

# Participant Engagement Module Training Manual

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COLORADO LONG-TERM SERVICES AND SUPPORTS  
(LTSS) ASSESSMENT TOOL



**COLORADO**

Department of Health Care  
Policy & Financing

Prepared by HCBS Strategies, Inc.  
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# Participant Engagement Module - Training

## Purpose

The purpose of the Participant Engagement module of the Assessment tool is to explore ways in which the participant can engage in the decision-making process and in controlling service delivery so that services meet his/her preferences and needs. A key component in the design of person-centered assessment and planning approaches is the engagement of participants (to whatever extent is possible for them). The module covers two aspects of participant engagement: self-advocacy and preferences for receiving and understanding information about services.

## Overview of Contents

**Self-advocacy** is the action of representing oneself, including views and interests. Self-advocacy includes effective communication, negotiation and asserting one's personal interests, desires, needs and rights. It also involves making informed decisions and taking responsibility for those decisions. For purposes of this module, the ability to self-advocate includes representing oneself in a range of circumstances. It may include formal meetings to plan services/supports or providing direction to service providers about how the participant prefers to receive supports.

The assessor should assume that every participant has some capability for self-advocating, even if the participant has challenges in understanding information or expressing him/herself. Some individuals may need encouragement, assistance and/or training to self-advocate. Other individuals may have a strong capacity for self-advocating but will need information to be presented or structured in a manner that is understandable to them. The practice of person-centered assessment and discussion includes finding ways to help the participant engage to the extent possible and desired. The sections contained in this module include the following:

- 1. Self-advocacy** – Explores the participant's perceptions, abilities and experience with self-advocating.
- 2. Receiving and Understanding Information** – Identifies the participant's preferences for receiving information about services.
- 3. Referrals and Goals** – Identifies goals and referral needs for engagement in service planning and delivery.

## General Instructions for Completing the Module

The module includes items to reflect the perceptions and interest of the participant. The assessor will need to use interviewing techniques to gather information needed to code this module. Please review the guidance for examples on how to start these conversations. In the Section Instructions, the guidance provides some examples of prompts for items.

In some situations, the assessor may obtain or receive information from others who know the participant. This information can be taken into consideration for purposes of assessing support needs for self-advocacy, however the intent of the module is to reflect the **perceptions and interests** of the participant and not others.

## Special Instructions for Children and Age-Specific Items

This module contains items that may be skipped or only asked of participants of a specified age. Items and response options in orange font are intended for children. Other items may include directions to skip for participants below a certain age.

## Section Instructions

### Section 1: Self-advocacy/Advocacy

The assessor will record the participant's perceptions about his/her ability and interest in self-advocating. The assessor should explain the purpose of the section. For example:

*It is important to have you involved in making decisions about your services. I want to talk with you for a few minutes about what you see as the best way to do this.*

If the participant has a guardian, the guardian and the participant should work together to respond to the items in this section. For participants with challenges in understanding or responding, the assessor should still work to elicit responses.

Assessment Item	Guidance
<b>Section 1: Self-advocacy/Advocacy</b>	
<p><b>1. Participant is able to self-advocate.</b></p> <ul style="list-style-type: none"> <li><input type="radio"/> Yes</li> <li><input type="radio"/> No [Do not complete module.]</li> </ul> <p>For participants &lt;14, skip to Item 2.</p>	<p>Assessors should assume that all participants can indicate his/her preferences or choices in his/her own way. This may occur through verbalization, gestures, devices, or other forms of communication.</p> <p>For purposes of this module, the ability to self-advocate includes representing oneself in a range of circumstances. It may include formal meetings to plan services/supports or direction to service providers about how the participant prefers to receive supports.</p> <p>Select "No" only if the participant is incapable of any meaningful engagement and explain in the text box provided.</p> <p>Item 1 will only be asked of participants age 14 and older. If the participant is under age 14, the assessor will work with the parent/guardian to determine the capacity and desire to advocate on behalf of the participant.</p>
<p><b>2a. Speaking up for self/participant about what he/she needs:</b></p> <ul style="list-style-type: none"> <li><input type="radio"/> No assistance needed or wanted at this time</li> <li><input type="radio"/> Speaks up/asks for what is needed but could benefit from self-advocacy/advocacy training</li> <li><input type="radio"/> Needs some ongoing assistance to self-advocate/advocate</li> </ul>	<p>Indicate the response that most closely represents the participant's perceptions. For example:</p> <p><i>Linda, let's talk about any help you need to speak up for yourself or to ask for what you want. Are there areas in which you need help to feel comfortable to do so?</i></p> <ul style="list-style-type: none"> <li>• <i>Do you know who to talk to if you are unhappy with your services? Would you feel comfortable with that or have you ever had to do that?</i></li> </ul>

Assessment Item	Guidance
<b>Section 1: Self-advocacy/Advocacy</b>	
<ul style="list-style-type: none"> <li><input type="radio"/> Must depend on someone to let others know what he/she wants</li> <li><input type="radio"/> Other:</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Do you feel like you are listened to by people who support you?</i></li> </ul>
<p><b>2b. Knowing and understanding rights and responsibilities</b></p> <ul style="list-style-type: none"> <li><input type="radio"/> No assistance needed or wanted at this time</li> <li><input type="radio"/> Somewhat familiar with rights/responsibilities but could benefit from additional training</li> <li><input type="radio"/> Needs ongoing support/assistance to understand rights and responsibilities</li> <li><input type="radio"/> Depends on someone else to know about and advocate for rights and responsibilities</li> <li><input type="radio"/> Other:</li> </ul>	<p>Indicate the response that most closely represents the participant’s perceptions. For example:</p> <p><i>Linda, you have certain rights in planning and receiving your services. For example, you have the right to choose the provider of your services. You also have some responsibilities. For example, if you will be gone to your daughter’s home for a visit, you should let your provider know that you will not be at home to receive your in-home service. What help or assistance do you need to feel comfortable to know and understand your rights and responsibilities?</i></p> <ul style="list-style-type: none"> <li>• <i>Do you have information about your rights and responsibilities? Do you need someone to help with explaining those rights and responsibilities?</i></li> <li>• <i>If you felt your rights were being ignored, would you be comfortable in doing something about it? What help do you think you might need?</i></li> </ul>
<p><b>2c. Navigating LTSS system issues</b></p> <ul style="list-style-type: none"> <li><input type="radio"/> Able to take the lead/work with the participant and case manager to develop a plan meeting needs/preferences</li> <li><input type="radio"/> Could benefit from training about increasing leadership/engagement and working with others to develop a plan for LTSS</li> <li><input type="radio"/> Needs ongoing assistance to engage in the development of a plan for LTSS</li> <li><input type="radio"/> Must depend on someone else to navigate system and work with others to develop a plan that meets his/her needs and preferences</li> <li><input type="radio"/> Other:</li> </ul>	<p>LTSS systems may seem overwhelming to many people. The primary focus of this item is to address the ability of the participant around:</p> <ul style="list-style-type: none"> <li>• Continued financial and functional eligibility (including reporting information necessary for continued eligibility)</li> <li>• Leading and/or engaging in the planning for LTSS programs and services</li> <li>• Making informed choices about services and providers</li> </ul> <p>Indicate the response that most closely represents the participant’s perceptions.</p>
<p><b>2d. Ability to help others understand needs and preferences for how supports/services get delivered.</b></p> <ul style="list-style-type: none"> <li><input type="radio"/> Is able to effectively explain needs and preferences in planning and directing how services should be delivered</li> <li><input type="radio"/> Could benefit from training on how to explain needs and preferences for</li> </ul>	<p>This item focuses on the participant’s capacity to self-advocate for how services are delivered. This includes explaining needs and preferences during the planning process as well as directing staff performance of support activities (e.g., assistance with personal needs, etc.)</p> <p>Indicate the response that most closely represents the participant’s perceptions.</p>

Assessment Item	Guidance
<b>Section 1: Self-advocacy/Advocacy</b>	
<p>planning and directing how services should be delivered</p> <ul style="list-style-type: none"> <li><input type="radio"/> Needs ongoing support/assistance to explain needs and preferences for planning and directing how services should be delivered</li> <li><input type="radio"/> Must depend on someone else to explain needs and preferences in planning and directing how services should be delivered</li> <li><input type="radio"/> Other:</li> </ul>	
<p><b>3. Describe any barriers, opportunities, or challenges for the participant/parent/guardian related to items 2a-d.</b></p>	<p>Briefly summarize any challenges or opportunities for the participant in being able to self-advocate. For example:</p> <p><i>Linda feels reluctant to ask for a change in schedule for her in-home services, even though the current schedule conflicts with other activities she would like to do. She is worried about inconveniencing her staff person. She agreed to work with her daughter and case manager to develop a quarterly schedule to present and discuss with her provider.</i></p> <p><i>Linda would like to attend a meeting to learn more about how to self-advocate.</i></p>
<p><b>4. Indicate whether participant parent/guardian wants to be contacted by an advocate representative/advocacy agency for further information.</b></p> <ul style="list-style-type: none"> <li><input type="radio"/> No. Is already involved with self-advocacy/advocacy organization, mentors or peer group</li> <li><input type="radio"/> No. Does not want to be contacted</li> <li><input type="radio"/> Yes. Wants to be contacted for help with or training in self-advocacy/advocacy</li> <li><input type="radio"/> Unsure or no response</li> </ul>	<p>If the participant is not familiar with advocate representatives, briefly discuss the role of an advocacy agency/representative. For example:</p> <p><i>Linda, the next item is about whether you would like to be contacted by an advocate representative. This person would work with you to ensure that you understand your rights and can provide you with information about your options. Would this be something you're interested in?</i></p> <p>Staff should also mention that advocate representatives typically don't work within the SEPs/CCBs, and an additional referral will usually be necessary if the participant wishes to be contacted. Examples include ombudsman and Centers for Independent Living.</p> <p>Indicate the response that most closely represents the participant's perceptions.</p>

## Section 2: Receiving and Understanding Information

This section includes items to find out about participant preferences and needs for receiving and understanding information related to programs and services.

Assessment Item	Guidance
<b>Section 2: Receiving and Understanding Information</b>	
<p><b>1. Indicate ways in which the participant/parent/guardian is able to obtain and understand general service information. Check all that apply. !</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Able to read and understand letters, pamphlets, booklets, etc.</li> <li><input type="checkbox"/> Able to fill out health forms</li> <li><input type="checkbox"/> Prefers verbal information (e.g., audio booklets, screen reader, video explanation)</li> <li><input type="checkbox"/> Needs to have someone review and explain information being received.</li> <li><input type="checkbox"/> Needs assistance to answer questions related to health or other needs</li> <li><input type="checkbox"/> Will ask for assistance if not clear about the information.</li> <li><input type="checkbox"/> Would attend meetings or seminars if available.</li> <li><input type="checkbox"/> Prefers to use online tools to research information, if available.</li> <li><input type="checkbox"/> Other _____</li> </ul>	<p>This item is mandatory. Indicate the responses that most closely represents the participant’s preferred method(s) of receiving information. Check all that apply.</p>
<p><b>2. Participant needs materials in alternative formats, such as large type or braille versions of written information. !</b></p> <ul style="list-style-type: none"> <li><input type="radio"/> No</li> <li><input type="radio"/> Yes. Describe preferred format _____</li> </ul>	<p>This item is mandatory. Staff should indicate any alternative mechanisms for understanding information.</p>

## Section 3: Participant Direction

The Participant Direction section provides guidance to a discussion about Participant-directed service delivery options. These early conversations help the participant or, parent/guardian to be aware of the options. The assessor may not review all the delivery options at the initial intake meeting as participants and/or parents/guardians may be overwhelmed with the amount of information they have received. A decision about choosing a Participant-directed option is not expected at the time of assessment. This will occur during the development of the Support Plan.

For many participants/parents/guardians, information provided during the assessment may be the first introduction to Participant-directed service options. The assessor should complete this module if one of the following scenarios applies to the participant:

- It is the participant’s initial assessment
- Participant is enrolled in a HCBS waiver and is not receiving supports through a Participant-directed service delivery option

The assessor does NOT need to complete this module with participants who are already using a Participant-directed option. However, the assessor should examine whether they are in the most appropriate Participant-directed option during the support planning process.

**Item 1**

1. Determination of participant’s/parent/guardian(s)’ interest in participant-direction

If you/your child are/is eligible for long term services and supports, you may have the option to self-direct some of those services, depending on what you/your child are/is eligible for and services that are chosen. This means that with the support of your case manager you will have an active role in selecting who comes into the home, when they come into the home, and what they do when they come into the home. This is different than traditional home health, personal care or homemaking services provided through an agency. In participant direction, you or a representative acting on your behalf control how services are delivered, including choosing and managing caregivers.

If you're interested we can get you additional information about these options. If you are not interested right now, that's okay and if you change your mind we can talk it about it at another time.

*Also, if your/your child’s needs or goals change, you may want to change the chosen service delivery model, if available, including making changes to the allowed budget and the people who provide you services. If this is the case, contact your case manager to discuss service options*

Is participant/parent/guardian(s) interested in participant direction? 

- Yes, describe information provided and next steps in supporting the discussion
- No, describe why not, \_\_\_\_\_
- Participant/parent/guardian(s) not ready to discuss participant-direction, identify timeframe for bringing up discussion again: \_\_\_\_\_

**Section 4: Referrals and Goals**

This section contains items and information important to move forward to support planning. Referrals may be made prior to the Support Plan.

Assessment Item	Guidance
<b>Section 4: Referrals and Goals</b>	
<b>1. Participant/Parent/guardian information for setting up Support Plan meeting completed?</b> 	This item is mandatory.

Assessment Item	Guidance
<b>Section 4: Referrals and Goals</b>	
<ul style="list-style-type: none"> <li><input type="radio"/> No [Complete Personal Story, Section 3 Items if participant agrees.]</li> <li><input type="radio"/> Yes</li> <li><input type="radio"/> Chooses not to complete</li> </ul>	<p>The Personal Story module contains information about preferences for setting up the Support Plan meeting. The participant may have already provided information for this item in the Personal Story.</p> <p><b>If participant did not already complete the items and is agreeable to having the assessor assist in completing,</b> the assessor will work with the participant to complete the items for the “My Support Planning Meeting” section (Section 3) of the Personal Story module.</p>
<p><b>2. What is important to the participant/parent/guardian in self-advocating/advocating and engaging around his/her/the participant’s services?</b> </p> <hr/>	<p>Indicate any goals or outcomes the participant would like regarding self-advocating or maintaining/improving engagement in planning and controlling services.</p> <p><i>For example: Linda would like to meet with self-advocacy organizations to find out more about the support and training they can provide to her.</i></p>
<p><b>3. Support and/or information needed and desired by participant/parent/guardian for engagement and self-advocacy/advocacy:</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Contact with agency, advocate or peer-advocate to provide additional information or navigation assistance</li> <li><input type="checkbox"/> Training to increase self-advocacy/advocacy capabilities</li> <li><input type="checkbox"/> Information about options for advocacy or self-advocacy support</li> <li><input type="checkbox"/> Assistance to meet reasonable accommodation needs _____</li> </ul>	<p>Indicate any follow-up desired by the participant.</p> <p>Check all that apply.</p>
<p><b>4. Referrals</b> </p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Aging and Disability Resources for Colorado (ADRC)/No Wrong Door</li> <li><input type="checkbox"/> Center for Independent Living (CIL)</li> <li><input type="checkbox"/> Area Agency on Aging (AAA)</li> <li><input type="checkbox"/> Colorado Chapters of The Arc</li> <li><input type="checkbox"/> Colorado Cross-Disability Coalition (CCDC)</li> <li><input type="checkbox"/> Colorado Gerontological Society</li> <li><input type="checkbox"/> Other advocacy agency: _____</li> <li><input type="checkbox"/> Other _____</li> </ul>	<p>Indicate any referrals needed or desired.</p>
<p><b>5. Support Plan Implications:</b> _____ </p>	<p>Indicate any considerations or action steps related to support planning.</p>

Assessment Item	Guidance
<b>Section 4: Referrals and Goals</b>	
	<i>For example: Linda is interested in Participant-directed options.</i>
<b>6. Recommended changes, clarifications or other issues: Describe any changes to the items (included changes to training) in this section that the case manager believes will make the items clearer and/or collect more useful information.</b>	Describe any recommendations for improving the assessment module or training, including adding/removing items or items that require further clarification.