

# Colorado Department of Health Care Policy and Financing Consumer Directed Care

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## Consumer Directed Care Evaluation Survey Instrument & Methodology

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## Introduction

This document outlines the proposed survey methodology to be used by TriWest Group (TriWest) to measure participant and attendant satisfaction with two Colorado participant-directed care programs (Consumer Directed Attendant Support Services and In-Home Support Services). The proposed survey methodology will also measure self-reported health outcomes for participants.

This document outlines the proposed sampling strategy and methods for administering surveys. In addition, this document outlines proposed survey language for introducing the survey and outlining the principles of informed consent to participant. The final section of this document includes four tables of potential survey questions:

- 1) Recommendations of the questions we believe are the best to include for this evaluation work. These questions are based on questions identified in a previous review of evaluations conducted in similar programs, nationally.<sup>1</sup>
- 2) A list of secondary questions. This includes questions that were identified in the literature and could be good questions, but may not be a high of a priority, given the desire to limit the amount of time a respondent needs to complete the survey.
- 3) A list of questions that we believe could make up a separately administered attendant survey. We plan to work with Department staff to explore options for how this survey could be administered.
- 4) Finally, we include questions that we do not think match well with the goals of this evaluation effort. We present these questions for Department staff to review and determine whether any of them represent information vital to the evaluation effort and may be worth including despite increasing the survey length.

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<sup>1</sup> Further details can be found in the Evaluation Recommendations document.

## Survey Sampling

The ultimate aim of this evaluation is to compare the experiences and outcomes of participants in the Consumer Directed Attendant Support Services (CDASS) and In-Home Support Services (IHSS) programs with those who receive “traditional” state benefits (private duty nursing and long-term home health care). However, individuals each enter the CDASS and IHSS programs through different Medicaid waivers, based on their health needs. Because these populations are likely to be very different, we will utilize a stratified sampling methodology to pull groups of respondents from each waiver type.

We are proposing to draw a sample of participants, grouped (stratified) by a combination of program enrollment (CDASS, IHSS, or traditional [agency- or home-based, long-term home health]) and waiver eligibility. This will ensure an overall sample of respondents that is, first and foremost, representative of the populations surveyed, and that also contains enough surveys within each subgroup to allow for comparison and/or to statistically control for any differences based on waiver type and/or types of services received as a result of medical need. (Clients can participate in either the CDASS or IHSS under one of five individual waivers—four waivers for the CDASS program and three waivers for the IHSS program, two of which overlap across the two programs). We also propose to identify a comparison group of participants in traditional agency- or home-based services (long-term home health) who would be eligible for one of the five waivers. Subgroups are listed in the “Survey Sampling Approach” table on the following page.

If the total subpopulation is smaller than the target of 50 completed surveys, we will include the entire sub-population in the sample and take extra efforts to increase response rates (including making follow-up telephone calls, sending reminders and additional copies of the surveys, etc.).

In addition, consumers participating through the Medicaid Elderly, Blind and Disability (EBD) Waiver make up a disproportionately large proportion of participants. Therefore, to gain representative samples for these groups, we have elected to use a randomly selected sampling frame that will allow us to reach a target number of surveys equal to 10% of that population, leading to a larger number of surveys for those groups.

The target comparison group will be a randomly sampled group of individuals who are not participating in CDASS or IHSS services. These will be individuals who meet waiver criteria and who receive agency-based care or home-health care (private duty nursing or long-term home health care).

Survey Sampling Approach			
Survey Group	Target Completed Surveys (30% Response)	Sample Frame (Random Sample Requested from Department)	Total Population Served
CDASS/BI Waiver	30	54	54
CDASS/CMHS Waiver	50	173	173
CDASS/EBD Waiver <sup>2</sup>	300	1,000	3,413
CDASS/SCI Waiver	30	58	58
<b>Total CDASS Sample</b>	<b>410</b>	<b>1,285</b>	<b>3,164</b>
IHSS only/EBD Waiver (adults)	200	675	2000
IHSS + Long Term HH	50	165	346
IHSS/CHCBS Waiver (pediatric)	50	165	405
IHSS/SCI Waiver <sup>3</sup>	--	--	--
<b>Total IHSS Sample</b>	<b>300</b>	<b>1,005</b>	<b>2,751</b>
State Plan – Long Term HH only	50	165	--
State Plan – Private Duty Nursing	50	165	NA
State Plan – LTHH and Personal	100	300	NA
State Plan – Pediatric (Personal)	50	165	NA
State Plan – Pediatric (LTHH)	50	165	
<b>Total Comparison Group<sup>4</sup></b>	<b>300</b>	<b>960</b>	<b>NA</b>
<b>Total Sample</b>	<b>1,010</b>	<b>3,250</b>	<b>NA</b>

The sampling frame will include all clients receiving services at any time during SFY 2017, regardless of enrollment date.

<sup>2</sup> This will include a distribution of CDASS clients who receive just personal care/home health services, long-term home health care or both. Because of the size of the sampling frame and the random sampling method, this should match the population overall.

<sup>3</sup> The total population of this group falls below the “Safe Harbor” threshold, meaning there is a risk of identifying an individual just by virtue of group membership. The IHSS/SCI Waiver group will be included with the IHSS/EBD waiver group for the purpose of survey sampling.

<sup>4</sup> Total populations for these groups is not known at this time. If the actual total population is less than the sampling frame requested, we will ask the Department to the entire population, rather than a random sample.

## Survey Administration

We have had the opportunity to meet with the Participant Directed Programs Policy Collaborative (PDPPC) and with Department staff to discuss past survey experiences and potential concerns of participants who will be asked to complete a survey. Overall, the choice to make the survey administration anonymous is the best option to alleviate participants' concerns and could potentially increase response rates.

Individual identifying information will not be collected in the surveys. However, each survey will be marked according to the respondent's program/waiver grouping (e.g., CDASS/EBD) so that responses can be coded by targeted subgroup. We will also give respondents an option of completing demographic information to help us determine the degree to which our samples match the population. However, we will caution survey participants that the combination of naming their waiver/program and providing specific demographic information could make their survey potentially identifiable.

Respondents will have the option of completing a hard copy of the survey via U.S. mail or an online survey through Survey Monkey. Please see the descriptions of survey waves provided below.

Two weeks prior to launch of the survey, we will provide a statement to the Department that it can disseminate widely through email, its website, and hard copy to distribution lists, asking participants to be aware that they may have been selected to participate in a survey and to underscore the importance of completing and returning it promptly. We will ask the Department to disseminate this statement at the start of each of the three survey "waves."

### Wave One

All respondents will initially be sent a hard copy of the survey via U.S. mail. It will include a letter outlining the reason for the survey, an explanation that TriWest has been contracted by the Department to conduct the survey, and assure that surveys will be anonymous. We will also offer participants a \$10 Target or Kroger (King Soopers) gift card as a token of our appreciation for their time.

Respondents will be given the option to return the hard copy survey through the U.S. mail in a self-addressed, stamped envelope, or to complete the survey online, via a website. A second self-addressed stamped envelope and postcard will be included to allow respondents to provide contact information to receive their gift card separately from their survey (this will keep their survey responses anonymous).

If respondents choose to complete a survey online, there will be a separate link to a website at the end of the survey, where they can provide contact information to receive their gift cards. Contact information will be stored separately from survey responses. We will ensure that there will be no way this information can be accessed.

Respondents will also be provided with contact information for a HCPF representative in case they have questions/concerns about the survey (TriWest will provide HCPF staff with a frequently asked questions [FAQ] document that can be used if anyone has questions about the survey). Additionally, we will provide respondents with a phone number and email address for TriWest staff in case they have questions or if they would like to request to complete the survey by telephone or through an in-person interview. We will do everything possible to include individuals requesting an in-person interview who live outside of the Front Range area; we will work with the Department to plan for this potential need.

### **Wave Two**

One week following the initial survey distribution, we will send a follow-up/reminder postcard to all respondents, making sure that distribution lists for these postcards do not include any addresses that match requests for incentive gift cards or include individuals who called to request a different survey administration method.

### **Wave Three**

Two weeks following the initial survey distribution, we will send a new survey package to all respondents, making sure that distribution lists for new surveys do not include any addresses that match requests for incentive gift cards or include individuals who called to request a different survey administration method.

Following this distribution, we will analyze counts of returned surveys by subgroup (program/waiver) to determine the degree to which target response rates have been met. For groups that fall below the target, we will begin conducting follow-up telephone calls to remind individuals to return surveys or to offer to conduct the interview by telephone. These efforts will continue until the target sample size is reached, or through April 15, 2018.

We will continually monitor progress on response rates and work with the Department to take additional action if rates appear to be lower than expected. The largest risk is that, for very small subgroups, too few surveys will be returned for analysis. However, because those groups are small, targeted outreach should be manageable.

## Survey Contents

The survey will contain three parts, as outlined below.

### Introductory Letter

The introductory letter will include a brief statement about the purpose of the survey and explain individuals' rights to decline to participate. It will underscore that responses will be kept anonymous. Individuals will be offered a \$10 gift card in exchange for completing a survey, but to receive the card, they must provide contact information (mailing address). Respondents will be given an opportunity to provide that information completely separate from their survey responses. However, respondents will be alerted that by providing this contact information, one TriWest staff member will then know who completed a survey and, by inference, who did not complete a survey. Respondents will be offered an opportunity to call TriWest to have their names permanently removed from the survey sample pool. They will also be informed that TriWest staff will not disclose to the Department any information regarding which individuals responded and which did not. All survey results will be reported in aggregate and no individual will be identified.

Once the Department approves the survey methodology, we will work with both Department staff and the PDPPC to draft a letter that contains language appropriate for participants.

### Survey Questions

We conducted a review of prior evaluations of other states' participant-directed care programs and identified a large number of questions for possible use. Table 1 on the following page contains our recommendations for questions that align with the goals of this evaluation effort. We have made few, if any, modifications to these questions since some have been successfully used with similar populations in the past. We propose to work with the Department to make any modifications to the question that would improve clarity or to incorporate details specific to the Colorado programs. However, we recommend against other changes. Because some of these questions have been used in other evaluations, we would like to have the ability to make some comparisons between Colorado and other states. We are continuing to explore the degree to which this is possible, based on our review of the literature.

The recommended question set contains 30 yes/no or "Likert scale" questions. While this is a substantial number of questions, we believe that most respondents will be able to complete the survey in under 30 minutes. We will also include two optional open-ended questions at the end of the survey: "What is most helpful to you about the CDASS/IHSS/traditional services you receive?" and "What could be done to improve your experience with the CDASS, IHSS, agency, or home-based services program?"



We will adjust the wording of questions for surveys we send to recipients, depending on whether the survey is being mailed to someone enrolled in the CDASS, IHSS, or agency/home-based services program.

Table 1. Recommended Questions – First Priority	
Question	Response Set
Do you receive all services as specified in your service plan?	Yes/No/Don't Know
Do the services you receive meet your needs and goals?	Yes/No/Don't Know
As a direct result of the services I received, I am better able to do the things I want to do.	Likert Scale <sup>5</sup>
Are services and supports helping you to live a good life?	Yes/No/Don't Know
Do you believe that the result of your "level of care assessment" identifies your real needs?	Yes/No/Don't Know
Does your care plan include all of the things that are important to you?	Yes/No/Don't Know
Are you the primary decider of what is in your service plan?	Yes/No/Don't Know
Does your service coordinator help you get what you need?	Yes/No/Don't Know or NA
Overall, how satisfied are you with the [CDASS/IHSS/traditional] program?	Likert Scale
Do your attendants treat you with courtesy and respect?	Likert Scale
How hard was it, overall, for you to find attendants to help that you were satisfied with?	Likert Scale
Are services delivered in a way that is respectful of your family's culture?	Yes/No/Don't Know
How often do you feel lonely, sad, or depressed?	Likert Scale
How would you rate your overall mental or emotional health?	Likert Scale
Can you see your friends and family when you want to?	Yes/No/Don't Know
Can you get to the places you need to go, like work, shopping, or the doctor?	Yes/No/Don't Know
Do you make choices about your everyday life, including housing, roommates, daily routines, case manager, support staff or providers, and social activities?	Yes/No/Don't Know
If you work, did you choose where you work?	Yes/No/NA
Do you choose where you go during the day?	Yes/No/Don't Know
Does your attendant help you do things the way you want them done?	Yes/No/Don't Know
Can you make changes to your budget/services if you need to?	Yes/No/Don't Know

<sup>5</sup> Likert scale questions will be a 4-point scale: Very Much, Somewhat, A Little, Not at All, and will contain a Don't Know/Not Applicable option. Wording will be adjusted but all Likert scale response options will follow this pattern.

Table 1. Recommended Questions – First Priority	
Question	Response Set
Can you choose or change what kind of services you get and determine how often and when you get them?	Yes/No/Don't Know
I have the freedom to make my own decisions.	True/False/Don't Know
Are you free to take risks when you want to?	Yes/No/Don't Know
Does your attendant provider allow you to make your own mistakes?	Yes/No/Don't Know
I have someone who will listen to me when I need to talk.	Likert Scale
How often do you get the social and emotional support you need?	Likert Scale
Is there someone you can count on in an emergency?	Yes/No/Don't Know
Do you have adequate transportation when you want to go somewhere?	Yes/No/Don't Know
I have regular opportunities to be part of the community.	Likert Scale

While we believe the above questions represent the best set of options, there are others that were discovered during our literature review that the Department may feel are more important than those we have selected. We have included these here for consideration.

Table 2. Questions to Consider – Second Priority	
Question	Measure
Does your case manager help coordinate all the services you receive?	Yes/No/Don't Know
Do the people who are paid to help you do things for you the way you want them to be done?	Yes/No/Don't Know
Do you communicate with your attendant provider in the language that you prefer?	Yes/No/Don't Know
I have choices about the activities I want to do.	True/False
Do you have options about where and with whom to live?	Yes/No/Don't Know
Does your attendant pay attention to your choices, such as what you like to eat, where you want to go, or what you want to do?	Yes/No/Don't Know
In the last year, were you offered the option to self-direct some or part of your services?	Yes/No/Don't Know
Are you able to make an informed choice on whether to self-direct your supports and services?	Yes/No/Don't Know
When you want to, how often can you get together with these friends who live nearby?	Likert Scale

Table 2. Questions to Consider – Second Priority	
Question	Measure
Where I live makes it easy for me to get around in the community as I desire.	Likert Scale
Do you self-direct your supports and services with employer authority and/or budget authority?	Yes/No/Don't Know
Do you self-direct arrangements through a fiscal intermediary?	Yes/No/Don't Know
Do the services/supports focus on your goals?	Yes/No/Don't Know
How would you rate your overall health?	Likert Scale
Were you admitted to the hospital in the last year?	Yes/No/Don't Know
Generally, are you satisfied with the amount of contact you have with friends?	Yes/No/Don't Know
Generally, are you satisfied with the amount of contact you have with your family?	Yes/No/Don't Know
Do you like how you usually spend your time during the day?	Yes/No/Don't Know
Does your attendant listen to what you have to say?	Likert Scale
I have control over what I do and how I spend my time.	True/False

We also want to work with the Department to determine the feasibility of surveying attendants to determine their overall perspectives and satisfaction with the program. Should this be possible, we recommend the following the questions for a brief Attendant Survey.

Table 3. Recommended Questions – Attendant Surveys	
Question	Measure
During the past 12 months, has your overall health suffered because of your caregiving responsibilities?	Yes/No/Don't Know
In your experience as a caregiver, have you ever had a doctor, nurse, or social worker ask you about what you needed to take care of yourself?	Yes/No/Don't Know
In the last year, have you received any training to help you take care of [person]?	Yes/No/Don't Know
Do you get enough information to take part in planning services for your [person]?	Yes/No/Don't Know
Before [person] left the hospital or was discharged, did you receive clear instructions about any medical/nursing tasks you would need to perform for [person]?	Yes/No/Don't Know
Have you received caregiver training or education, including participation in support groups, to help you make decisions and solve problems in your role as a caregiver?	Yes/No/Don't Know

Table 3. Recommended Questions – Attendant Surveys	
Question	Measure
In your experience as a caregiver, have you ever had a doctor, nurse, or social worker ask you about what you needed to help care for [person]?	Yes/No/Don't Know
Have you been included in discussions about your client (with client's consent)?	Yes/No/Don't Know
In your experience as a caregiver, how often do you feel that caregiving causes you stress?	Likert Scale

For the Department's reference, the remaining questions that were identified in the literature review are included in Appendix 1 of this document. We believe the inclusion of these questions would make the survey too long without providing enough additional helpful information to warrant the extra length.

### Thank You and Instructions for Receiving a Gift Card

Respondents will also receive a note card and separate return envelope they can use to request a gift card as a thank you for participating in the survey. This will allow their responses and identifiable information to be transmitted separately. We will provide a different address for returning these cards than the one used to return surveys. Respondents will also be given the option of calling to leave a voice mail or completing a secure online form as an alternative method for receiving the card. This information will be kept only until the survey period closes so that individuals who have received gift cards can be excluded from follow-up survey waves, to avoid sending reminders to those who have already completed a survey.

## Appendix 1

The following table lists the remaining questions that were identified as potential survey questions during the literature review. While many are good questions, they were deemed either less relevant or largely duplicative of the final 30 questions being recommended.

Table 4. Questions Deemed Less Relevant for this Evaluation	
Question	Measure
Has a case manager helped you solve a problem that you have told them about?	Yes/No/Don't Know
Does your attendant respect your privacy?	Yes/No/Don't Know
Do your attendants make sure you have enough personal privacy when you dress, take a shower, or bathe?	Yes/No/Don't Know
Do you feel your attendants have the right training to meet your needs?	Yes/No/Don't Know
Do your attendants know what kind of help you need?	Yes/No/Don't Know
Do you feel your attendants know what kind of help you need with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?	Yes/No/Don't Know
Is it difficult for you to find attendant providers for your care?	Yes/No/Don't Know
My worker is sensitive and responsive to customs and traditions of my culture or background.	Yes/No/Don't Know
In your experience as a caregiver, how often do you feel that caregiving interferes with your work?	Yes/No/Don't Know
How much of a financial strain would you say that caring for [person] is for you?	Likert Scale
Do your caregiving responsibilities make it difficult to meet your essential household expenses?	Yes/No/Don't Know
Does your care plan identify family/unpaid caregivers?	Yes/No/Don't Know
In the last year, have you used any service that took care of [person] so that you could take some time away from helping?	Yes/No/Don't Know
How difficult is it to get affordable services in [person's] local area or community that could help you care for [person], like delivered meals, transportation, or in-home health services?	Likert Scale
How frequently are you in pain?	Likert Scale
To what extent do you feel that physical pain prevents you from doing what you need to do?	Likert Scale
Pain affects my well-being.	Likert Scale
Were you re-admitted to the hospital within 30 days of last hospitalization?	Yes/No/Don't Know

Table 4. Questions Deemed Less Relevant for this Evaluation	
Question	Measure
If you have a diagnosis of hypertension, was your blood pressure adequately controlled during the last year?	Yes/No/Don't Know
Have you visited the ER in the last year?	Yes/No/Don't Know
Were you screened for clinical depression using a standardized tool and follow-up plan documented?	Yes/No/Don't Know
Did you have one or more falls in the last year?	Yes/No/Don't Know
Was a health risk assessment completed within 90 days of enrolling in CDASS/IHSS/traditional program?	Yes/No/Don't Know
If you have a problem falling, walking, or balancing, did you discuss this with your practitioner and receive treatment in the last year?	Yes/No/Don't Know
If you are at risk of falling, have you received a fall-risk intervention?	Yes/No/Don't Know
Did you discuss exercise with your doctor this year?	Yes/No/Don't Know
Are you self-directing your HCBS?	Yes/No/Don't Know
If you do not have an integrated job in the community, would you like one?	Yes/No/Don't Know
Do you have an integrated job in the community?	Yes/No/Don't Know
When you want to, how often can you do things in the community that you like?	Likert Scale
Are you doing volunteer work or working without getting paid?	Yes/No/Don't Know