

Colorado Department of Health Care Policy and Financing Consumer Directed Care

Evaluation Recommendations for Consumer Directed Care Programs

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Introduction

In December of 2017, the Colorado Department of Health Care Policy and Financing (Department) contracted with TriWest Group (TriWest) to conduct an evaluation of consumer-directed care service programs in Colorado (also known as participant-directed care programs). The overall goal of this evaluation effort is to provide the Department with an analysis of the benefits, health outcomes, service satisfaction, and costs of consumer directed service delivery options (Consumer Directed Attendant Support Services and In-Home Support Services).

This document provides recommendations for conducting the evaluation. Included recommendations are based on reviews of recent studies of similar programs in other states, discussions with the Department and stakeholders regarding the general desired evaluation focus, a 2015 report on the Consumer Directed Attendant Support Services (CDASS) program issued by the Office of the State Auditor, and Department and stakeholder responses to audit report findings.

Summary of Review of Other State Evaluation Efforts

Initially conceived in the 1960s, consumer-directed care (also known as self-, patient-, member- or participant-directed care) aims to provide individuals with more choice and control over their own personal care and services. Its prevalence has since proliferated, and government health programs have structured waivers and requirements for states to increase their self-directed program offerings. The Medicare Prescription Drug, Improvement, and Modernization Act of 2003 required new methods to deliver and evaluate consumer-directed care (Nadash and Crisp, 2005, pp. 1-5), and the CMS Innovation Center in 2017 issued a Request for Information on consumer-directed care and market-based innovation models. While there is considerable freedom for states and funding authorities to personalize their self-directed options, all Medicaid programs share four common characteristics: a person-centered planning process, a service plan, an individualized budget, and assistance to support self-direction (Medicaid.gov).

Currently, many states operate consumer-directed options under a suite of Section 1915 waivers that promote self-determination. Common components of these programs are home and community-based services (HCBS), which provide an alternative to residential care or nursing home placement (Sands et al., 2012, p. 2). These personal care services (PCS) provide assistance with activities of daily living (ADL), including dressing, meal preparation, feeding, laundry, and housekeeping. Colorado offers two options for consumer-directed HCBS: Consumer Directed Attendant Support Services (CDASS) and In-Home Support Services (IHSS). Both programs offer more individual autonomy than traditional agency-administrated services, albeit to varying degrees. CDASS participants oversee the hiring, training, evaluation, retention, and wages for their own personal care attendants (PCAs). A Financial Management Service agency ensures compliance with all state and federal hiring regulations, and it is responsible for processing employment applications, background checks, and payroll administration. IHSS participants retain individual control, but they partner with an agency for support in hiring and managing PCAs (Colorado Department of Health Care Policy & Financing, 2018).

To prepare for the impending CDASS and IHSS evaluations, this review looked at existing evaluations of similar Medicare- and Medicaid-funded HCBS programs. The review found a relative dearth of information available—particularly pertaining to patient outcomes and cost analysis—and the literature has long noted these gaps (Wiener et al., 2002; Robert Wood Johnson Foundation, 2004; National Council on Disability, 2004; Wiener et al., 2007; Ottmann et al., 2013). Evaluation and study challenges include small sample sizes, disparate programming that stymies meta-analyses (National Council on Disability, 2004, p. 9), interrupted delivery due to legislative and administrative changes, lack of communication between departments (Robert Wood Johnson Foundation, 2004, p. 4), and a lack of case studies (Wiener et al., 2002, p. 89). Most frequently, evaluations rely on self-reported measures of consumer satisfaction (Ottmann et al., 2013, p. 564).

Because reliable and validated measures are still relatively rare in these nascent evaluations, this review also looked at established measures of quality in HCBS as determined by the National Quality Forum's (NQF) comprehensive report *Quality in Home and Community-Based Services to Support Community Living: Addressing Gaps in Performance Measurement*. For state programs, relevancy was determined by program overlap and similarity, waiver type, and state demographics.

Home and Community-Based Services: Defining Quality

NQF contracted with the Department of Health and Human Services (HHS) "to develop a shared understanding and approach to assess the quality of HCBS, to identify gaps in current HCBS quality measurement, and to highlight high-leverage opportunities for measure development. Understanding the quality of HCBS becomes increasingly important as funding from federal, state, and local governments as well as private and third-party payers shifts from institutional to community-based settings, and demand for HCBS rises" (NQF, 2016, p. 4). This two-year project sought to operationalize and standardize HCBS quality measurement to make evaluation feasible and reliable, more effectively identify and share best practices, and better serve the growing population demanding HCBS.

Quality measures were evaluated against five criteria: "that they be based on evidence, demonstrate an opportunity for improvement, be clearly specified and scientifically tested, show that it is feasible to readily collect data for the calculation of the measure, and establish that the performance results can be used for both accountability and performance improvement" (p. 8). Using these criteria, as well as a lengthy and rigorous series of discussions among the committee and stakeholders, the NQF final report identifies fourteen characteristics of high-quality HCBS (pp. 9-10):

- A person-driven system that prioritizes individual choice, goals, and preferences;
- Promotes social connectedness (ensuring individuals are able to interact with others as they like);
- Flexible services that respect individual preferences and goals;
- Integrates health and social services;
- Protects privacy, dignity, independence, and respect;
- Allows the individual to determine the balance of personal risk and safety;
- Supplies and supports an appropriate workforce to serve as Personal Care Attendants (PCAs);
- Supports family caregivers;
- Engages participants in the design, implementation, and evaluation of HCBS;
- Promotes equity by reducing disparities in access and services;
- Manages resources to ensure long-term sustainability and affordability;
- Is appropriately funded to deliver accessible, affordable, cost-effective services;

- Supplies valid and meaningful outcome data to all stakeholders; and
- Requires accountability through measurement and reporting.

NQF notes that their initial review of measures found many of them to be healthcare-focused. While this may seem intuitive, NQF determined the measures did not capture or reflect the unique qualities of HCBS. Considered as a whole, the NQF characteristics value individual preference and choice with an emphasis on dignity and direct participation, so the ideal high-quality HCBS may perhaps best be described as flexible and humane.

State Models

States are currently operating and evaluating many innovative Medicaid and Medicare programs. Models described here operate under the same HCBS waivers and serve similar populations as Colorado's CDASS and IHSS programs.

Iowa. Iowa's Consumer Choices Option (CCO) allow participants greater control over services to help them remain in their homes and communities. Six waivers offer a CCO under the state's HCBS programs: AIDS/HIV, Brain Injury, Physical Disability, Intellectual Disability, Health and Disability, and Elderly. Members may receive self-directed personal care services and self-directed community and employment supports.

- **Self-directed personal care services.** These services help participants remain in their homes:
 - Cleaning services,
 - Homemaking tasks,
 - Meal preparation,
 - Showering/bathing assistance,
 - Laundry assistance,
 - Medication management,
 - Supervision,
 - Assistance with mobility transfers,
 - Personal grooming,
 - Shopping, and
 - Transportation.
- **Self-directed community and employment supports.** These services help participants maintain independence and community integration:
 - Self-direction and self-advocacy skill development,
 - Training on use of medical equipment,
 - Personal and home skill development,
 - Time and money management skill development,
 - Social skill development training,

- Career preparation skill,
- Career counseling,
- Job searching/placement,
- Personal care development,
- Social support,
- Companionship, and
- Safety and emergency preparedness skill development (Iowa DHS, 2015).

Once participants have enrolled in the CCO, they select an Independent Support Broker (Broker) to assist with budgeting, obtaining appropriate supports, and ongoing budget monitoring. If the participant cannot find a Broker, their case manager may assist with locating and retaining an appropriate Broker. The Broker then works with the participant to develop the Individual Budget and ensure that appropriate supports are secured (Iowa DHS, 2007). Participants interview and hire their own support staff; the state of Iowa contracts with Veridian to administer and oversee payroll and tax responsibilities (Iowa DHS, 2015).

Iowa HCBS Waiver Enrollment and Waitlists		
Waiver	Enrolled	Waitlist
Intellectually/Developmentally Disabled	12,263	0
Aged	10,521	0
Physically Disabled	3,621	5,013
Children	1,107	2,356
HIV/AIDS	36	0
Traumatic Brain Injury/Spinal Cord Injury	1,352	1,136
Totals	28,900	8,505

(Kaiser Family Foundation)

Virginia. Individuals participating in Virginia’s consumer-directed personal care services (PCS) program are enrolled primarily under the commonwealth’s Elderly or Disabled and Intellectual Disability waivers. The current program, Elderly or Disabled with Consumer Direction (EDCD) Waiver, helps participants remain in their homes. Eligible services include:

- Adult day health care,
- Medication monitoring,
- Personal care aide services,
- Respite care,
- Personal emergency response system,

- Transition coordination, and
- Transition services (DMAS, 2009).

Teams from Virginia’s Department of Health and county social services determine eligibility via a universal assessment instrument. Eligible individuals then choose between self-direction of their own support services or receiving agency-directed care. Those opting for self-direction recruit, hire, and manage their own direct care worker(s). Participants must work with a service facilitator, who provides support and limited quality monitoring over the course of enrollment. Similar to Iowa’s relationship with Veridian, Virginia contracts with a private company to oversee administrative, regulatory, and payroll duties for the direct care workers (Claypool & O’Malley, 2008, pp. 10-12).

Virginia HCBS Waiver Enrollment and Waitlists		
Waiver	Enrolled	Waitlist
Intellectually/Developmentally Disabled	10,282	16,583
Aged/Disabled	30,134	0
Physically Disabled	397	0
HIV/AIDS	6	0
Totals	40,819	16,583

(Kaiser Family Foundation)

Washington. The consumer-directed New Freedom Program is being evaluated against the Community Options Program Entry System (COPES), which provides comparable services without the same level of individual control. Initial results suggest that participants are extremely satisfied with New Freedom, with over 90% reporting they feel satisfied or very satisfied. The state reports that New Freedom and COPES cost roughly the same to administer, and participants of both programs have no significant differences in their monthly per capita spending on acute and long-term care services (Washington State Auditor’s Office, 2014, p. 4). Additionally, as NQF articulated concerns about demand and costs, Washington believes New Freedom is self-selecting to the point of efficiency: only participants who are able and willing to take on the extra effort to manage their care will choose to do so. Participants who are uninterested or unable will not select New Freedom (p.11).

Eligible services. Both COPES and New Freedom cover in-home services:

- Personal care services,
- Skilled nursing care,
- Specialized medical equipment,
- Personal emergency response unit,



- Home delivered meals,
- Transportation assistance,
- Adult day care/day health care,
- Transition services from institutional to home setting,
- Client support training, and
- Environmental modifications (p.12).

Additionally, the following services are available exclusively in New Freedom:

- Eye glasses and vision care;
- Hearing aids;
- Herbal and OTC medication;
- Hygiene and sanitary supplies;
- Dietary support;
- Vehicular modifications;
- Physical therapy, exercise, and gym memberships;
- Alternative medicine treatments; and
- Additional services pending case-by-case authorization.

Both programs are administered by Washington's State Department of Social and Health Services – Home and Community Services Division (DSHS-HCS). Once individuals apply, DSHS-HCS conducts an initial assessment, determines options and discloses them to the individual, and refers individuals to the appropriate providers (pp. 7-12). COPES clients receive an allowance of care service hours, which can be used to purchase services within defined service areas. Hours must only be used for the approved service area and cannot be transferred or shared between areas. New Freedom clients' service hours are converted into a monthly lump sum (individual budget), which they then use to purchase services in accordance with their care plan. This program also allows participants to save unspent funds for later use or to purchase services/items that would otherwise exceed their monthly budget (p. 13).

Additionally, both programs include social workers to assist and support participants. COPES provides case managers with whom participants can collaborate and develop their care plans; the case manager is responsible for vendor payments. For New Freedom participants, the social workers serve as care consultants rather than case managers. Working within their established budget, the participant (or authorized representative) prepares a Participant Centered Spending Plan, which must be subsequently approved by the care consultant (p.13).

Washington has other ongoing evaluations of New Freedom and is also implementing a new Community First Choice consumer-directed option. Community First Choice will be a statewide option (as opposed to New Freedom running in just two counties), and Washington

has already implemented lessons learned from New Freedom (p. 17). The auditors note that effective communication is key to a successful start, and New Freedom has begun offering additional trainings to better clarify operations, procedures, and expectations (p. 23).

Washington HCBS Waiver Enrollment and Waitlists		
Waiver	Enrolled	Waitlist
Intellectually/Developmentally Disabled	12,347	0
Aged/Disabled	40,930	0
Children	83	0
Totals	53,360	0

(Kaiser Family Foundation)

Summary of Colorado State Auditor Evaluation Recommendations and Stakeholder Response

One of the four Consumer Directed Attendant Support Services (CDASS) program recommendations made in the 2015 State Auditor report was for the program to conduct a comprehensive evaluation, specifically, “including the benefits, health outcomes achieved, and costs compared to other service delivery options.” This recommendation was based on audit findings from 2015 that seemed to indicate higher costs for CDASS participants than for those in other service delivery options. However, as stipulated in the audit report, and later reinforced in the stakeholder response to audit recommendations, this costs analysis did not control for several important factors, including the types of services being delivered or the specific service needs of clients.

Stakeholder responses to the audit report underscored several important considerations for future evaluation efforts. These responses are described briefly below.

Sampling Questions and Concerns

The state audit report contained, understandably, a fairly small sample of records reviewed for various elements of program compliance. Record reviews take a great deal of time and are extremely expensive as a result. However, stakeholders were concerned that the inclusion of only new program enrollees may have biased the results. Additionally, there was some concern that the review reflected a lack of detailed understanding of program operations, particularly from the participant’s perspective.

While this evaluation does not include a record review or revisit other audit findings, these stakeholder perspectives still contain valuable insights.

Cost Analysis Considerations

The primary stakeholder concern regarding program cost analyses involved the necessity for comparing costs across participants with similar needs. Specifically, the stakeholder response stated:

“Home health agencies conduct their own assessment of needs. Those assessments most often match the home health agencies availability of staff, not the needs of the client.

Most of the high needs clients are on CDASS because home health agencies will not serve them. High needs include people on ventilators, tracheotomies, quadriplegics and people transitioning out of nursing facilities.”

Stakeholders underscored that CDASS serves some of Colorado's most severely disabled citizens. They reflected there is no other model that will serve these citizens in the community. This makes comparisons across programs difficult.

There were additional concerns regarding which costs were included in the audit's analysis:

"All costs are included in CDASS whereas home health agency costs do not include acute care costs. Home health agencies acute care costs are often significant and do not require a prior authorization. Additional service related to acute care episodes used by CDASS clients becomes part of their ongoing expenditures and may result in an adjusted allocation."

It seems clear from this statement that any comparative analysis of costs includes not only the costs attributed to a specific program, but also *all costs for services* incurred by program participants (including any costs attributed to participants for similar services, but which may have been excluded from the audit's analysis).

Cost Analysis Should be Based on Annual Expenditures

Stakeholders commented that the CDASS program features an annual budgeting process:

"It is not allocated by dividing the annual allocation by 12 to create a monthly spending limit. Therefore, clients may be overspent for several months during higher needs and still be within the Annual Budget. Claiming clients are overspending without reviewing the client's full year utilization and any adjustments made by the Case Manager and only reviewing a partial year month creates a false conclusion. The Allocation Management Protocol assures annual allocations are not exceeded by helping the client and case manager monitor monthly expenses. CMS supports this type of budget flexibility in consumer directed programs because of a client's disability they might need more services during certain times of the year. Essentially, as long as the annual allocation is not exceeded the monthly allocation can and often does fluctuate."

One important feature and intent of these kinds of consumer-directed programs nationwide is the ability for increased flexibility to meet client needs. Stakeholders reflected that seasonal or otherwise short-term fluctuations in client needs creates differences in the amount of expenditures from month to month. Cost analyses will need to consider this in reporting on program expenditures.

Need to Include Discussion of Client Wellbeing Outcomes

Stakeholders noted that “the audit posits that if the hours allowed are not used that client needs may not be met. This can be determined not by how many hours were billed, but based on the wellbeing of the client.”

Stakeholders reported a desire to see a direct discussion of the following specific questions:

- *What are the number of emergency room visits?*
- *How many hospitalizations and the length of the hospitalization?*
- *What are the health outcomes of clients as opposed to peers with a similar disability?*
- *Are the attendants more satisfied [with their work] (which leads to better care)?*

Proposed Evaluation Framework and Design

In order to address the evaluation questions outlined by the Audit Report and by the Department, while also taking into account stakeholder feedback, we propose a mixed-methods evaluation framework. The evaluation will incorporate quantitative data on costs, health outcomes, and participant satisfaction, as well as qualitative data from key informant interviews. Qualitative data will be used to design specific analyses methods and questions, and provide an important context for evaluation findings.

For comparative analyses, we propose a quasi-experimental post-hoc evaluation design. This design is largely dictated by the nature of the programs being evaluated. Because participants are not randomly assigned to one of the three program conditions (CDASS, IHSS, or traditional home health services), and because there is not an appropriate “no treatment” group available, an experimental design is not possible. However, it is still possible to achieve many of the same goals of an experimental design. Attributing differences to program efforts rather than external circumstances, for example, can be achieved by carefully matching comparison groups based on key participant characteristics. In addition to “traditional” services, TriWest will work with the Department and stakeholders to determine the degree to which it may be appropriate to include participants who are receiving long-term home health services or private duty nursing services in the comparison group. We will use information gained from key informants and work closely with the Department to identify a set of variables that can be used to match comparison group participants with our CDASS and IHSS groups. These will include demographic variables, as well as variables indicative of care needs (for example, diagnosis codes, prior utilization, medications prescribed, etc.).

Additionally, it is important to note that the aim of the evaluation being proposed is to make comparisons across different “treatment” options (participation in a program), not to compare the effect of participation in a program to those who receive no “treatment.” This is an important distinction because there is an assumption that all programs provide some benefits to participants, so any findings of differences in outcomes across groups are likely to be modest.

Data Sources

While details vary, all the programs reviewed in developing these recommendations rely on participant surveys and health data to track participants’ outcome and satisfactions. Costs are less frequently and explicitly discussed, particularly in depth.

Based on our review, and in order to align with previous state evaluations and federal recommendations, we propose four primary sources of data for the evaluation:

- Key information interviews (KIIs) and meetings (focus groups) with program stakeholders (those implementing program elements, policy and decision makers and representatives of program participants),
- Surveys of program participants (including both clients and/or authorized representatives and attendants),
- Program enrollment data to identify the pool of potential respondents to be sampled for surveys, and
- Secondary analysis of Medicaid data files (enrollment, claims/encounters, drug benefit, and provider).

Key Informant Interviews and Stakeholder Meetings (Focus Groups)

Between 30 and 40 key informants will be interviewed in the first two months of the evaluation. The purpose of these interviews will be to ensure that evaluators have a necessary understanding of important program policies and procedures, relevant state statutory authorizations and requirements, implementation processes, strengths and challenges, and important evaluation questions/metrics of program success.

In addition to key informant interviews, we propose to facilitate two stakeholder meetings/focus groups to discuss the evaluation. The purpose of the first group will be to review evaluation recommendations with the group and to ensure that the proposed methodologies are appropriate to the evaluation questions and take into account the unique considerations for these populations. While the goal is to always ensure that the evaluation objectively reports findings and recommendations, it is necessary to ensure that it is also credible. This credibility is strengthened when stakeholders have input into and endorse the proposed measures and methods. The second meeting will be held to review preliminary findings and receive stakeholder feedback on analysis results.

TriWest will ask the Department to send an email (or hard copies of a notice) soliciting potential key informants for interviews. The solicitation will go to members of the Participant Directed Programs Policy Collaborative, IHSS stakeholder groups, and other key stakeholders on the Department's distribution list. Interested respondents will be asked to respond directly to a TriWest scheduler with their contact information as well as a description of their specific stakeholder role.

If the number of potential respondents who offer to participate in interviews exceeds available resources to conduct the interviews, TriWest will create a stratified random sample of respondents to ensure a representative sample of key informants.

Participant Surveys¹

Various surveys and measures have been used to evaluate consumer-directed care programs. While there are few validated measures available now, past evaluations were often held back by a lack of common standardized resources. The work of NQF has given us the benefit of a standardized set of measures that may prove useful to this evaluation effort.

We propose the use of self-report/self-administered participant surveys in order to gather data on participant opinions, satisfaction, and health outcomes. We propose to send hard copies of surveys via U.S. post and to also provide an online survey response option. We will solicit respondents by email in cases where an email address is available. In cases where participants' needs require an alternative option, we propose telephone or in-person interviews. In cases where an in-person interview is the best option for respondents who live outside of the front range area, we will make a concerted effort to schedule and conduct in-person interviews in clusters around the state to ensure there is at least some representation from different areas.

Current Department practice, based on federal recommendations, for patient surveys (based on the administration of the Consumer Assessment of Healthcare Providers and Systems [CAHPS]) is to target a sample size of 50 completed surveys per smallest grouping unit of interest for the analysis (in the case of CAPHS, practice is to target 50 completed surveys per each individual healthcare provider within a practice). CHAPS administration also relies on estimated response rate ranges of 25% to 40% to help determine how many potential respondents to sample.

We propose drawing 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 additional copies of the surveys and

¹ A more detailed description of the survey sample, methodology and proposed survey instrument can be found in the Consumer Directed Care Survey Tool & Methodology document.

reminders, etc.). In addition, consumers participating through the Medicaid Elderly, Blind and Disability (EBD) Waiver make up a disproportionality 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.

Survey Sampling Approach			
Survey Group	Target Completed Surveys (30% Response)	Sample Frame (Random Sample Requested)	Total Population Served
CDASS/BI Waiver	30	54	54
CDASS/CMHS Waiver	50	173	173
CDASS/EBD Waiver ²	300	1,000	3,413
CDASS/SCI Waiver	30	58	58
Total CDASS Sample	410	1,285	3,164
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 ³	--	--	--
Total IHSS Sample	300	1,005	2,751
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	
Total Comparison Group⁴	300	960	NA
Total Sample	1,010	3,250	NA

² 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.

³ 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.

⁴ 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.

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

We also recommend consideration of implementing a survey with attendants/caregivers. We will explore the feasibility of sampling and obtaining contact information for these caregivers.

Medicaid Data Files: Service/Cost Data

Once the final outcome and cost data elements needed for the analysis have been finalized, we will work with Department staff to create a data request for four Medicaid data sets:

- Claims/Encounter Data,
- Program Enrollment Data,
- Drug Benefits, and
- Provider (to cross reference service provision details).

We propose requesting these Medicaid data files for state fiscal years (SFY) 2012 through SFY 2017 for all program participants who received services during SFY 2016 and SFY 2017 (regardless of enrollment date). The date parameters will be for all claims/encounters occurring for participants beginning with the start date of enrollment in either CDASS or IHSS and for all service dates between their enrollment date and December 2018. We are requesting the data be pulled the first week of April 2018. This will allow for a three-month lag time for Medicaid claims to be entered.

We will request records for all participants of traditional home health services, including those who utilize home health and agency based care through a Medicaid waiver during SFY 2017, as well as the encounter data for all claims from the first date of traditional home care services (or enrollment date, if available). We propose using this pool to statistically create “matched” comparison groups of participants in traditional home health care and private duty nursing who have similar risks, needs, and demographic characteristics as CDASS and IHSS participants.⁵ In cases where a participant receives both IHSS and traditional home health services, that participant will be included in the “IHSS group” and be removed from the comparison group. However, the evaluation will include care utilization patterns like this one to statistically control for cost differences. We will discuss the development of specific elements we will use for matching the comparison group during key informant interviews, during the initial stakeholder

⁵ We will work with the Department to identify available data fields that can be used to identify a matched comparison group using a technique called “propensity score matching.” This will allow us to attempt to identify a pool of comparison consumers who are not enrolled in CDASS or IHSS services, but who are as similar as possible in demographics (age, race, gender, geographic location) and in level of medical care needed (using diagnosis codes, prior utilization patterns, medications prescribed, etc.).

meeting, and with Department staff.

We will also explore with Department data staff the feasibility of extracting Medicaid claims/encounter data for any program (or comparison) participants in the 12 months prior to program enrollment (or start of traditional services). It is unclear what percentage of participants would likely have been eligible for Medicaid services prior to program enrollment.

Describing Service Participants

We will report on the number of participants receiving services through one of the three groups (CDASS, IHSS, traditional) during calendar year 2017. We will discuss results of comparison group matching, including an assessment of the degree to which the comparison group matches the CDASS and IHSS evaluation groups on key characteristics.

We will incorporate data from key informant interviews (KIIs) and focus groups to provide context regarding the nature of participant needs, how those needs differ across groups, and specific group features that may affect both outcome and cost analysis. This information will help to frame the presentation of outcome and cost findings.

Assessing Participant Satisfaction

In the evaluations that were reviewed, participant satisfaction was typically measured through surveys administered in person or over the phone. When necessary, proxies or surrogates were used to help collect answers. We are proposing to use a combination of hard copy paper (via U.S. mail) and online surveys, supplemented with telephone or in-person interviews for individuals for whom a paper or online survey is difficult to complete. In cases where the participant is under 18 years old, the survey will be sent to the authorized representative (AR) to complete. For adults who utilize ARs, we will work with the Department to create a methodology for the AR to complete the survey either with or as a proxy for the participant in cases where it seems warranted.⁶ In other surveys conducted across the country, participants generally reported being at least as satisfied with their care as control groups in traditional models.

The following table includes potential questions developed by the NQF that may be asked of participants regarding their satisfaction with services. We have included a broad list here to document what has been done in other jurisdictions, nationally. The Survey Tool & Methodology document draft contains TriWest recommendations of a smaller subset of these questions best suited to this evaluation effort.

Service Delivery and Effectiveness	
Subdomain: Delivery	Source
Percent of survey respondents who reported receiving all services as specified in their service plan.	MLTSS KS

⁶ Greater detail regarding the survey procedures can be found in the Survey Tool & Methodology document.



Subdomain: Person's needs met and goals realized	Source
Percent responding "yes" to: Do the services you receive meet your needs and goals?	NCI-AD
Percent strongly agreeing with: As a direct result of the services I received, I am better able to do the things I want to do.	MHSIP-ACS
Percent responding "yes" to: Are services and supports helping you to live a good life?	NCI-ACS

Person-Centered Planning and Coordination	
Subdomain: Assessment	Source
Percent responding "yes" to: Do you believe that the result of your "level of care assessment" identifies your real needs?	NMPQR
Subdomain: Person-Centered Planning	Source
Percent of members reporting that their care plan includes all of the things that are important to them.	MLTSS WI
Percent of participants reporting they are the primary deciders of what is in their service plan.	MLTSS MN
Percent responding "yes" to: Do the services and/or supports focus on the person's goals?	POMs
Subdomain: Coordination	Source
Percent HCBS members who report: Their service coordinators help them get what they need.	MLTSS HI
Percent responding "yes" to: Has a case manager helped you solve a problem that you have told them about?	MNCES
Percent responding "yes" to: Does your case manager help coordinate all the services you receive?	POMP-CMS

We also recommend asking respondents: "Overall, how satisfied are you with the [CDASS/IHSS/traditional] program?"

Additional satisfaction areas may be of interest to the Department and stakeholders. If these questions are included in a participant survey, it will be important to stress to respondents the importance of completing this survey privately (or with a friend or family member who is not a personal attendant).

Workforce	
Subdomain: Person-centered approach to services	Source
Percent of members reporting that the people who help with personal care always treat them with courtesy and respect.	MLTSS WI
Percent responding “yes” to: In the past year, did the people who are paid to help you respect your privacy?	MNCES
Percent responding “yes” to: Do your workers make sure you have enough personal privacy when you dress, take a shower, or bathe?	HCBSEOC
Percent responding “yes” to: Do the people who are paid to help you do things for you the way you want them to be done?	NCI-AD
Percent responding “yes” to: Does your attendant provider listen to what you have to say?	EAZI
Subdomain: Demonstrated competencies, when appropriate	Source
Percent responding “yes” to: Do you feel your staff have the right training to meet your needs?	NCI-ACS
Percent of members reporting that the people who help them with personal care know what kind of help member needs.	MLTSS WI
Percent responding “yes” to: Do you feel your workers know what kind of help you need with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?	HCBSEOC
Subdomain: Sufficient workforce number, dispersion, and availability	Source
Percent responding “no” to: Is it difficult for you to find attendant providers for your care?	EAZI
Percent responding “not very hard” to: How hard was it, overall, for you to find someone to help that you were satisfied with?	C&C9MO
Subdomain: Culturally competent	Source
Percent responding “yes” to: My worker is sensitive and responsive to customs and traditions of my culture or background.	MAHCSS
Percent responding “yes” to: Are services delivered in a way that is respectful of your family’s culture?	NCI-AFS, NCI-FGS
Percent responding “yes” to: Do you communicate with your attendant provider in the language that you prefer?	EAZI

In addition, Mathematica created a comprehensive Aged/Disabled Questionnaire for individuals enrolled in home and community-based service waiver programs. The questionnaire measures demographic compositions, health, levels of support, functionality, and details on the types of

care received (CMS, 2006, p. 2). The protocol can be found [here](#) (CMS, 2006, Appendix) and in Appendix B of this document.

National Core Indicators (NCI). NCI is a collaboration between the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute. The program began in 1997 and now administers several surveys targeting adults with intellectual and developmental disabilities and the elderly and disabled. The surveys are administered across multiple states and data is available to help establish benchmarks (NCI, 2018). The elderly/disabled survey is included in Appendix C. We propose reviewing both the Aged/Disabled Questionnaire and the NCI survey with the Department to select potential survey questions.

It may also be desirable to conduct a shorter survey with care attendants in order to gauge their overall perceptions of, and satisfaction with, their roles in the programs. Potential questions, based on NQF recommendations, are listed below.

Caregiver Support	
Subdomain: Family caregiver/natural support well-being	Source
Percent responding “no” to: During the past 12 months, has your overall health suffered because of your caregiving responsibilities?	GSS-CRR
Percent responding “rarely” or “never” to: In your experience as a caregiver, how often do you feel that caregiving interferes with your work?	POMP-CSS
Percent responding “rarely” or “never” to: In your experience as a caregiver, how often do you feel that caregiving causes you stress?	POMP-CSS
Percent responding “yes” to: 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?	CGUS
Percent of caregivers responding 4 or 5 on a 5-point scale to: How much of a financial strain would you say that caring for [person] is for you?	CGUS
Percent of caregivers responding “yes” to: Do your caregiving responsibilities make it difficult to meet your essential household expenses?	CGUS
Subdomain: Training and skill-building	Source
Percent responding “yes” to: 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]?	CGUS
Percent responding “yes” to: In the last year, have you received any training to help you take care of [person]?	NSOC

Caregiver Support	
Percent responding “yes” to: 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?	POMP-CSS
Subdomain: Family caregiver/natural support involvement	Source
Percent responding “yes” to: Do you get enough information to take part in planning services for your family member?	NCI-AFS, NCI-FGS
Percent responding “yes” to: 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]?	CGUS
Percent of HCBS consumers whose care plan identifies family/unpaid caregivers.	1915(c)
Percent of unpaid caregivers who report that they have been included in discussions about the HCBS consumer (with HCBS consumer’s consent).	International Measure
Subdomain: Access to resources	Source
Percent responding “yes” to: In the last year, have you used any service that took care of [person] so that you could take some time away from helping?	NSOC
Percent responding “not at all difficult” to: 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?	CGUS
Percent of caregivers responding “yes” to: In the last year, have you used any service that took care of [person] so that you could take some time away from helping?	NSOC

Assessing Health Outcomes

We propose assessing health outcomes using two methods: client surveys and Medicaid claims/encounter data.

Many of the sources of potential survey questions noted above include suggestions/models for asking respondents to their own report of health outcomes.

Holistic Health and Functioning	
Subdomain: Individual health and functioning	Source
Percent reporting that they feel lonely, sad, or depressed “not often,” “almost never,” or “never.”	NCI-AD
Percent rating overall mental or emotional health as good or better.	HCBS/EOC
Percent rating overall health as good or better.	HCBS/EOC
Percentage of members who remained stable or improved in frequency of pain.	MLTSS NY
Percentage of members who remained stable or improved in experiencing depressive feelings over the follow-up period.	MLTSS NY
Percent responding “not at all” or “a little” to: To what extent do you feel that physical pain prevents you from doing what you need to do?	WHOQOL-BREF
Participants in the Demonstration who remained stable or improved in ADL functioning between previous assessment and most recent assessment.	MLTSS NY, AZ, others
Percent disagreeing with: Pain affects my well-being.	OPQOL
Percent of MLTSS members in HCBS/NF setting with selected mental health and substance abuse disorder diagnoses.	MLTSS NJ
Subdomain: Health promotion & prevention	Source
Percent of HCBS members who were re-admitted to the hospital within 30 days of last hospitalization	MLTSS NJ, NY
Percentage of members 18-85 years of age who had a diagnosis of hypertension and whose blood pressure was adequately controlled during the measurement year.	MLTSS CA
Percent of HCBS members who had ER utilization.	MLTSS NJ
Percentage of patients ages 18 years and older screened for clinical depression using a standardized tool and follow-up plan documented.	MLTSS CA
Percentage of members who had one or more falls in the last six months.	MLTSS NY
Percent of HCBS members who were admitted to the hospital.	MLTSS NJ
Moderate and high-risk members with a health risk assessment completed within 90 days of enrollment.	MLTSS IL

Holistic Health and Functioning	
Percent of Enrollees with a problem falling, walking or balancing who discussed it with their practitioner and got treatment for it during the year.	MLTSS MI, IL, others
Percentage of members in long-term care who are at risk for falling and who are seen by a practitioner and receive fall risk intervention.	MLTSS IA
Percent of plan members who discussed exercise with their doctor and were advised to start, increase or maintain their physical activity during the year.	MLTSS OH

We also propose using Medicaid claims and encounter data files to assess participants’ health outcomes. Depending on the population (elderly vs. long-term disabled), outcomes in the evaluations that were reviewed were typically measured by incidents of hospitalization, individuals’ ability to return to their community (following hospitalization), and deaths. Walsh et al. (2006) used admission and discharge data from hospitals and nursing facilities. Frequently cited indicators are emergency department visits, hospital admission records, nursing facility records, and mortality rates.

These indicators are consistent with stakeholders’ suggestions that the evaluation include the number of emergency department visits, as well as the number and length of hospitalizations, as outcome measures.

Assessing Other Participant Benefits

We propose exploring the inclusion of other questions compiled by the NQF to assess other participant benefits.

Person-Centered Planning and Coordination	
Subdomain: Assessment	Source
Percent responding ‘yes’ to: Do you believe that the result of your “level of care assessment” identifies your real needs?	NMPQR
Subdomain: Person-Centered Planning	Source
Percent of members reporting that their care plan includes all of the things that are important to them.	MLTSS WI
Percent of participants reporting they are the primary deciders of what is in their service plan.	MLTSS MN
Percent responding “yes” to: Do the services and/or supports focus on the person’s goals?	POMs
Subdomain: Coordination	Source
Percent HCBS members who report: Their service coordinators help them get what they need.	MLTSS HI
Percent responding “yes” to: Has a case manager helped you solve a problem that you have told them about?	MNCES
Percent responding “yes” to: Does your case manager help coordinate all the services you receive?	POMP-CMS

Choice and Control	
Subdomain: Personal choices and goals	Source
Percent responding “yes” to: Can you see your friends when you want to?	NCI-ACS
Percent responding “yes” to: Can you get to the places you need to go, like work, shopping, or the doctor’s office?	MFPQOL
Percent of HCBS members who report: They make choices about their everyday lives, including housing, roommates, daily routines, case manager, support staff or providers, and social activities.	MLTSS HI
Percent responding “true” to: I have choices about the activities I want to do.	PART-E
Percent responding “yes” to: Does the person have options about where and with whom to live?	POMs
Percent responding that the consumer chose or helped choose: Who chose (or picked) the place where you work?	NCI-AD

Choice and Control	
Percent responding that the consumer chose or helped choose: Who chose (or picked) where you go during the day?	NCI-AD
Subdomain: Choice of services and supports	Source
Percent responding “yes” to: Do the people who are paid to help you do things the way you want them done?	NCI-AD
Percent responding “yes” to: Does your attendant provider pay attention to your choices, such as what you like to eat, where you want to go or what you want to do?	EAZI
Percent responding “yes” to: Can you make changes to your budget/services if you need to?	NCI-ACS
Percent responding “yes” to: Can you choose or change what kind of services you get and determine how often and when you get them?	NCI-AD
Percent of waiver participants whose record contains documentation indicating a choice of either self-directed or agency-directed care.	MLTSS KS
Percent of HCBS consumers who are self-directing their HCBS.	GA 1915(c) waiver
Subdomain: Personal freedoms and dignity of risk	Source
Percent responding “true” to: I have control over what I do and how I spend my time.	PART-E
Percent responding “true” to: I have the freedom to make my own decisions.	PART-E
Percent responding “yes” to: Are you free to take risks when you want to?	TXPES
Percent responding “yes” to: Does your attendant provider allow you to make your own mistakes?	EAZI
Subdomain: Self-direction	Source
Percent of members reporting that, in the last 12 months, they were offered the option to self-direct some or part of their services.	MLTSS WI
Percent of MLTSS members opting to use self-direction.	MLTSS NJ, SC, others
Participants who self-direct their supports and services do so with employer authority and/or budget authority.	MLTSS NY
Participants are able to make an informed choice on whether to self-direct their supports and services.	MLTSS NY
Change in the percent of dollars paid for consumer-directed community supports over time.	MLTSS MN
Members using self-directed arrangements through a fiscal intermediary.	MLTSS MI
Rate of increase for enrollees using self-directed arrangements.	MLTSS MI, TX, others

Community Inclusion	
Subdomain: Social connectedness and relationships	Source
Percent responding “always” to: I have someone who will listen to me when I need to talk.	PROMIS-ES
Percent responding “always” to: How often do you get the social and emotional support you need?	NHIS-01
Percent responding “yes” to: Is there someone you can count on in an emergency?	MNCES
Percent responding “yes” to: Generally, are you satisfied with the amount of contact you have with friends?	MNCES
Percent responding “yes” to: Generally, are you satisfied with the amount of contact you have with your family?	MNCES
Percent responding “always” to: When you want to, how often can you get together with these friends who live nearby?	HCBSEOC
Subdomain: Meaningful activity	Source
Proportion of individuals who do not have an integrated job in the community but would like one.	MLTSS NY
Proportion of individuals in sheltered workshops who transition to integrated community-based employment.	MLTSS NY
Proportion of individuals who have an integrated job in the community.	MLTSS NY
Percent responding “always” to: When you want to, how often can you do things in the community that you like?	HCBSEOC
Percent responding “yes” to: Do you like how you usually spend your time during the day?	NCI-AD
Percent responding “yes” to: Are you doing volunteer work or working without getting paid?	MFPQOL
Subdomain: Resources and settings to facilitate inclusion	Source
Percent HCBS members who report: They have adequate transportation when they want to go somewhere.	MLTSS HI
Percent responding “always” to: I have regular opportunities to be part of the community.	ORIES
Percent responding “always” to: Where I live makes it easy for me to get around in the community as I desire.	ORIES
Percent of HCBS members living in [group quarters] who report: They are able to see their families and friends when they want.	MLTSS HI

Cost Analysis

The analysis of costs was far less prevalent and explicit in the available evaluations. This may be influenced by the fact that the programs—as they currently exist—are generally limited by quotas and caps. Governments and program administrators typically expect costs to rise because of high demand for desirable programs. To prevent this, states limit the number of beneficiaries and impose strict eligibility criteria (Tilly et al., 2000, pp. 4-5).

Based on recommendations from auditors, stakeholders, and a review of the literature, we believe the most important features of the cost analysis will be as follows:

- Comparisons across similar groups of clients (based on risk and needs as well as prior health status and demographic variables),
- Inclusion of comprehensive health care costs, and
- Consideration of unique needs of CDASS and IHSS participants.

Cost Change Analysis

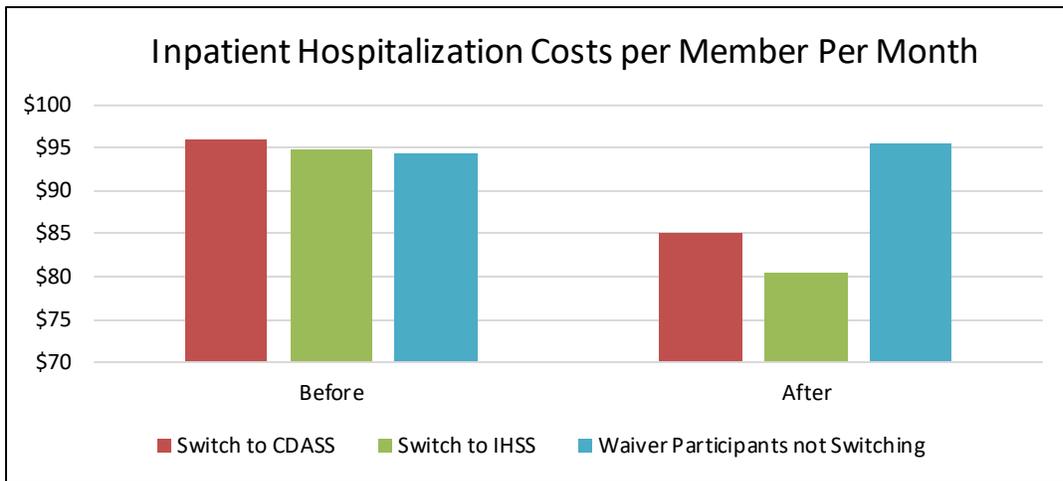
We recommend using difference-in-difference techniques to measure treatment effects on inpatient services and emergency department utilization costs, as well as overall service costs. We generally measure difference-in-difference with regression-based techniques, which help in controlling for confounding variables such as implementation phase, degree of exposure to key policy changes, and geographical area. The difference-in-difference regression can also be used to identify whether higher satisfaction with CDASS and IHSS services are correlated with lower costs.

We recommend using before and after cost data to conduct a comparative test on costs for consumers in each of the identified program areas (CDASS, IHSS) and “non-utilizing waiver” (traditional services) clients. We will compare the total costs in a specific time period (e.g., six months) prior to enrollment in either CDASS or IHSS, or costs for a fixed (e.g., six-month) period for the non-utilizer waiver group (comparison group), to the same length of time post-program enrollment, or the time period consecutive to the first-time period, for the comparison group. We will conduct regression based difference-in-difference tests for statistical significance.

These comparisons should be made at four levels: 1) by individual service type (personal care, homemaker, and health maintenance), 2) subtotal costs for all IHSS and CDASS services, 3) subtotal costs for all services based on participants’ waiver type, and 4) total costs.

We will work with the Department to identify the optimum pre- and post-time periods, including identifying fixed “before” and “after” time periods for the comparison group (since there is no enrollment date to define “before” versus “after”). While the RFP recommends six-month time periods, it may be more effective to use a trailing 12-month timeframe to

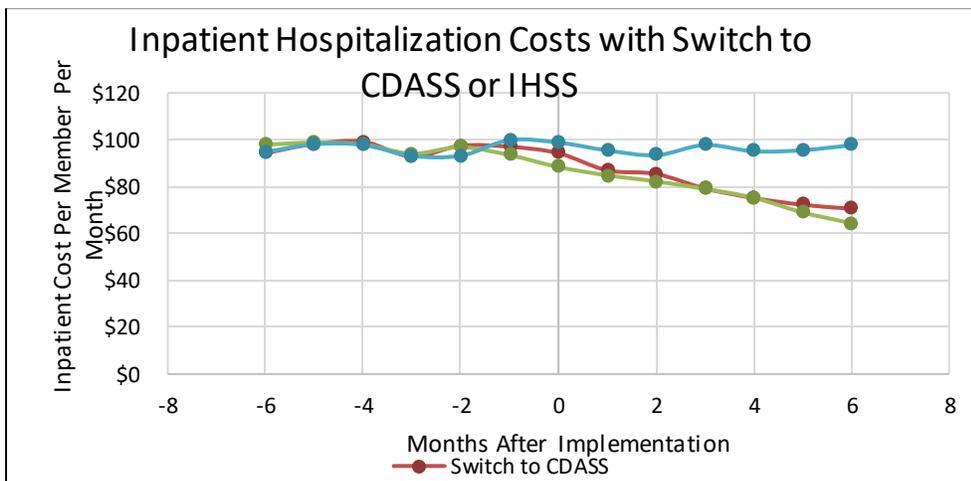
aggregate costs given the somewhat seasonal nature of healthcare costs distributions. See the chart below for an illustrated example. (Note: This is not real or estimated data).



We also recommend the use of difference-in-difference tests to compare before and after costs for the two treatment groups—CDASS and IHSS (the first difference)—to before and after outcomes of a comparison group (the second difference). This method helps control for factors unrelated to the intervention influencing the change in outcomes over time.

We will use propensity score matching to match treatment and comparison clients with similar characteristics. This method will generate a more robust comparison group.

We will also conduct a trend-over-time analysis of costs for both the CDASS and IHSS programs (using average cost per client per day) as well as the comparison group on waiver participants not utilizing CDASS or IHSS services.



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