



DETAILED SUMMARY OF THE MEETING OF THE ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (IDD) WAIVER REDESIGN STAKEHOLDERS

1570 Grant Street, Hibiscus Conference Room, 1st Floor
Denver, CO 80203

January 16, 2019
11:00 A.M. – 1:00 P.M.

1. Meeting Attendees

A. Stakeholders Present:

In room: Pat Chamberlain, Jessica Eppel, Ellen Jensby, Sara Leeper, Abigail Negley, Jodi Walters, Charlene Willy

On phone/chat: Gerrie Frohne, Kevin Graves, Patrick Hackney, Rob Hernandez, Michelle Hoffner, Bob Lawhead, Carol Meredith, Laurel Rochester, Leslie Rothman, Stephan Shaughessy, John (no last name), Scott (no last name)

B. Department Staff Present:

Lori Thompson, Matt Baker, Alicia Ethredge, Katie McGuire, Scott Nelson, Rebecca Spencer, Zach Ulrich

C. Resources Present - Supporting Waiver Redesign:

Kady Predota (Consumer Directed Care Network), Elle Dornan (Steadman Group), Carla Lewis (Steadman Group), Cathy Rudd by phone (Steadman Group), Sharon Steadman (Steadman Group)

2. Welcome and Introduction

Sharon Steadman from the Steadman Group introduced herself as the facilitator for this meeting. She thanked the stakeholders for participating (in person, via chat, and by telephone). She asked speakers to identify themselves when they speak and reminded everyone that the meeting is being recorded. She reviewed housekeeping items and the Department's Mission. The facilitator reminded the participants of the content of the Working Agreement:

- Treat each other with respect and honor one another as whole individuals.
- Value diversity in experiences and perspectives.



- Robust examination and discourse improves our work.
- Engage with each other as partners.
 - Direct communication
 - Solution-oriented collaboration
- Respect accommodations needed by others to participate.

The facilitator reviewed the agenda:

- 11:00 Overview of Today's Meeting
- 11:10 Review November 28, 2018 Meeting Summary
- 11:15 Self-Direction Continuum
- 11:45 Nurse Practice Act
- 12:15 Individualized Budgets
- 12:45 Wrap-Up and Adjourn

The facilitator noted that the Department has specific questions that will be asked to guide input from the stakeholders.

The facilitator briefly explained the materials for today's meeting noting that they include the following:

- November 28, 2018 Meeting Summary
- January 16, 2019 Meeting Agenda
- January 16, 2019 PowerPoint Presentation
- Service Crosswalk
- Statute Crosswalk
- CDASS/IHSS "What Fits" Handout

The Department provided additional explanation about the two crosswalks that will be emailed to the stakeholders:

Service Crosswalk – Provides high-level crosswalk between proposed and existing waiver services and compares which services align in coverage. Within each service, there is also a breakdown of proposed self-direction. This section provides a checklist for stakeholders to give input on the scope of self-direction they recommend for the services. More information will be provided about self-direction in a presentation later during this meeting.

Statute Crosswalk – This crosswalk is more comprehensive and compares authorities across services as well as provides more detailed content across services. It is intended to be a resource for stakeholders through the end of the redesign process.

3. Review November 28, 2018 Meeting Summary

- The facilitator asked those present if they had any comments or revisions to make to the November 28, 2018 Meeting Summary.
- A stakeholder asked that comments from family members about the prior meeting be entered into the record. The list of comments drafted by the family members was submitted after the meeting and is attached as Addendum 1. The comments read into the record follow:

- Family concerns shared with actuary – There should be no interruption or change in services or budget for those currently on the Home and Community Based Services – Developmental Disabilities (HCBS-DD) waiver. The actuary should use individualized budgets and Service Plan Authorization Limit (SPALs) to base projections on, not what has been used. Budgets should be based on needs of the individual. There are many reasons that hours should not be used, especially if there is a shortage of qualified workers willing to work for the pay offered particularly in rural areas. If cost savings measures are being considered to bring people off the waitlist and stay within the same budget, then alternative models for the delivery of services should be considered. Currently Community Centered Boards (CCBs) are paid for case management and administrative fees then PASAs take 35-50 percent. The individual receiving services ends up with 40-50 percent of what is left. A model that is able to significantly reduce overhead and administrative fees should be considered. This is in line with Consumer-Directed Attendant Support Services (CDASS).
- It took a long time for CDASS to be approved for the Supported Living Services (SLS) waiver. When the waivers are combined, will it still be available? The Department responded affirmatively. Can there be a pilot program for individuals where they control an account for their own services, including those receiving residential services? One of the missions of the Waiver Implementation Council (WIC) was to have the right services delivered at the right time, etc. The reality of the system is that there is no fluidity, changes in Supports Intensity Scale (SIS) level are rare, difficult to obtain, and people wait for years to get funding. How will changes in need be met with the combined waiver? How can the current method be improved?
- There is a new needs assessment tool being worked on to improve the SIS. How will this tool drive individual budgets, how will the decision for residential services be made, will a SIS level determine who gets residential services, and how will this work?

4. Self-Direction Continuum

Lori Thompson provided a summary of the continuum of self-direction options available:

Agency-Based/Provider Managed – Traditional model that has existed for decades. Agency manages overall service budget, staff and provides quality oversight.

Paid Family Caregiver Model – Evolved out of 2008 Family Caregiver Act. Implementation guidelines issued in 2010. The most significant change this law made was to allow persons receiving residential services to receive those services in the family home and family members could be paid to deliver any of these services. Legally Responsible Persons cannot be paid to provide services under this model. This means that spouses, and parents of children cannot be paid to provide services under this model. This also means guardians who are family members (or any other relative) can be paid family caregivers.

In Home Support Services (IHSS) – Operates similarly to family caregiver. Client selects, trains and supervises attendants. Agency manages the services budget and is responsible for quality oversight.

Consumer Directed Attendant Support Services (CDASS) – This model is the most self-directed on the continuum. The client selects and supervises attendants and manages their allocation/budget.

There was a question about why CDASS is not available on the DD waiver. The stakeholder who raised this issue described a situation where the agency is taking so much of the fee, that the waiver makes no difference in availability of services. The Department commented that this is exactly the kind of information that it wants. This comment will be fleshed out further during the question and answer period of the meeting.

There was also a comment about the requirement that an agency be involved in order for family caregiver services to be provided. The Department responded that the guideline requiring a family caregiver be an employee of an agency is no longer in place, although arranging for the service still needs to go through a Program Approved Service Agency (PASA). It was noted that the Department wants to change this in the redesigned waiver. It was also noted that there are a number of reasons CDASS, or other forms of self-direction, has not been implemented in the DD waiver (other than paid family caregiver), but the Department is moving in the direction of implementing self-direction to the extent possible.

Chat comments: CDASS should be added for all waiver services

Is there a prohibition for guardians to be Host Home providers? The Department responded that there has never been a prohibition for guardians to be Host Home providers. However, it was noted that “family” does not meet the regulatory definition of Host Home provider. The definition in the regulation is that a Host Home provider is a non-relative. The Department removed language in the waiver that the paid family caregiver had to be an employee of a Program Approved Service Agency (PASA). However, a PASA can have a contractual relationship with a paid family caregiver or employ them, if the parties choose to do that.

There was a question about whether there is a prohibition against an agency (or a person being paid to deliver services that is a **non-relative**) being a guardian and whether that is a conflict of interest? The Department responded that additional research is needed to clarify this question, but noted that some PASAs are guardians. *See the attachment to this summary for clarification information from the Guardianship Alliance.

Kady Predota from Consumer Directed Care Network explained that her company is the training and operations vendor for consumer directed services in Colorado. They provide client and Authorized Representative training for CDASS, case manager training for CDASS and IHSS, and will be training providers for IHSS. Consumer Directed Care

Network is a national company operating in 17 states. Ms. Predota gave an overview the specifics of the IHSS and CDASS service delivery options as they operate in Colorado. (See “Participant Directed Service Options – Colorado” PowerPoint presentation slides 11-32.)

There was a request for clarification on the term “Relative Personal Care” used in Ms. Predota’s presentation. She explained that the difference between Personal Care and Relative Personal Care is that a relative (family member) performs the Personal Care Service. She also explained that there is a limitation of 40 hours per week for Relative Personal Care (this can be split among multiple family members), if otherwise authorized by the plan. However, a relative may be able to perform other Health Maintenance tasks in excess of this limit, if they are qualified to perform those skilled services.

The following comments were made on the chat:

One stakeholder commented that IHSS was enacted in 2002 and that Barb Ramsey was key in getting the legislation passed.

A number of stakeholders noted that under the current IHSS and CDASS model people with high behavioral needs and low (or no) medical needs do not have their budgets extended to meet these needs or have these needs met in their Health Maintenance budgets.

Another stakeholder indicated that all services within the redesigned waiver should have an option for self-direction. The Department acknowledged that it has heard this comment.

Another stakeholder said families should have option to self-direct without being an employee or Independent Contractor for an agency and that the services should be available regardless of where they live (e.g., in their own home, or in the family home).

There was a question about whether Supported Community Connections was available under CDASS in the SLS waiver, and if not, why not. The Department indicated that the services chosen for self-direction under the SLS waiver were based on the current approach in the other waivers. Moving forward, everything will be looked at. The Department will continue to look at ways to increase choice and allow clients to live the lives they choose, possibly including Support Community Connections as a self-directed service.

A stakeholder said there was frustration because families wanted the whole range of services available for self-direction in the SLS waiver and hope that this process will have a better outcome because this is a primary issue for families.

Chat comment: In California, under the IHSS program, people with high behavioral needs can get budgets and use the service because protective supervision is part of the budget.

Ms. Predota commented that California is well known for its in-home support services option, but noted that its program is different from Colorado's.

The stakeholder commented that California's definition of protective supervision is "observing the behavior of the non-self directing, confused, mentally impaired or mentally ill recipient and assisting as appropriate to guard the recipient against injury, hazard or accident."

Ms. Predota reviewed the CDASS Authorized Representative and Attendant requirements (slides 23 and 24 of the PowerPoint). There was a request from a stakeholder to include the statutory citation setting forth those requirements. The stakeholder said that the reason for including the citation is to clarify that the Authorized Representatives can be paid if they rescind the designation. The attached Addendum 2 describes who may be appointed as a guardian or conservator of an adult along with the statutory citation.

There was a question about how the Authorized Representative demonstrates they don't have a physical or emotional impairment. Ms. Predota said the Authorized Representative signs an affidavit attesting that they meet the requirements. There is currently no background check for Authorized Representatives.

One stakeholder asked whether a guardian is permitted to be an Authorized Representative. Ms. Predota responded affirmatively but noted that the guardian/ Authorized Representative cannot also be a paid caregiver.

There was some discussion around the confusion associated with the roles of guardians, Authorized Representatives, and CDASS Authorized Representatives. Ms. Predota said that a CDASS Authorized Representative is solely for directing CDASS services. That person cannot be a paid caregiver.

The Department acknowledged that there is a lot of confusion around guardians that are not relatives and whether they can be paid caregivers, Authorized Representatives, and CDASS Authorized Representatives. Ms. Predota provided an example: Mom can be a guardian and a paid caregiver and dad can be the Authorized Representative. Such an arrangement does not violate any rules.

One stakeholder asked how overhead costs are worked out between the Financial Management Service (FMS) provider and the individual's budget. Ms. Predota explained that the client establishes the wage rate (somewhere between minimum wage and \$39.30 hour). One stakeholder noted that the client's authority to set the wage is often left out of the process. Ms. Predota continued: This base rate and "cost to you" comes out of the budget. The "cost to you" includes employer taxes such as FICA. FMS is paid a monthly fee for each client by the Department for the other services it provides – processing payroll, filing taxes, and issuing W-2 forms to Attendants. These payments to the FMS do not come out of the client's budget.

One stakeholder asked whether Consumer Direct Care Network of Colorado is simply a different agency that provides services other than the PASAs. Ms. Predota said no and that HCPF pays for training and support services it provides without deducting those from client budgets. The stakeholder said that an issue that will come up is family caregivers considering becoming PASAs because so much overhead is taken by the PASA and family members are not getting services. The question is will any future self-direction be any different? Ms. Predota indicated that unlike IHSS providers, CDASS employers do not have to hold a business license. The client or the client's family does not have to establish itself as a PASA in order to participate in CDASS. The FMS establishes the client as the legal employer of record and performs the administrative, human resources functions on their behalf.

The Department noted that it understands stakeholders expressing the following:

- Family members want all services to have a self-direction option in the redesigned waiver.
- Family members should be able to deliver service directly and be paid.
- Family members and advocates want to remove the middleman and not have the overhead of the PASA (agency), or have to become a PASA itself. Colorado is a long way from being able to implement the Cash & Counseling model, which has a lot of federal constraints, but does intend to offer as many services as possible with self-direction as an option.

Comments from the Chat: Families want fewer middlemen.

One stakeholder commented that as a person that runs a family PASA, even if CDASS was available in the redesigned (IDD) waiver, the stakeholder would still have to be a PASA because her son has high needs.

One stakeholder asked whether legislation could solve the problem. The facilitator and the Department agreed that if this question concerns CMS requirements around the Cash & Counseling model, federal legislation would be needed to reduce barriers. The Department noted that there are a lot of steps in between and its current focus is on offering a self-direction option for more services.

The facilitator reminded the group that there are multiple ways to provide input:

- Directly through participation in this meeting
- For those participating through the chat function, the chat box
- Email to the facilitator (SharonIDDwaiver@steadmangroup.com)

The facilitator then went through the questions that the Department seeks input on related to self-direction:

- **Which services would you most like to be self-directed and what priority?**
 - The consensus of the stakeholders present was that all services should have self-direction as an option, irrespective of service delivery location.

- The Department noted that there is nothing prohibiting self-direction in one's own home versus the family home.
- The Department stated that certain professional services (e.g., behavioral, dental) can only be rendered by a licensed individual and can't be self-directed. However, the vast majority of direct support services will be explored for their compatibility and feasibility with allowing for a continuum of self-direction options.
- One stakeholder said that it is necessary to add services to the current CDASS model, with new definitions for protective oversight, like services in the WIC work. If those could be managed under CDASS, the stakeholder would probably not have to be a PASA.
- Parking Lot Issue: Definition in the Family Caregiver statute may be a barrier to providing services in the family home, not the waiver. There was also some discussion that perhaps Department of Labor regulations (e.g. employee versus Independent Contractor distinction) may be a factor.
- The Department commented that looking at how the targeting criteria for the models are written into rule may address why one stakeholder's child does not qualify for certain types of CDASS because of low medical needs. The Department said this is the kind of information it needs to hear in order to navigate where the rule or statute may be creating a barrier. Additionally, the Department wants to build on what is currently in place with CDASS on the newly expanded SLS model.
- **Which services are the most difficult to find providers for?**
 - Various stakeholders noted the following services are most difficult to find providers for: Homemaker, Personal Care, job support, non-professional, non-medical (because rates are so low). One stakeholder also noted that there is a significant amount of training required -- 60 hours – before one can be hired to be a family caretaker.
 - Based on information collected from the 20 CCBs by Alliance Colorado a few years ago, the following services were difficult to find providers for: Respite, Supported Community Connections, Professional Services, Basic and Enhanced Homemaker, Behavioral Services, day program (Specialized Habilitation).¹
 - From Chat: Competent live-in support (Residential Habilitation)
 - One stakeholder noted that as we look at the continuum of self-direction, there are a lot of very involved family members that will support a client's desire for self-direction. At the same time, there are lots of individuals in services that might not have that kind of support, but should still have the ability to self-direct, if they choose. Individuals without family should not be excluded from electing self-direction and the system needs to accommodate their needs as well.

¹ Following the meeting, a representative from Alliance Colorado emailed the facilitator and added "day program (specialized habilitation) to the list.

- **What should be the standards of oversight from HCPF and the Colorado Department of Public Health and Environment (CDPHE)?**
 - IHSS
 - CDASS
 - Family Caregiver Models
 - The Department said that one of the barriers to a Cash & Counseling model is sufficient oversight. Oversight is also an issue for those individuals without involved family members who want to self-direct.
 - A few stakeholders recommended streamlining or decreasing the burden of the Medicaid recertification process and diverting those funds to quality oversight.

5. Nurse Practice Act

The facilitator said that the Department seeks input on the following questions related to the Colorado Nurse Practice Act (NPA):

- **If you were to waive portions of the NPA, what tasks would you delegate?**
- **What are the potential risks or considerations around waiving additional tasks?**
- **What other recommendations do you have regarding the NPA?**

One stakeholder said that the NPA waives supervision in a lot of cases, which are affected by consumer direction. Nurse delegation interferes with people being able to self-direct.

The stakeholder suggested that the stakeholders review the text of the NPA in order to identify the elements that need to be changed and then meet with the nursing board and discuss which elements are barriers to consumer direction.

The stakeholder suggested that risks are up to individuals to assume. This issue should be ironed out with the nurses.

6. Individualized Budgets

The facilitator said that the Department seeks input on the following questions related to individualized budgets:

- **How do you define individualized budgets?**
- **What ideas do you have for individualized budgets?**
- **How can individualized budgets help us ensure we have enough resources while still meeting individuals' needs?**

One stakeholder noted that residential services currently are paid on the basis of a daily rate and asked whether that would continue. She asked whether it is tied to the client's

SIS level. She indicated that she believed it would be nearly impossible to document and bill for this service in 15 minute increments.

7. Wrap-Up and Adjourn

The facilitator reviewed the Adult IDD Waiver Redesign Stakeholder Input Process to explain how input is being solicited throughout this process. (Slide #40 of presentation) The questions discussed today will be sent electronically to the stakeholders. They will also be discussed during the upcoming task groups.

The facilitator reviewed the upcoming calendar noting that the task groups will meet during January and February. The charge for the task groups is to provide input on the change log items. In order to facilitate discussion in smaller groups, there will be two task groups, each one discussing the same issues. The task groups will each meet three times. Anyone who wants to be added to a stakeholder task group should contact the facilitator.

One stakeholder asked that anyone be able to listen to both stakeholder groups. The facilitator confirmed that this is permitted.

The stakeholder also suggested that a mutual email option be offered to those stakeholders who want to share their email contact information so they can discuss process issues between these meetings via email. An alternative is to establish a listserv. It was suggested that at the stakeholder meetings attendees may disclose their email addresses should they wish to communicate with other stakeholders.

One stakeholder asked for the dates and times of the task group meetings. The facilitator said a communication would be sent to the stakeholders with this information.

One stakeholder asked for clarification about whether the end result of this process is an amendment to the existing waiver. The Department confirmed this is correct.

One stakeholder suggested that the task group members be identified by their affiliation in order to better understand their perspective.

The facilitator thanked the stakeholders for participating.

Addendum 1

WIC

November 28, 2018

Meeting notes

Family Concerns shared with the Actuary

1. There should be no interruption or change in services or budget for those who are currently on the HCBS DD Waiver.
2. The Actuary should use individual budgets (SPAL's?) to base projections on, not what has been used. The budget is based on the needs of an individual. There are many reasons hours may not be used, especially that there is a shortage of qualified workers who are willing to work for the pay being offered (particularly in rural areas).
3. If cost saving measures are being considered to bring people off the waitlist and stay within the same budget, then alternative models for the delivery of services should be considered. Currently, CCB's are paid for case management and administrative fees, then PASA's take 35% to 50%, and the individual receiving services ends up with 40% to 50% or what is left.

A model that is able to significantly reduce overhead and administrative fees should be considered.
4. It took a long time for CDASS to be approved for SLS. When the waivers are combined will this still be available? Can there be a pilot program for individuals where they control and account for their own services, including those receiving residential services?
5. One of the missions of the WIC was to have the right services delivered at the right time in the right place, etc. The reality of the system right now is that there is no fluidity. Changes in SIS level are rare and often difficult to obtain. Some individuals with significant changes in need wait for years to get funding that more adequately meets their needs. How will changes in need be met with the combined waiver? How can the current method be improved?
6. There is a new needs assessment tool being worked on to improve the SIS. How will this tool drive individual budgets? How will the decision for residential services be made? Will a SIS level determine who gets residential services? How will this work?

Addendum 2

Who can be a guardian or conservator of an adult?

Any person, age 21 or older may be appointed as a guardian and/or conservator. However, under Colorado law, long-term care providers are prohibited from serving as guardian or conservator for a person for whom they provide care unless related by blood, marriage or adoption. (C.R.S.15-14-413 (5)) In addition, professional guardians and conservators (who earn a fee for their services) may not serve the same person as both:

- guardian/conservator
- guardian/direct service providers; or
- conservator/direct service provider. (C.R.S.15-14-413 (6)(a))

Provided by: Jodi Walters, Executive Director
Parker Personal Care Homes