY, INCLUDING FOR ANY LOSS, DAMAGE, OR INJURY (INCLUDING DEATH) ARISING FROM OR IN CONNECTION WITH THE USE OF THE MANUAL IN WHOLE OR IN PART.

# Statement of Purpose

This manual was created for caregivers of young children with cerebral palsy. The manual is intended to help caregivers prepare for and build competence to deliver home-based therapy. The therapy outlined is specific to the HEIGHTEN study (ClinicalTrials.gov Identifier: NCT05346887).

The manual summarizes important material. Caregivers may have more questions and are encouraged to speak with their therapy team. This manual is divided into sections with dividers to make it easy to find specific content. This format was chosen to make the manual a handy resource.

Caregivers are encouraged to provide feedback about the manual. Please share any ideas or suggestions with the research or therapy team. The principal investigator for this study, Dr. Adam Kirton, can be reached at adam.kirton@ahs.ca

# About the HEIGHTEN study

#### Who is HEIGHTEN for?

HEIGHTEN stands for Home-based Early Intensive Hemiparesis Therapy: Engaging Nurture. HEIGHTEN is a research study for children from 3 months to 2 years old with confirmed or suspected cerebral palsy (CP) and a weaker hand. This weakness is from an injury to the brain around the time of birth. It's usually not clear why the injury happened. The damage doesn't progress but can cause difficulties learning movements. These difficulties often become more obvious throughout childhood.

## Why should my child do therapy?

Occupational therapy (OT) can help children with CP improve movement skills on their weaker body side. HEIGHTEN is an OT-based program that focuses on hand and arm skills. Some children with CP may find certain movements harder than others because of different types and locations of brain injury. However, the type of movements that are challenging tend to be similar. The HEIGHTEN study was designed to target these challenging movements.

In this manual, your child's weaker hand will be called the "assisting hand". This terminology has been chosen because this hand usually helps (assists) the stronger hand.

## Is the HEIGHTEN therapy tailored to my child and family?

Every child and family are different. The HEIGHTEN therapy is built on this knowledge. The therapy approach is child- and family-centered. This means that you are involved in decision-making for therapy content. You are the expert on your child's needs and abilities and what will work for your family.

HEIGHTEN is a goal-directed therapy program. Occupational therapists and caregivers decide <u>together</u> what each child's goals are for the program. Your child will practice skills that will help complete his/her goals. This means HEIGHTEN is tailored to each child. We call this "individualized" therapy.



#### How is therapy done in HEIGHTEN?

Caregivers help children practice for 30 minutes each day for 18 weeks. Most of the therapy happens at home. Caregivers learn to help their child practice different skills. Occupational therapists and therapist assistants coach caregivers and children once a week. This may happen in-person or on a video call.

HEIGHTEN uses two therapies: constraint induced movement therapy (CIMT) and bimanual therapy. Both therapies encourage your child to use his/her assisting hand and arm. The more your child uses his/her assisting hand and arm, the easier it may become to move. Therapy might help your child do things like reaching, moving fingers, or picking up objects. This is because with more practice, your child's brain may better control movement of the assisting side.

During CIMT, your child's preferred hand is wrapped up ("constrained") so it can't be used. This encourages your child to use the assisting arm and hand in structured practice designed by the OT. Your child will practice things with one hand, like touching toys, reaching for objects, or picking up food. For CIMT, practice focuses on using just the assisting arm and hand.

During bimanual therapy, your child uses both hands together ("bimanual"). Your child may practice things like clapping, holding a cup with two hands, or opening a book. These actions



normally use two hands. Each hand may do the same movement, like in clapping. Or each hand may do a different movement, like holding a container while the other hand takes the lid off.

CIMT and bimanual therapy are both "evidence-based." This means research supports use of these therapies. In research studies, children have improved use of their assisting hand/arm after CIMT and after bimanual therapy. Some children improve more than others. Researchers are trying to learn why this is.

Both therapies can help improve hand and arm skills, and one is not better than the other. CIMT is often done before bimanual therapy. Improving one-handed skills in CIMT may help bimanual practice. This research study starts with CIMT to really focus on the assisting side. After doing CIMT for several weeks, children may start bimanual therapy.

## How will the preferred arm be constrained?

A soft mitt, pictured below, will be given to you. This mitt will be placed on your child's preferred hand during CIMT practice. If you like, you can decorate the mitt or find other creative ways to encourage your child to wear it. If the mitt isn't working for your child, let your therapy team know. They can help find other ways to "hide away" your child's preferred hand. The most important thing is that the constraint is safe and tolerable.



## Can constraint damage the preferred arm?

Research has shown that constraining the preferred hand is not harmful. The development of your child's preferred side will not be affected by constraint.

Your child's skin may be irritated by the mitt. If this happens, let your therapy team know. They know of other ways to "hide away" the preferred arm.

## Why do we practice so much?

Repetitive, structured practice can help improve movement skills, and may lead to lasting changes. This is because of brain plasticity, the ability of the brain to change itself. With repetitive practice, children's brains may change to improve movement control of the assisting hand arm.

Research in older children shows that the more children practice, the more they improve. For older children, about 60 hours is the minimum amount of practice for noticeable improvements. This makes daily practice important. Young children practice better in short bursts. Your child will practice for 30 minutes each day in HEIGHTEN. The practice doesn't need to be all at once. Practice can be in short bursts that add up to 30 minutes. This is called "distributed practice" since practice is spread over the day. The HEIGHTEN study is 18 weeks long, or about 4 months. This adds up to 60 hours of practice.

At the end of HEIGHTEN, occupational therapists will provide suggestions for continued practice. Your child may continue to benefit from therapy after 60 hours.

## why do we do therapy at home?

There are many benefits to home therapy. First, home therapy makes it easier to practice a lot. You don't need to travel. You don't need to plan appointments around daily naps. You can practice during play, mealtime, in the bath, or wherever and whenever works best for you and your child.

It is important that therapy becomes part of your routine. If it is part of your routine, your child can continue improving skills after HEIGHTEN is over. Practice using your own toys, in your home, and during your regular activities may make it easier for therapy to become a part of your daily routine.

## why am I in charge of daily therapy?

Caregivers deliver therapy in HEIGHTEN. There are a few reasons for this. You can practice when it fits best in your day. You will learn how to support your child's learning of new movements.



You will learn how to continue helping your child after HEIGHTEN is over. Your child will get more practice time since you can practice daily at home. We also hope you will feel more confident in your ability to support your child.

Delivering therapy might feel like a big job. You will have support to learn how to make it easier. Your clinicians (an occupational therapist or therapist assistant) will help you each week. You can ask questions and share any problems or successes you had during the week. All caregivers can be involved, but the same caregiver(s) need to attend the weekly sessions with the clinicians for continuity of care.

#### How will I meet the clinicians?

You may meet your clinicians (an occupational therapist or therapist assistant) in-person or over a video call each week. You and your therapy team can decide which type of visit will work best.

## what is the program schedule like?

For all children, the first 13 weeks of HEIGHTEN will be CIMT. Bimanual practice occurs in weeks 14-18 once your child is older than 9 months. This is because children begin to learn bimanual skills around 8 months of age.

Age	Program Week	Daily practice
Under 9 months	1-18	30 minutes CIMT
9 to 18 months	1-13 14-18	30 minutes CIMT 20 minutes CIMT + 10 bimanual
18 to 24 months	1-13 14-18	30 minutes CIMT 10 minutes CIMT + 20 bimanual

During week 18, your occupational therapist will help you plan for continuing practice after HEIGHTEN is over.

#### when do assessments happen?

There are three assessments. These assessments help researchers determine whether the therapy led to improvements. Each assessment will take 1.5 to 2 hours. The assessments will happen at a rehabilitation centre: Glenrose Rehabilitation Hospital in Edmonton, AB or Early Childhood Rehabilitation Centre in Calgary, AB. Appointments will be booked Monday to Friday during work hours.



#### what happens at assessments?

An occupational therapist and therapist assistant will complete tests and ask you questions. During this time, a team member can help entertain your child.

The table below lists tests that will happen at each assessment.

Baseline Assessment (less than 1 week before therapy)	Follow-up 1 Assessment (less than 1 week after therapy)	Follow-up 2 Assessment (8 weeks after therapy)
Goal setting Movement Tests Wear Activity Watch for 48 hours Video Analysis Questionnaires: Preparedness Depression Stress Sense of competence	Goal scoring Movement Tests Wear Activity Watch for 48 hours Video Analysis Questionnaires: Preparedness Depression Stress Sense of competence	Goal scoring Movement Tests Wear Activity Watch for 48 hours Video Analysis Questionnaires: Depression Stress Sense of competence Review demographics
Child development Demographics Medical record review	Satisfaction with therapy	3 1

#### 1. Goal Setting/Scoring

A trained therapist will help you identify three to five goals for your child's therapy. You will evaluate whether these goals were achieved at the follow-up assessments. Names of measures:

- Canadian Occupational Performance Measure (scored by caregiver)
- Goal Attainment Scaling (score by therapist)

#### 2. Movement Tests

A trained therapist will complete a 15-minute play session with your child. Your child will wear watches on both wrists to record arm movement. The assessment will be video recorded. We will use this video to assess how your child uses each hand/arm. One of three assessments will be done, depending on your child's age:

- Hand Assessment for Infants (HAI) for children 3-10 months old
- Mini Assisting Hand Assessment (mini-AHA) for children 10-18 months old
- Assisting Hand Assessment (AHA) for children 18 months and older



#### 3. Hand Function

After observing your child move, the therapist will classify your child's hand function. This will be done for children over 12 months old. Name of measure:

• Mini Manual Ability Classification System (mini-MACS)

#### 4. Activity Watch

Two activity watches will be sent home with you. Your child will be asked to wear these watches, one on each wrist, for 48 hours (2 days). These watches monitor arm movement.

#### 5. Video Analysis

A short video (30 - 60 seconds) of your child reaching will be recorded. The video will be used by a program called *MediaPipe* to examine how each hand/arm moves.

#### 6. Questionnaires

You will be asked to complete a series of standard questionnaires. The questionnaires will ask about your: child's birth and family history; anxiety and depression; stress; perceived competence; child's development; hopes and opinions about therapy. These questionnaires will take 30-45 minutes to complete. Names of questionnaires:

- Hospital Anxiety Depression Scale (HADS)
- Perceived Stress Scale (PSS)
- Parenting Sense of Competence scale (PSOC)
- Ages and Stages Questionnaire-3 (ASQ-3)
- Perceived Preparedness
- Program Satisfaction

#### 7. Medical Record Review

A research team member will review your child's medical record. If available, we will record information about your child's birth and diagnosis. If your child has had a brain MRI, the research team will review these images.

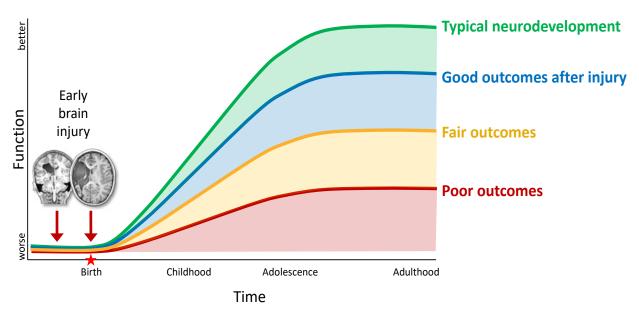
**Note:** All videos of your child will be kept confidential. All research data, records, and videos will be stored electronically on a secure network with encryption and password protection. Only research team members will have access to these data and records.



# About the Participants

## why are children so young in the HEIGHTEN study?

Children under the age of 2 years may have increased potential for brain plasticity. With increased brain plasticity, there may be greater improvements in how the brain controls movement. By improving hand and arm function early, children may have an improved developmental trajectory. A 'developmental trajectory' tracks how children progress as they age. Therapy may 'boost' a child's developmental trajectory to be closer to typical development.



#### How do children learn hand and arm skills?

Hand, wrist, and finger movements are often called "fine motor" skills because they use small muscles and small movements. Children may learn these skills in a predictable pattern, because one skill builds on another. Children may learn different skills at different times. Every child is different.

Child development is often monitored with developmental milestones. Milestones describe most - but not all - things children can do at a certain age. Your child may not learn skills at the predicted age. That is okay. Your child will learn in a way that suits him/her. You are doing therapy to help her/him learn skills.

#### What movements will children learn in the HEIGHTEN study?

HEIGHTEN focuses on movements that can be more challenging for children with hemiplegic CP. Children with hemiplegic CP often keep hands fisted and arms close to their body. These are flexed positions. Moving out of flexion may be difficult. These are often the movements learned in HEIGHTEN therapy. Depending on your child, he/she may work on straightening their elbow, turning their palm up (by rotating the forearm), straightening their wrist, opening their hand, and/or pulling their thumb away from the palm. In the Appendix of this manual, you will find detailed explanations of these movements.

#### What skills will children learn in the HEIGHTEN study?

Your child will focus on skills that suit her/his development and abilities. With the assisting hand, children may focus on reaching, pre-grasping, grasping, holding, releasing, and manipulating. Manipulating is moving an object with the fingers and hand. The object can be on a surface or held in the hand (in-hand manipulation). Children will be encouraged to reach across their body, towards the preferred side. This is called crossing midline, and can be challenging for children with CP.

Depending on your child's age, your child may practice two-handed skills. These may include reaching, holding, and transferring objects between hands. Sometimes hands do the same action ('symmetrical' actions), like clapping. Sometimes hands do different actions. One hand may hold or stabilize an object while the other hand does an action, like holding a container with one hand and opening it with the other. Or both hands do actions, like pouring from cup to cup.

The skills listed above may also develop strength and eye-hand coordination. Eye-hand coordination is using vision to guide movement.

## Will my child always have an "assisting" hand?

Yes. Almost all children, with or without cerebral palsy, develop a preferred (dominant) hand. The other hand is less preferred (non-dominant). The dominant hand is quicker and more skilled. The non-dominant hand is most often used for holding and stabilizing. These hand preferences usually become evident around 2 years of age.

For children with hemiplegic CP, there may be a greater difference between hands. This difference may be noticed at an earlier age. The assisting hand may be called a "helper hand" or "assisting hand" because it is rarely used on its own. By developing skills on the assisting side, your child's hand and arm may become more skilled and used more.



# Caregiver as Therapist: Engaging Your Child

# How do I engage my child in therapy?

You can engage your child by being engaged yourself. Give your child your full attention.

Toy selection and presentation is also important for keeping your child engaged and motivated to use their assisting hand. You want your child to feel successful as well as challenged. Here are things to consider:

- Choose toys that are developmentally appropriate, i.e., that match your child's social and physical skills
- Choose toys that your child can easily grasp/interact with
- Choose some toys that are just a bit challenging for your child
- Place toys so your child can easily grasp/reach them
- Show interest/excitement when your child interacts with toys
- Your therapy team will help you identify toys that are a good match for your child.



## How do I know if my child is engaged?

Therapy will be most successful if your child is engaged in the activities. You will be trying new activities with your child. To know if he/she is engaged, you will watch for non-verbal cues. Some are more obvious than others. Below is a list of cues that many children use. You may notice your child using other cues.

Engagement Cues	Disengagement Cues
(I like this!)	(I don't like this/I need a break)
<ul> <li>Stops moving</li> <li>Gazes intently at the object</li> <li>Reaches out to the object</li> <li>Turns head or eyes to the object</li> <li>Stretches fingers or toes towards you/object</li> <li>Smiles</li> <li>Coos</li> <li>Has eyes wide open</li> <li>Has a brightened face</li> <li>Raises his/her head</li> </ul>	<ul> <li>Turns eyes away</li> <li>Turns head away</li> <li>Cries or becomes fussy</li> <li>Burps, hiccups, passes gas</li> <li>Has droopy eyelids</li> <li>Falls asleep</li> <li>Squirms away</li> <li>Yawns</li> <li>Places hand in mouth</li> <li>Frowns</li> <li>Has dull-looking eyes</li> <li>Wrinkles forehead</li> </ul>

A disengagement cue can mean that it's time to change the activity, or that it's time to take a break. Remember, practice can be in short time blocks. If your child is disengaged, plan another practice block later in the day.

## How do I make changes to activities?

Sometimes, you may need to modify the activity to engage your child. Below are some examples. Your therapy team can help problem-solve ways to engage your child.

Things my child doesn't like	Things I tried in responding to "I don't like it cues"	How my child responds
Reaching for objects with her assisting hand	I only tried reaching activities for 5 mins instead of 20 min.	She did not cry this time
Stacking blocks with his assisting hand	I encouraged him to knock over the blocks after stacking	He did not give up stacking the blocks as quickly
Using both hands together	I sang action songs ("if you're happy and you know it")	She clapped on her own a few times

## Do I need an exact plan for each therapy session?

You will have a home program that provides suggestions for what to do. Your child may or may not do the exact activity you had planned. That's okay. Therapy will be more successful and fun if you follow your child's lead. Following your child's lead will help keep your child engaged. You can follow her/his lead by:

- 1. Watch: quietly observe your child's interests and cues.
- 2. Wait: give your child time to explore or create an activity.
- 3. Follow: copy what your child is doing.

Following your child's lead shows your child that you are both interested in the same thing.

## How do I challenge my child?

Challenging your child is important for learning and skill development. But activities can't be too hard, or your child may become frustrated or discouraged. Activities can't be too easy, or your child may not try or become bored. You want to target the 'just right challenge'. This is when activities aren't too hard OR too easy for your child.

How do you know what the 'just right challenge' is? Start with an activity that you know your child can do and likes to do. Then build on the activity, making it a little trickier. To introduce the challenge, you will first follow and then model:

- 1. Follow: copy what your child is doing.
- 2. Model: add to what your child is doing by showing him/her a new action or step with the same toy or activity.

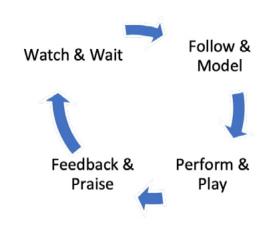
Watch your child for cues. If the activity is now too hard, you will see disengagement cues. Respond to these cues to adjust the level of challenge.

Your therapy team will provide suggestions on how to make activities harder or easier. Some ideas include changing the object (e.g., size, texture, weight), changing where you present the object (e.g., closer or farther away, stable surface or dangling). Another way to adjust the challenge is for you to be more or less involved in the activity. For example, helping your child move a rattle (physical support) is easier than pointing at the rattle (gesturing).



## How do I encourage my child?

Feedback and praise are wonderful ways to encourage and teach your child. The best time to encourage your child is after she/he has had a chance to try the activity. You will find that therapy activities have a rhythm. First, watch & wait. Then, follow & model. Next, let your child perform and play. Then provide feedback and praise on what he/she did. Repeat. This is referred to as a "teaching loop".



There are different types of feedback and praise you can provide. You can use broad praise, like "You did it!" You can use task-related comments, like "Great throw!" Task-related praise comments on the activity your child is doing. Cheerleading can also be used, with phrases like "You can do it, don't give up!" What type of feedback/praise you choose to use is up to you and you can see what your child prefers.

## Can therapy be fun?

Yes, therapy can be fun! To make it fun, practice will always be done while playing. You and your therapy team will find ways to practice movements while playing. You will use toys and games during therapy. You may even forget you're doing therapy.

Being playful and creative doesn't always come easily. That's okay. As you and your child practice, you will both learn. Your therapy team can help you think of ways to make therapy fun and playful.

## what if my child doesn't like therapy?

The beginning of therapy can be hard. Your child may not like the mitt on his/her preferred hand. It can also be very frustrating having to use the assisting hand and arm. This can be hard for both the child and caregiver. Remember, your child will adjust to the mitt, and therapy will become easier. Being consistent will help with the adjustment. Your therapy team will be ready to help you with this adjustment.



# Preparing for Home Practice

#### How do I know what to do?

Your therapy team will give you a home program. This document will provide suggestions on movements to work on each week. The document will also have a practice diary, where you will track practice time. You can write notes to share with your therapy team. Note any questions, challenges, or successes you experienced while practicing at home.

In the Appendix, you will find examples of home programs. Each child's home program is different. Your therapy team will make a program that is specific for your child.

#### where should we do therapy?

A space that is quiet and calm is best. Remove anything that distracts your child. Turn off the TV or radio and keep your phone on silent. You and your child need to able to really focus on moving his/her assisting hand and arm.

## when should I do therapy?

Your therapy team will help you identify times in your routine that may be easier to practice. Pick times when your child is alert (not sleepy). Practice can happen during play time, mealtime, and/or bath time. Before you start, make sure you have at least 10 minutes of time where you can fully focus on your child.



## How do I position my child for therapy?

It is important to place your child in a stable position. You want your child to feel secure when moving his/her assisting hand and arm. This means being in a position where your child does not have to work head control or sitting/standing balance. Suggested positions are listed below, but you can also discuss options specific to your child with your therapy team.

- 1. Children with limited head or trunk control:
  - Lying on the floor
  - Side lying with the assisting arm on top
  - Rolled towels, customized pool noodles, or small pillows can used if needed to create an ideal position
- 2. Children developing head and trunk control:
  - Car seat
  - Bouncer seat, positioned so that it doesn't bounce
- 3. Children with good head control and/or good or developing trunk control:
  - Floor seater with tray
  - Children with good head and trunk control
  - Sitting on the floor
  - In a chair that provides an upright and stable seating position
  - Rolled towels, customized pool noodles, or small pillows can used if needed to create an ideal position. Ask your therapy team for suggestions.
  - Highchair with tray

## How do I position myself for therapy?

You want to be in a position where you can make eye contact with your child. This will help you observe your child's reactions. You also want to be in a comfortable position to present different toys to your child.

## what toys or objects do I need?

You don't need any special toys or objects. You do not need to buy anything. Items in your house are often great objects for therapy, like wooden spoons. Any object or toy that your child is interested in is a great object.

Your therapy team will help you identify things that are appropriate for your child. You may want to collect a bin of these things to keep handy for practice times. As your child grows and learns new movements, toy preferences will change. Safe toys that are not choking hazards for your child are preferred.

Your therapy team will suggest toys based on your child's current skills. Below is a list of some toys, objects, and food to give you an idea of things that might be used:

#### Toys

#### Blocks

#### Bubbles

- Duplo pieces
- Toy people, animals, food
- Balloons, balls
- Stickers
- Pompoms
- Sensory balls (noise, textures)
- Shakers, rattle
- Push and go toys
- Chunky/knob puzzles
- Drum

#### Household Objects

- Foil paper
- Tissues in tissue box
- Bin of dry rice
- Foam soap
- Ice cube tray/egg carton
- Squirt bottle

#### Food

- Shredded cheese or cheese strings
- Small cereal (e.g., puffs, O cereal)
- Fruit (e.g., banana, blueberries)
- Peas
- Teething biscuits



## what activities will we do in therapy?

The activities you do will depend on your child's interests, age, and skill level. The home program your occupational therapist provides will have activity suggestions specific to your child. Activities are meant to be easy to do, so you don't need a lot (or any) set-up or clean-up time. Activities will be simple things that you may already know how to do. This will make it easier to teach your child.

Activities may engage your child's senses. Often the focus is on senses of touch, sight, and sound. These senses inform movement. For example, if an object looks squishy, you pick it up more gently. Using information from the senses, or "sensory processing", can be more challenging for children with cerebral palsy. Children need practice using their senses to learn how adjust movements for a variety of objects. This is why activities in HEIGHTEN may focus on sensory play. Sensory play may include things like water play, handling textured balls, or poking play doh.

At the end of the manual, there are some example home programs. These provide an idea of activities that might be in your child's home program. You will see activities like shaking a rattle, exploring books with flaps, action songs, ball play ... the list goes on.



# Weekly Therapy Sessions

## what are the expectations for therapy sessions?

Therapy sessions are meant to support you, the caregiver, in delivering home-based therapy. The session may be practice with your child, or a conversation without your child.

There are no expectations for you or your child during therapy sessions. It is OK if your child is upset or not willing to engage, or if he/she is asleep. Young children are not expected to perform their best during scheduled appointment times. The therapy team understands that your child's routine and mood are often changing.

If a play session isn't possible, you will have a conversation with your therapy team. Your therapy team will answer questions and problem-solve any challenges that you may have experienced during the week.

## In-person therapy sessions: What do I bring?

Bring your home program, you, and your child (if possible). Your home program will include your notes about home practice. Your therapy team will have toys ready.

## Virtual therapy sessions: How do I prepare?

Have your practice diary near you. You can use any device for virtual visits. A large mobile screen is ideal, like a tablet or laptop. Place your device in a stable position that has a view of you and your child. You will need both of your hands free for play. If possible, position your child appropriately for therapy with your toy bin nearby.



# Preparing for First Assessment

## Should I bring questions for my therapy team?

During the first assessment, you will have lots of time to ask questions and discuss HEIGHTEN with your therapy team. You can write down questions before your visit. You can also ask any questions that come to mind during the visit.

## How will we set goals for therapy?

Goal setting in HEIGHTEN is collaborative. You and your occupational therapist (OT) will decide on therapy goals together. You are the expert on what is meaningful to you and your child. Your OT is an expert in rehabilitation for children with CP. Together, you can identify goals for therapy that are both important and achievable.

Your OT will ask you about movements or activities that are hard for your child. This conversation is usually a starting point for identifying therapy goals. Your OT may suggest possible goals after talking with you. Goals will be based on your and your child's needs and strengths.

It can be challenging to think of goals for young children, since they are quickly growing and developing. It is okay if you don't have any goals in mind. You and your OT will work together to identify goals that are meaningful to you and your child.

Here are some example goals:

- Use right hand to bat at a hanging toy, like a mobile (4-month-old)
- Use right hand to grasp an easy-to-grasp toy (e.g., o-ball) held by caregiver at midline (6-month-old).
- Use left hand to reach and grasp a small toy from the table/tray (10-month-old).
- Hold/keep a toy in the left hand while poking with the right hand (10-month-old).
- Use both hands when eating yogurt, by using the assisting hand to stabilize the bowl and the preferred hand to use a spoon (18-month-old).

Children of the same age may have very different goals. There are no "right" or "wrong" goals. The best goal is one that is individualized and important to you and your child.



# Study Forms

#### Example Home Programs

Three example home programs are below. You may notice similarities between these examples. The same activities can be used for different target movements. You will receive an individualized home program, designed specifically for your child.

## Example 1: CIMT

#### **TARGET MOVEMENTS:**



#### 1. Reaching:

Gradually reaching a farther distance in front.



#### 2. Grasping:

Focus on gradually extending her thumb more.



#### 3. Holding on:

Focus on holding onto a toy in the palm of her hand.

#### STRATEGIES FOR HOME PRACTICE:

- Start with practicing grasping and reaching separately:
- For reaching Encourage reaching out to place his hand on a toy.
- For grasping Present toys close to his palm, off the table to start.
- Wait and pause when you present the toy to give time to actively extend his fingers vs.
  placing the toy in his palm.
- Give gentle support at his elbow as needed to support him with opening his hand.
- Include wider toys to encourage opening his hand as much as possible.

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#### HOME ACTIVITY IDEAS: \*while wearing mitt on preferred hand

- Banging a drum or toy piano.
- Feeling different textures, such as puree food, shaving cream or foam soap on the tray.
- Feeling streamers, pompoms, ribbons, or string of beads in a small bowl.
- Holding a teething biscuit or dissolvable food that fits in his palm. Examples: Mum-Mum, Veggie straw, Arrowroot.
- Rattles, bells, or shakers that make a sound.
- Toys with rings or links to take off, such as a ring stacker.
- Toys with a small base to hold and explore, such as little people, toy animals, or blocks.
- Knocking down a block tower you make.
- Pushing a big ball forward to you.
- Board books with textures or flaps.
- Toys with big buttons to push.



## Example 2: CIMT

#### **TARGET MOVEMENTS**



#### 1. Reaching:

Gradually reaching a farther distance.



#### 2. Grasping:

Working towards grasping a toy between thumb and fingertips.



#### 3. Holding on:

Holding a toy for gradually longer durations.

#### STRATEGIES FOR HOME PRACTICE:

- Give gentle support at your child's elbow as needed to support him with initiating with his left hand at first.
- Start with practicing grasping and reaching separately:
- For reaching:
  - o Encourage reaching out to bang, spin, swipe or touch a toy.
  - o Gradually present a smaller toy to reach to, as he is able to reach a bit further.
- For grasping:
  - Start with presenting toys close to his palm at shoulder height.
  - o Gradually move the toy down to the tray for child to grasp.
- Wait and pause when you present the toy to give time to actively flex his fingers.
- Start with grasping wider toys (handle/blocks/small ball) to encourage extending thumb.

#### HOME ACTIVITY IDEAS: \*while wearing mitt on preferred hand

- Banging a drum or toy piano.
- Feeling different textures, such as puree food, shaving cream or foam soap on the tray.
- Feeling streamers, pompoms, ribbons, or string of beads in a small bowl.
- Holding a teething biscuit or dissolvable food that fits in his palm. Examples: Mum-Mum, Veggie straw, Arrowroot.
- Rattles, bells, or shakers that make a sound.
- Toys with rings or links to take off, such as a ring stacker.
- Toys with a small base to hold and explore, such as little people, toy animals, or blocks.
- Knocking down a block tower you make.
- Pushing a big ball forward to you.
- Board books with textures or flaps.
- Toys with big buttons to push.

## Example 3: Bimanual

#### TARGET MOVEMENTS:





1. Using both hands together for exploring and combining toys.

#### STRATEGIES & HOME ACTIVITY IDEAS:

- Big toys Encouraging lifting a large, lightweight toy that requires both hands to lift. For example: large toy truck/bus, large book or puzzle board, large doll, or stuffed animal.
- **Big ball games** Encourage pushing a big ball forward with both hands to pass to you or to knock down a tower or other toys.
- Cloth bag Place Duplo, balls, little cars, or other smaller toys in a small cloth bag
  with a drawstring or Velcro closure. Encourage holding the bag open with his left
  hand and taking toys out with his right hand. Start with presenting the bag already
  open.
- Opening container Practice with little containers to take the lid off to find a
  pompom or snack item. For example, small David's tea container, empty cream
  container, or plastic egg. Present the container with the lid on and already loose.
- Musical instrument play Encourage banging a toy piano with both hands. Hold
  one drumstick in each hand to bang on a drum. Try holding the side of a small pot
  lid or drum with his left hand and banging it with a spoon or drum stick with his
  right hand. Try holding the handle on top of two small pot lids (one in each hand)
  to knock together like cymbals.
- **Water play** At bath time, play with large sponges (one in each hand) to squeeze to make waterfall. Try with a large sponge that requires both hands to hold. Play with foam soap or shaving cream on the side of the tub to encourage spreading on the vertical surface with both hands.
- **Snack time** Give snack food in a little cup to hold in his left hand and feed himself with his right hand. Try with a snack cup with a handle on the side. Encourage drinking from a sippy cup with two handles. Practice holding a small yogurt cup in his left hand and dipping spoon or removing spoon from cup to taste from.
- **Action songs** Sing slowly and encourage simple two-handed actions. For example: "If you're happy and you know it": clap your hands, sing hooray (both hands up); "Twinkle twinkle little star: open and close hands, both hands up.
- In and out play Present a little cup that fits in the palm of his left hand with little people or little animals inside to take out with his right hand.
- Together and apart Play with big Duplo or Velcro food to hold one side in each hand to pull apart.

## Practice Diary

The practice diary is very simple. Below is an example of a completed diary. Add as much detail as you can because these notes will help your clinicians support you.

Day	Time (mins)	Comments
Monday	10 + 10 + 10	Hard to fous today, practiced during mealtime
Tuesday	15 + 15	Two good practice sessions today. She was looking away a lot, so I switched activities often to keep her attention.
Wednesday	20 + 10	She realy liked pushing the light up buttons.
Thursday	30	Played in the bath for a long time. She didn't mind wearing the mitt this time.
Friday	10 + 10 + 10	I tried to increase the challenge, but I think it made it too hard. We were both frustrated.  Ask OT/TA for help with progressions.
Saturday	15 + 15	She doesn't like when I try to support her elbow. Are there other ways to help her?
Sunday	15 + 15	First practice was going really well, but then the doorbell rang, and we were distracted. Second practice was ok.

#### Other comments:

<sup>-</sup> Can I have more ideas for bath activities? That was the easiest practice this week

# Resources (Appendix)

#### Development of Fine Motor Skills

The table below is for reference. Not all children develop these skills in the order or at the ages listed.

#### 0-3 months old

- Fisted hands
- Random arm movements
- Looks at own hand
- Bring hands to mouth
- Uses whole arm to swing at targets
- Begins to hold objects in hands
- Fingers close around object in response to light pressure on palm

#### 3-6 months

- Hands are open most of the time
- Grasps rattle with palm
- Holds rattle for 1 minute
- Brings toys to mouth
- Shakes rattle
- Bangs 2 toys together
- Uses both arms to reach for toys
- Begins to move objects from one hand to the other
- Holds hands together

#### 6-9 months

- Begins to grasp and hold objects
- Uses all fingers ('raking grasp') to move objects
- Uses index finger to poke objects
- Removed objects from containers
- Begins to hold a bottle
- Rotates wrist when shaking a rattle
- Squeezes objects with a fist
- Plays with their hands

#### 9-12 months

- Can poke or point with one finger
- Turns pages in a book, a few pages at a time
- Begins to put small objects in a container
- Starts using index finger and thumb to grasp objects ('pincer grasp')
- Moves objects between hands
- Uses a fisted grasp to hold crayons/markers
- Can hold two objects in one hand

#### 12-18 months

- Claps hands
- Waves goodbye
- Stacks two blocks
- Scoops objects with a spoon/shovel
- Puts small objects in a container
- Scribbles on paper
- Begins to fit shapes into a puzzle
- Uses a pincer grasp
- Holds a marker in an upside-down position, thumb down

#### 18-24 months

- Puts rings on pegs
- Begins to hold crayon with fingertips and thumb
- Marks or scribbles
- Stacks 3-4 blocks
- Opens packages
- Turns pages one at a time
- Strings 3 beads on a lace
- Begins snipping with scissors

## Skill Progressions for Grasping

Development of grasping skills can be grouped into three levels:

- 1. Pre-grasping and reaching
- 2. Grasping
- 3. Refinement of grasping and object manipulation

These levels can be broken down into smaller skills, as described below. Information has been adapted from: Eliasson, A.C., & Sj0strand, L. (2015). Baby-CIMT manual [PDF]. Retrieved <u>HERE</u>

## Pre-grasping and reaching:

The first level focuses on reaching purposefully, or "goal-directed" reaching. This level also focusses on pre-grasping, which describes movements that children do before they can grasp toys. These are movements like touching or moving toys. To encourage these movements, it is important that your child likes the toy/object. It is also important that the toy is placed close to your child's hand.

What your child does	What you do	Suggested toys/activities
Begin reaching towards toys by touching, moving, and hitting them from a close position.	Show interesting toys and hold toys near your child's hand where they can easily see them.	Toys that make noise (like keys, rattles, maracas), colourful strings, light up toys, toys that play music.
Holds toys placed in their hand without dropping.	Put toys in your child's hand. You may need to help your child keep focus to keep holding.	Big plastic rings, small rattles, plastic spoons, and maracas.
Holds objects in their hand while moving their arms to wave or flap the toys around.	Give your child time to explore the objects and their own abilities.	Big plastic rings, small rattles, plastic spoons, and maracas. Toys with noise help keep your child's attention.
Scratching, pre-grasping, and squeezing.	Hold toys in front of your child or place toys on your child's tummy.	Hair bands, soft material (like a cloth or mitt), and tissue paper.
Trying easy grasping motions.	Place toys close to your child's hand, increasing the distance as it gets easier for your child. Some children may reach before grasping.	Strings, sticks, spoons in different colours, positioned and adjusted close to hand to be easy to grasp.
Reaching at a distance	Position toys at a distance where your child needs to reach for the object.	Balloons and/or tower of blocks to knock over.

## Grasping:

The second level focuses on grasp ability. Children often start to grasp as they explore objects. They may grasp and then interact with a toy by doing things like banging the toy or putting it in their mouth ("mouthing"). With repetitive practice, grasping actions become more precise. The grasp will look smoother. Interacting with different shapes and sizes of toys will also help your child learn how to adjust their grasp for each object.

What your child does	What you do	Suggested toys/activities
Grasps easy-to-grasp objects from easy positions. Often drops the object after grasping.	Hold toys in easy positions for your child to grasp from, like right in front of his/her hands and oriented in the same direction as the palm of the hand. Expect your child to drop the toy, especially when you present a new toy.	Plastic spoons, objects with thin handles, o-balls, bag-clips, and maracas.
Grasps objects in different positions, including reaching to grasp objects at different distances.	Hold toys at different distances. Increase the challenge by increasing the distance from your child.	Any toy of interest, with a size and shape that your child can grasp.
Increases the frequency and speed of grasping and releasing actions.	Frequently provide toys of that your child can grasp. This encourages releasing, which is important skill linked to grasping.	Use a variety of objects from different locations to encourage many grasping repetitions.
Explores objects using different actions, like waving, banging, pressing, and mouthing.	Provide objects with different shapes, sizes, sounds, and textures.	Packages, rubber objects, and cones.
Explores objects using finger movements, like squeezing and regrasping.	Provide objects with different surfaces/textures and objects that can change shape (be squished).	Things from nature can be an option, like twigs or wrapping or tissue paper.
Increases precision in grasping, by orienting the arm/hand and adjusting grip size.	Provide objects that need to be grasped in a special way, like toys with a handle. Place them in different positions that encourage your child to open their hand and rotate their wrist.	Bigger toys, sticks. Objects with handles.

## Refinement of grasping and object manipulation:

The third level focuses on grasping more precisely. This involves adjusting the hand appropriately for the object. Children need to interact with all different types of objects in different positions to learn how to adjust their hand and arm. At this level, children begin to use less awkward grasps. Object manipulation is also observed. This involves using an object for an intended purpose, like pushing buttons or pulling the lid off a container.

What your child does	What you do	Suggested toys/activities
Grasps, releases, and drops objects of different sizes and in different positions.	Place toys at different distances and in different locations, like on the table or in boxes. This will encourage your child to try to grasp and release objects from different positions.	Small toys, objects with small bases, and fragile things such as crackers and cereal. Baskets and boxes of different sizes for the chosen objects. Play giveand-take games to pass toys back and forth.
Positions their hand before grasping, independent of the toy's location.	Place or hold objects to promote wrist rotation and other hand adjustments.	Stickers or small toys.
Grasps with increased precision using the tips of their fingers, making it possible to handle more fragile objects.	Present small objects in different locations.	Small toys, pearls, and buttons (can be on a string for safety) placed in bowls. Objects with small bases, such as standing dolls.
Points at pictures and presses buttons	Encourage your child to use their index finger. Show them how by modeling the action.	Books with a lot of details/pictures, finger puppets. Toys with action buttons.
Catches moving objects.	Vary the speed of moving objects. Roll objects along the floor or table.	Balls of different size.
Completes simple sequences of actions.	Introduce activities with sequenced step that your child can understand. The activities may have two or more steps.	Place a spoon in a cup; remove an object from a bowl; lift an upside-down cup to grab a hidden cube; press buttons on toys to make sounds.

# Types of Grasps in Infancy and into Toddlerhood

Crude Palmar Grasp A crude palmer grasp involves grabbing at objects with the pinkie side, or palmar side, of their hand. The thumb is not used yet.	
Palmar Grasp The entire hand and thumb are used to grasp at objects.	
Radial Palmar Grasp The thumb side of the hand is used more to grab at objects, although all fingers are involved.	
Raking Grasp The fingers are bent (flexed) to bring objects into the hand.	
Radial Digital Grasp The middle finger to thumb does the grasping. In the beginning, the pads of the fingers are used to grasp, not the fingertips.	
Inferior Pincer Grasp The pads of the index finger and thumb are used to grasp.	
Pincer grasp The tips of the index finger and thumb are used to grasp the object.	
Palmar Supinate Grasp This is a fisted grasp, with the thumb wrapped around the top of the object.	
Digital Pronate Grasp The fingers point down towards the bottom of the object. All fingers are used.	

#### Hand and Arm Movements

Your therapy team may introduce you to anatomical terms of motion. Terms typically describe a movement around a joint. For example, "shoulder extension", where the shoulder is the joint and extension is the movement. Movements can be grouped into opposites:

- Flexion/extension
- Adduction/abduction
- Supination/pronation

Те	rminology	Motion	Diagram
	Flexion	Move upper arm forwards.	
Shoulder	Extension	Move upper arm <i>backwards</i> .	
Shou	Abduction	Move arm sideways, <i>away</i> from the body.	
	Adduction	Move arm sideways, towards the body.	
wo	Flexion	Bend elbow, bringing wrist closer to the upper arm.	
Elbow	Extension	Straighten elbow.	

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Wrist	Flexion	Bend wrist so palm faces towards the arm.	T
	Extension	Bend wrist so palm faces away from the arm.	
	Pronation	Rotate the forearm into a palm <i>down</i> position.	7
	Supination	Rotate the forearm into a palm <i>up</i> position.	
Thumb	Abduction	Move thumb sideways, <i>away</i> from the palm.	S. S
	Adduction	Move thumb sideways, <i>towards</i> from the palm.	5
Finger	Flexion	Bend fingers towards palm.	
	Extension	Straighten fingers away from palm.	S. S