

Consumer Directed Care

Key Informant Interviews Summary

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4450 Arapahoe Avenue, Suite 100, Boulder, CO 80303

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Introduction

In December 2017, the Colorado Department of Health Care Policy and Financing (HCPF or “the Department”) contracted with TriWest Group (TriWest) to conduct an evaluation of consumer-directed care service delivery options in Colorado (also known as participant-directed care service delivery options). The overall goal of this evaluation effort is for our team at TriWest 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 [CDASS] and In-Home Support Services [IHSS]).

We contacted over 40 key informants in the first two months of the evaluation. The purpose of these interviews was 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.

Our objectives for conducting these key informant interviews with stakeholder groups were to 1) develop a deeper understanding of the CDASS and IHSS service delivery options from a variety of stakeholders’ perspectives, 2) finalize the list of outcomes that need to be achieved, and 3) explore specific survey options to determine the method most likely to yield higher response rates and ensure enough responses for sufficient statistical power. We randomly selected interviewees based on their role in consumer-directed care services (whether they were direct participants, service providers, and/or advocates) and which services they had experienced. We created the selection pool from the response and interest to an email invitation we sent to the Participant-Directed Programs Policy Collaborative (PDPPC) membership, an invitation on HCPF’s website, and partner-agency outreach efforts. This resulted in a sample size of 42 informants. All 42 were contacted to complete a key informant interview. Three of these requested that we send them a paper copy of the interview questions rather than speak with them over the phone.

We conducted a total of 31 interviews with 35 key informants. The interviews occurred during the middle of February 2018 through the second week of April 2018. Since individual responses were confidential, all responses were kept anonymous and combined to provide content for this report.

We developed two protocols for the interviews. Drawing on best practices and input from HCPF staff, one protocol was developed for advocates of consumer-directed care services and the other was developed for consumers of consumer-directed care services. The content areas included: successes of and barriers to directing one’s care in Colorado, consumer satisfaction and choice of services, impact on quality of life health and well-being, and views on administrative oversight by the Department.

Interviewees*	Advocates / Personal Care Attendants / Program Staff	Participants	Self-Identified as Both Advocate and Participant
Stakeholder of the Consumer Directed Attendant Support Services (CDASS)	7	9	4
Stakeholder of the In-Home Support Services (IHSS)	5	3	1
Stakeholder of traditional home health services (Traditional/Home Health)	1	2	0
Totals	13	14	4

*Numbers do not total 35 as several interviewees self-identified in more than one category.

Interview Protocol

Sampling

The Department sent an email to solicit potential key informants for interviews. The solicitation went to members of the Participant Directed Programs Policy Collaborative (PDPPC), In-Home Support Services (IHSS) stakeholder groups, and other key stakeholders on the Department’s distribution lists and website. Interested respondents were asked to respond directly to a TriWest scheduler with their contact information and a description of their specific stakeholder role.

Because the number of potential respondents did not exceed available resources, we were able to contact all interested stakeholders and did not need to create a stratified random sample of respondents.

Scheduling

TriWest staff contacted potential respondents by phone or email and conducted 60-minute phone interviews with each.

Conducting and Documenting Interviews

To establish reliability of the interview process, TriWest staff conducted five interviews, using a pair of interviewers. These interviewers then met to refine the wording of questions, prioritize questions if time was limited, and identify potential follow-up/probative questions. Four staff members conducted interviews.



Because the interviews took place over the phone and the consumer's identity was not linked to the interview transcripts, we did not document informed consent. Agreement to continue the interview on the phone was taken as implied consent, as were the three interviews who requested and responded in writing.

We provide a detailed summary of interview responses in the following section of this report. Below, we feature some highlights from key informant interviews:

Many of the key informant interviewees identified themselves as both advocate and participant. Several of the interviewees were paid professional advocates and participants/employers of CDASS services. Participant satisfaction in the CDASS service was uniformly high.

Choice between two Consumer Based Care services is important to both advocates and participants. More than one interviewee stated Colorado was lucky to have this kind of variety.

Consumer-directed care allows participants to live a rich and full life of their choosing (when to go to bed, where to shop, the ability to work in the community, etc.). Respondents who had transitioned from traditional agency-based care to CDASS felt the transition was a positive one and that the services they receive now are of greater quality and meet their needs in a way traditional agency-based services did not.

While interviewees generally praised the program administration, several participants noted that case managers sometimes provide inconsistent or inaccurate advice. These respondents stated case managers could benefit from additional training and support in understanding the finer points of these services.

Colorado's consumer-directed care service delivery options are viewed with high regard in many long-term care circles locally and nationally. Multiple respondents stated they relocated to Colorado for access to these services.

Successes Seen in Consumer-Directed Care

We asked participants about how consumer-directed care services are working in Colorado, how these services allow for choice of *when and where* services are provided, and what is going

well now. In addition, we asked how satisfied participants are with the services they currently receive.

- Overall, CDASS participants are pleased with their services and state that they experience more control and ownership of their care and needs. Several stated that being an employer of their own personal care attendant enhances their person-centered care in a way they did not experience in the past.
- Interviewing, hiring, and supervising their own personal care attendants allows CDASS participants flexible schedules, consistency in attendants, and the ability to offer differential hourly rates based upon seniority/longevity. For all of these reasons, CDASS participants believe they are able to retain the same staff for a longer period of time. Some reported attendants who have been employed by them for up to eight and ten years.
- One IHSS agency provider states, *the majority of our clients (80%) are on IHSS. Many are supported by family members and friends. Now IHSS can pay these caregivers and we do unless they ask us to find other staff.* [The IHSS participant] *presents to us the people they want to provide support and we hire them because our clients know who they want.*
- Three interviewees stated they have found success in hiring “outside of the healthcare field,” which they believe can result in care attendants who are not as indoctrinated into the medical model, which views disabilities through risk and limitations as opposed to a full, supported life.
- Both IHSS and CDASS participants are satisfied or very satisfied with their care planning. Participants state they have ample opportunity for input on their care plans as well as the allocations they receive. Analogies used were “I drive the bus of my care/support team” and “my care plan is ‘made to order.’”
- One IHSS agency provider thought the growth in IHSS enrollment is an indication that IHSS participants are satisfied with their care and services.
- CDASS participants with higher needs—such as requiring 24-hour or intensive care—believe the only alternative for them would be facility-based care as agencies will not staff their level of need within the community because of both cost and risks. Participants were concerned that ceding control and losing access to their communities would have a negative impact on their quality of life.
- One family caregiver said they would like to see a hybrid model of IHSS and CDASS. This caregiver had a child in the IHSS service and a spouse in the CDASS service. The family found themselves three staff short during the summer time. It would have been nice to have “called an agency to find a backup for the backup. As a single employer, it is hard to keep an on-call pool of back-up staff. It is an economy of scale—you can’t keep your PRN staff busy enough so they seek other more reliable work; an agency can keep them busy.”
- Recent work to redefine the rules of IHSS service, currently in its first reading in front of the medical board, is expected to help remove several system and policy barriers

experienced by IHSS participants and their families. The process for participant input to the revised rules is seen as a success and the kind of inclusive process that is appreciated by participants, advocates, and families. Continued collaborative processes like this would be welcomed.

Barriers/Concerns About Consumer Directed Care

This content area captured responses from interviewees to questions about policy or system barriers, and if the administrative staff at the Department could do anything differently to build better structure and/or support for participants.

- There was continued concern (but no concrete examples given) about the “taking advantage of the system” or “abuse.” These concerns stem from the perceived flexibility and lack of oversight in the CDASS service which allows participants to hire their own personal care attendants with no required certification or background checks. It was suggested that more training be provided to CDASS participants who may or may not have a business background. Understanding and learning what is expected of the employer–employee relationship requires more than a four-hour training to be effective and ensure that no waste and abuse is occurring. Family members who are personal care attendants are particularly sensitive to this issue as they feel targeted and under greater scrutiny. IHSS provider agencies believe there needs to be greater monitoring of regulatory compliance and well-defined policies and definitions of common allocations, such as hours needed for wound care.
- The criteria and definition of what is considered a medical intervention needs to be reviewed and reconsidered. IHSS agencies could be allowed to waive the nursing scope requirements because there are several services an agency could provide at a lower level of care. Consideration should also be given to include preventive care into this definition. Services provided by home health nurses are helping participants remain in their home and out of high-cost skilled nursing facilities, yet the agencies feel they are not fully compensated for these services under the current definition.
- As IHSS continues to expand to meet demands of new enrollees, the Department could consider providing this service to other waiver programs (e.g., brain injury waiver or children’s extensive support waiver).
- Several participants and advocates shared concerns about the Electronic Visitation Verification (EVV) process. Issues of particular concern include the complexity of a web-based system, the level of computer literacy needed, the inconvenience to both Personal Care Attendants (PCA) and employers, potential personal health information security risks, and invasion of privacy; one respondent feels this level of “monitoring is equivalent to an incarcerated person’s ankle bracelet.” The overall concern is a move away from person-centered care to a process-centered focus that will limit an employer’s flexibility. It is a widely held belief that some participants would not be able

to understand the system and thus be forced to rely on an Authorized Representative (AR).

- Views on fiscal agencies were mixed. Some participants stated their Fiscal Management System (FMS) was “great and... works really well,” but others have experienced “hiccups” such as the need for “perfection” in documentation in order to proceed with services. Two different participants reported that ACES\$. Financial was doing an “excellent job.” One suggestion was to require the FMS to have baseline measures and outcomes so that some participants can shop for the best fit.
- IHSS enrollment paperwork can be time consuming. The amount of onsite classroom training can be burdensome, particularly for families who require child care. Occasionally, documentation requirements, such as a physician’s attestation or order, may take time and delay the enrollment process even further. Some suggested there could be a “fast track” or a temporary approval process that allows for a 60–90-day grace period in order to complete documentation requirements.
- IHSS time tracking is less fluid and flexible than CDASS time tracking. IHSS time tracking is task-focused and reported in 15-minute increments. This can be difficult to manage as not all tasks fit within the 15-minute time slot. For example, a participant might be scheduled for a health maintenance activity requiring food prep—typically allocated as a skilled task—but in practice this is done in conjunction with the health maintenance task; the 15-minute increment, however, only allows for one task designation. CDASS participants are better able to blend services in a more natural way than the rigid 15-minute increments. As another example shows, while a PCA is doing laundry, they may also be prepping food or bathing; there must be fluidity in time tracking to allow for efficiencies. Yet another family care provider related her frustration with the rigid time keeping: her husband had 15 minutes taken off his allocation for “washing dishes” because he uses a feeding tube, thus eliminating the need to do dishes.
- Transitioning from one state to another, or from one Regional Care Collaborative Organization (RCCO) to another within Colorado, can be challenging and fraught with delays and miscommunication, causing frustrations and confusion. Two interviewees spoke to the challenges of Single Entry Point (SEP) entities lacking knowledge of the three consumer-directed care services available to participants. Because of this lack of knowledge, there is a belief that SEPs promote home-based agency care because there is “less paper work and fewer hoops to jump through.”
- Finding, securing, and retaining housing that is certified according to the Americans with Disabilities Act— particularly under the Housing and Urban Development (HUD) waiver— is difficult. As one advocate said, “your services are tied to your physical address, and when your housing is unstable, it can place you at physical risk of your services being terminated.” If this were to occur, assisted living would be the only option for many.

- IHSS participants are bound by risks as defined by their agency's protocols, policies, and regulations, while CDASS participants define, assess, and manage their own levels of risk. One interviewee stated, "With a homebound restriction in IHSS and agency-based care, we are defeating any effort we may make in getting people back to work."

Choice and Satisfaction in Services

The choice-in-service content area captured responses from stakeholders to questions about which services they have had in the past, how these are different from current services, why they chose to change services, how the transitions from one service to another worked, and if these transitions have been positive or negative.

- Participants are overwhelmingly satisfied with their services in IHSS and CDASS. Most CDASS clients believe and are adamant that without this program (several are C4/C5 spinal cords injuries), they would not be in their own homes, be employed, and be able to participate in their community (e.g., dance classes, therapy groups, dating, attending cultural events or social gatherings). Rather, they would be "wasting" away in a skilled nursing facility or nursing home. One CDASS participant states, "[CDASS] allows me the confidence to live in my home, stay in my community, and compensates the person who I love and who loves me to be able to provide my care. It gives me security. It is a blessing." Multiple participants described CDASS as a "blessing."
- Although the majority of participants report being very satisfied with services, some gaps were identified. Day programs, for instance, may operate only during traditional business hours, making employment difficult for caregivers. There is also a lack of allocation for non-Medicaid covered items. One suggestion was to allow participants to use a percentage of "allocation savings" on these items (e.g., tires for accessible vans, house modifications after exceeding the \$14,000 lifetime max, accessible van). Backup staff can be difficult to find on short notice and require paperwork to employ. One participant asked why unpaid backup staff cannot be used and suggested they could simply submit an identification form rather than being required to submit a full employment form. This would allow friends and family members to serve as non-paid backup staff.
- Many CDASS participants report they are very happy with the primary and backup teams of PCAs they are able to hire and train. Some reported PCAs who have been with them for eight to 12 years. This level of longevity can have a positive affect on the quality and consistency of services as well as increase participant satisfaction. Low PCA turnover also reduces the need for retraining.
- There is a negative impact on participant satisfaction when they are forced to change services because they have moved to or changed waivers. This is most acute among children, who are more likely to move from one waiver to another in order to access more services, but experience interruptions in services because IHSS is not authorized

for the Children's Extensive Support (CES) waiver. Their families must then change services.

- A smooth transition from one service to another depends on which services are involved. Many participants see the service choices along a continuum and spoke to a natural flow from one level to another: traditional home health services to IHSS to CDASS. Operating outside or against this flow, however, can be problematic. The services along this continuum increasingly give more control, decision-making, and responsibility to the participant. The observation is that transitioning from traditional home health to IHSS is easy because participants have additional support from the agency, an emergency plan, and access to backup staffing. The next level of transition, from IHSS to CDASS, is common and can be very successful because participants have built-in, trained attendants who can move with a participant into their new services. There are concerns that a participant going from traditional home-based care to CDASS presents a higher learning curve and more immediate responsibility for decisions and care. This can sometimes feel like participants, families, and caregivers "are on the high-wire without a net."
- Agencies are unable to guarantee the same staff will provide services to a participant each day. This is difficult for participants and families on many levels. Consistency in PCAs is crucial for quality of care, satisfaction of services, personal safety, and timeliness.
- IHSS participants report a high level of satisfaction in having a nurse visit once a month. There is comfort in knowing that a trained professional oversees their needs and helps to prevent hospitalizations. The agency nurses act as a go-between with physicians and medical care teams. Skilled nursing care is needed in addition to non-skilled services. One agency director reported that two agencies stopped providing non-skilled services because the reimbursement was too low to make these needed services viable. A rate increase should be considered or agencies will continue to be forced to eliminate non-skilled services.
- Some participants would like to be able to choose their equipment and supply vendors. There have been times when Medicaid-approved vendors discontinued a particular product that clients prefer. One participant also referenced a months-long waiting list for repair services after a vendor recently bought out all local competitors without adequately expanding their services. This can be frustrating.
- When asked about how their lives would be affected if IHSS or CDASS services were not available, participants stated: *Self-determination equals quality of life and I would lose this. Our world would not look nearly as happy and full; I would not be in my home. Wouldn't have my new chair and wouldn't be mobile; I was able to get a custom made seat; in my nursing home they made those kinds of decisions for me; I get to decide how much time I spend in my chair, at the nursing home it was 3 hours then back down in my bed. I've had one visit to the ED for kidney stones, while in the nursing home I was*

hospitalized eight times. When I was in the nursing home it was 30 minutes from my family, my friends, and the church. I would have fewer choices and no transportation if CDASS wasn't here.

View of Administrative Oversight

The administrative oversight content area captured responses from interviewees about how the Department was doing in meeting the needs of consumers, if consumers felt heard, and if there was anything the administrative staff could do differently.

- The Department's website does not utilize tools to share information between participants or offer peer-to-peer contact/messaging. Can the Department better utilize social media tools to reach out and share best practices?
- Task management sheets are a challenge. Is it possible there could be a Department resource or liaison for families to contact if they have questions?
- There was considerable feedback about the services provided by case managers (CM). The feedback was mixed, and a general perception was that CMs are overworked, overwhelmed, and undertrained. Recommendations include:
 - A joint training with FMS, home-based agencies, SEPs, and CDASS employers in the same room so there is consistency in expectations definitions, rules, regulations.
 - Assign CMs based upon participants' geographic locations. One example that was provided involved a participant who lives in Durango, but their CM is in Colorado Springs. The CM has never visited the participant AND is not familiar with the participant's community or what local services are available.
 - Have the Department develop a pro/con crosswalk of all three services (traditional, IHSS, and CDASS) that also has a listing of "skills you will need" so that consumers can choose a service that best fits their skills, needs, and abilities.
 - CMs need to have more contact with the consumer. One participant suggested that when he received services from a Community Care Board (CCB), he met monthly with his case manager. He referred to this a "Cadillac Case Management" and felt that should be the standard for consumer-directed care.
 - More training for CMs is needed. Current training seems optional and does not require competencies or learning objectives. Thus, CMs do not understand the distinctions among the three CDC services.
 - Colorado should consider other models for CM training. For example, CMs in other states are required to have medical backgrounds to approve allocations for high-need, medically-complex cases such as C4/C5 paralysis.
 - Overages are approved over the phone, but this should be confirmed in writing as well. There have been times where a miscommunication occurred and there was no documentation for the Authorized Representative (AR), CM, and participant to refer to in order to resolve the issue.

- Consider a two-pronged approach for CMs in order to best serve clients: 1) educate CMs about the minutiae of the three available CDC services, then 2) facilitate an appropriate referral based upon needs, skill level, and desire for responsibility.
- In terms of managing annual allocations, allowing for flexibility across months is very good and recognizes that participants can have seasonal or episodic changes in their level of need. The focus should be on the annual allocation rather than the month-to-month variance.
- The Department’s administrative staff have been responsive and helpful, and CDC leadership is viewed in a positive manner. Several participants noted that phone calls are promptly returned and family members are treated as stakeholders and partners. It was observed this does not happen in all states, so this is a particular strength of CDC services in Colorado.
- Participants expressed appreciation for the Department acting as a mediator when a local SEP determines a participant is ineligible or has lost services.
- All efforts should be made to better support the role of ARs since they are volunteers who play a crucial role in the lives of consumers.
- There is concern about the responsiveness, timeliness, and knowledge of staff in the SEPs. There is a belief that it is difficult to get through on the phone, and paperwork gets lost whether mailed or dropped off to the drobox. Participants suggested that a “receipt request” be used when dropping off documents. Several participants told stories of relocating and subsequently being left homeless when benefits were erroneously cut because of lost paperwork and administrative errors, resulting in loss of income and disruption in prescription coverage during the appeal process.
- Two participants who have experienced CDC service delivery options in other states believe that Colorado has a generous allocation.
- There were mixed comments from family members regarding being limited to a 40 hour work week. Some feel this is positive and can reduce fraud and/or abuse; others feel it underpays family members who are providing care to their loved one 24 hours a day, seven days a week.
- One mother of a child enrolled in IHSS feels the program is a little “hands off” and that a more frequent check-in would be welcomed. Her experience is that the CM is supposed to check in every month, but now she only receives an email. When she responds to this email it feels like it goes into “a black hole” and she does not hear back. She wondered where the advocacy and community service referrals are.
- One participant believes the Department is “so much more supportive of participant-directed care now than 15 years ago.” He observed this shift was due to the growth of PDPPC bringing both sides to a better understanding. The Department’s commitment to PDPPC has made the relationship better and improved CDC’s grown. Over 7,000 people use CDC. The Department has been supportive and positive—it hosted training for CM agencies, listened to what advocates and participants need, and created choice in FMS

vendors. All of this is recognized as efforts to allow participants be treated as employers more than ever before.

- There is a perception that when multiple government agencies have access to a participant's records, things can go awry. When Supplemental Nutrition Assistance Program (SNAP) services, housing assistance, HHS, Medicaid, and CDASS all have access to a participant's records, the result can be confusion, miscommunication, and chaos. At least two respondents felt this caused decreased and/or reduced benefits for them.
- Advocates expressed concern about a lack of inter-agency agreement on rule interpretations and program expectations. Several state entities (i.e., HCPF, HHS, SEPs, and CDPHE) are involved in care and outreach, but they lack common definitions for services, supervision, and regulations. Respondents acknowledged that HCPF is attempting to standardized these items; however, these efforts have not yet yielded a shared understanding or common definition of services.
- Standardized care plans could help agencies and case managers by establishing common definitions, documentation, and shared expectations.