Appendix of the Workgroup to Review and Recommend Policies for the Maryland Self-Direction Program

Annapolis, Maryland
March, 2022

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April 19, 2021

Office of Honorable David J. Trone, Representative
Maryland's 6th Congressional District
1110 Longworth House Office Building
Washington, DC 20515

Sonny and Regan:

Thank you for meeting with leadership from the Self-Directed Advocacy Network of Maryland, Inc. (SDAN) and me on March 29th to seek clarification about specific issues concerning self-direction and sections of Maryland's Self-Direction Act from the Centers for Medicare and Medicaid Services (CMS).

As promised, attached is a draft letter for Congressman Trone to consider sending to the CMS regional officials responsible for Medicaid HCBS self-direction guidance.

We have also included a list of frequently asked questions regarding the issues to provide some additional context. We appreciate in advance your efforts on our behalf to garner clarification on these critical policy issues. We believe clarification from CMS will help inform the state of Maryland's plans for self-direction moving forward and allow advocates to collaborate with Maryland's Developmental Disabilities Administration (DDA) to strengthen the state's HCBS self-direction parameters.

We have also included a summary of the Senate discussion draft of the HCBS Access Act. Requested feedback to the Senate cosponsors is due on April 26th, and SDAN will share with you any input they provide. We appreciate your interest in this legislation and will keep you informed of any developments regarding introducing a House companion bill.

Please let me know if you would like to discuss any of the components of the enclosed letter to CMS in more detail. Thank you in advance for your assistance in this matter.

Warmly,

Karen Lewis Young

Karen Lewis Young
Delegate, District 3A – Frederick County

3 Attachments:

1. 2005 HB0988 - Individuals with Developmental Disabilities - Additional Rights and Services. Initial Maryland state bill signed into law in 2005, setting out the parameters of Self-Direct care. Specifically, See 7-1006(a)(3)(II).
2. MD Self-Direction Act was introduced in 2021 in the Maryland General Assembly
3. FAQs on the Self-Direction Act

April 21, 2021

Sharon Graham, Regional Administrator
Philadelphia Office of Local Engagement and Administrative Staff
Centers for Medicare & Medicaid Services
801 Market Street, Suite 9400
Philadelphia, PA 19107-3134

Administrator Graham:

I am requesting information to understand better the federal requirements related to self-directed options for individuals with significant disabilities eligible to receive Medicaid-funded home and community-based services (HCBS). The purpose of my outreach is to seek clear guidance and clarification on specific questions related to what states are and are not allowed to do under Medicaid HCBS self-direction.

Maryland's self-direction option was initially a model for community inclusion and participant autonomy created over 15 years ago. It provided advocacy and oversight from involved professionals with intimate knowledge of the participant, and it saved the state an average of at least 25% over traditional programming. Self-Direction was also transparent. It was clear to participants and state administrators the parameters of the self-direction, including resource allocation and documentation. However, in the past five years, changes to the program have resulted in less choice and control for participants. Advocates feel that the original self-direction model of individualized, efficient, person-centered care is now more standardized, state-centered, and costly. Despite various discussions between advocates and State policymakers, the State's Developmental Disabilities Administration (DDA) remains steadfast that proposed changes and restrictions are now CMS requirements.

Additionally, some time ago, I believe DDA received a CMS notification that Medicaid funds could not be used for certain services not listed in the state's HCBS waiver. Instead of amending the HCBS waiver to include these services, DDA opted to prohibit resources under self-direction to pay for such services. Thus, I am seeking to clarify federal regulations.

Recently, Maryland Delegate Karen Lewis Young introduced legislation to protect and preserve self-direction and build consensus between administrators, self-direction participants, and their families. Recognizing CMS allows states broad latitude to implement HCBS Medicaid Waiver programs, it would be helpful if your department could answer the attached questions regarding CMS regulations.

CMS is the federal authority responsible for providing support and oversight of state Medicaid agencies and sub-operational entities. As a legislative summer study has begun researching these challenges, it is helpful to receive some clarity from your department. Thank you for your insights into this matter.

Sincerely,

David Trone, M.C.

Inquiry for administrative staff of Centers for Medicare and Medicaid Services

1. Has CMS ever reduced or withheld the federal medical assistance percentage (FMAP) to a state for incorrect implementation of a self-direction option or waiver service? If so, how often has this occurred, and under what circumstances?

2. Has CMS ever reduced or withheld FMAP to a state due to a review and determination of non-compliance of state statutes concerning the provision of Medicaid-financed HCBS? If so, how often has this occurred, and under what circumstances?

3. How does CMS define and interpret "habilitative supports"?

    a. Does habilitative services include supervision of an individual to maintain health and safety and the performance of personal care supports?
    b. Does CMS prohibit the use of habilitative services for overnight supports under self-direction?
    c. Does CMS prohibit the use of personal care supports at night that are not considered habilitative in nature?
    d. Does CMS prohibit an individual from exercising employer authority for overnight supports delivered in their home or family home? If so, under what conditions?
    e. Can states prohibit individuals from hiring Direct Support Professionals of their choice to provide personal care supports at night, requiring the individual to use a provider agency?
    f. Does CMS believe this limitation would violate the HCBS settings rule because it restricts the choice of professionals providing the service?

4. Should Medicaid-funded HCBS states offer more than one fiscal management service (FMS) for individuals who opt for self-direction services?

5. Are states allowed to restrict or prevent individuals eligible for HCBS from pursuing self-direction?

6. Does CMS require that recipients maintain a documented hourly schedule?

7. Does CMS prohibit incidental overlap between the support brokers, case managers, or service coordinators?

8. Understanding in many states, including Maryland, case managers and service coordinators are employees of the state, and support brokers are employees of the participant, can support brokers provide the following services when requested by the participant and their team:

    a. Ensure the participant's home maintenance, including food and supply inventories?
    b. Manage the participant's employee schedules?
    c. Schedule participant's healthcare and medical-related appointments?
    d. Manage the participant's other daily needs, including health and safety needs?
    e. Ensure the participant's support services are functioning effectively and efficiently?

f. Assume administrative responsibilities, including approving and submitting staff timesheets, vendor payments (other than their own), tracking budgets, and suggest proper fund allocation?

g. Assure proper plan administration and timely submission of paperwork?

9. Does CMS prohibit transportation reimbursement for non-employee family members who provide required specialized vehicles?

10. Does CMS prohibit transportation reimbursement as a stand-alone service, including mileage used, under specific service categories like community development?

11. Does CMS include individual or family homes as a setting for receiving "community" based services?

a. If an individual is self-employed, a volunteer worker, or participating in recreational activities at their home utilizing support services, is the home considered a community setting or a facility?

b. Are these services considered personal habilitation, attendant services, community development, or individualized and integrated day services?

12. Does CMS prohibit the participant from being directly reimbursed for expenditures like transportation fees when in the community?

Inquiry for administrative staff of Centers for Medicare and Medicaid Services

1. Has CMS ever reduced or withheld the federal medical assistance percentage (FMAP) to a state for incorrect implementation of a self-direction option or waiver service? If so, how often has this occurred, and under what circumstances?

2. Has CMS ever reduced or withheld FMAP to a state due to a review and determination of non-compliance of state statutes concerning the provision of Medicaid-financed HCBS? If so, how often has this occurred, and under what circumstances?

Response to questions 1 & 2, there were no recent deferrals or disallowances related to HCBS. However, we did issue two disallowances in 2015 and 2014 for OIG audit related issues for the following.

1. **Maryland Claimed Unallowable Medicaid Costs For Residential Habilitation Add-On Services Under Its Community Pathways Waiver Program, Report Number A-03-13-00202, dated June 29, 2015 for $34,155,857 FFP.**
2. **Maryland Claimed Costs For Unallowable Room And Board And Other Residential Habilitation Costs Under Its Community Pathways Waiver Program, Report Number A-03-12-00203, dated September 2013, for $20,627,705 FFP.**

3. How does CMS define and interpret "habilitative supports"?

a. Does habilitative services include supervision of an individual to maintain health and safety and the performance of personal care supports? **HCBS Response: Yes, per Section 1915(c)(5)(A)**

b. Does CMS prohibit the use of habilitative services for overnight supports under self-direction? **HCBS Response: No, not under 1915(c) waivers or 1915(i) State plan HCBS. However, a state may choose to do so in their 1915(c) or 1915(i) programs.**

c. Does CMS prohibit the use of personal care supports at night that are not considered habilitative in nature? **HCBS Response: No, not under 1915(c) waivers or 1915(i) State plan HCBS. However, a state may choose to do so in their 1915(c) or 1915(i) programs.**

d. Does CMS prohibit an individual from exercising employer authority for overnight supports delivered in their home or family home? If so, under what conditions? **HCBS Response: This is not prohibited under 1915(c) waivers or 1915(i) State plan HCBS. However, a state may choose to do so in their 1915(c) or 1915(i) programs.**

e. Can states prohibit individuals from hiring Direct Support Professionals of their choice to provide personal care supports at night, requiring the individual to use a provider agency? **HCBS Response: States select the option to permit individuals to self-direct services and specify the conditions under which this can happen (including setting standards for service providers) in the individual 1915(c) program or 1915(i) benefit. States are permitted to operate 1915(c) waivers and 1915(i) benefits along with concurrent managed care authorities in order to limit the pool of providers in a manner that meets the requirements of the managed care authority.**

f. Does CMS believe this limitation would violate the HCBS settings rule because it restricts the choice of professionals providing the service? **HCBS Response: No, there is not requirement for states to select a self-directed service delivery option in the HCBS settings rule.**

State Plan Response: **CMS views habilitative services as those services that assist an individual to acquire skills for the first time or maintain skills. CMS allows states to cover habilitative services under the preventive services benefit at 42 CFR 440.130(c).**

HCBS Response: Per Section 1915(c) of the Social Security Act pasted here: (5) For purposes of paragraph (4)(B), the term "habilitation services"—
(A) means services designed to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings; and
(B) includes (except as provided in subparagraph (C)) prevocational, educational, and supported employment services; but
(C) does not include—
(i) special education and related services (as such terms are defined in section 602 of the Individuals with Disabilities Education Act[236] (20 U.S.C. 1401)) which otherwise are available to the individual through a local educational agency; and
(ii) vocational rehabilitation services which otherwise are available to the individual through a program funded under section 110 of the Rehabilitation Act of 1973[237] (29 U.S.C. 730).

4. Should Medicaid-funded HCBS states offer more than one fiscal management service (FMS) for individuals who opt for self-direction services?

State Plan Response: It is unclear if the question is asking about the number of FMS providers or the type of FMS offered. This answer may be different if CMS receives further clarification. This depends on the Medicaid Authority used. The 1915(j) authority requires that FMS is an administrative activity. States may limit the number of providers of administrative activities. Section 1915(k) allows a state to choose to provide the service as an administrative or a medical service. If the activity is provided as a medical service, then the state must adhere to free choice of provider requirements, and may not limit the number of qualified providers who can provide the service.

HCBS Response: For 1915(c) HCBS waivers, it depends on how FMS is provided in the approved waiver. If FMS is included as a waiver service, providers may not be limited. Individuals must be offered choice of providers unless there is an approved concurrent authority that would allow the state to limit choice of providers. If FMS is provided as an administrative activity, providers may be limited and individuals are not afforded choice of providers.

5. Are states allowed to restrict or prevent individuals eligible for HCBS from pursuing self-direction?

State Plan Response: All Medicaid self-direction authorities are considered an optional Medicaid benefit or service delivery option. As such, states are not required to make optional benefits or service delivery options available to Medicaid beneficiaries.

HCBS Response: Yes, self-direction is not a mandatory requirement but rather an option that states may elect in their 1915(c) waivers or 1915(i) benefit. We note that CMS strongly encourages the self-direction option.

6. Does CMS require that recipients maintain a documented hourly schedule?

State Plan Response: States must develop a plan of care, and or conduct a needs assessment that feeds into a services plan. The needs assessment and services plan must explain the number of

hours a person is authorized to receive. The beneficiary should have flexibility to decided when the services they receive are provided.

Section 12006(a) of the 21st Century Cures Act requires states to implement electronic visit verification of all personal care services. EVV systems must verify:

- **Type of service performed;**
- **Individual receiving the service;**
- **Date of the service;**
- **Location of service delivery;**
- **Individual providing the service;**
- **Time the service begins and ends.**

A schedule could be used in conjunction with an EVV system.

HCBS Response: No, states specify the process for verifying and authorizing payment for services.

7. Does CMS prohibit incidental overlap between the support brokers, case managers, or service coordinators?

State Plan Response: **States should prevent duplication of payment for all Medicaid services. However, there is no prohibition on incidental overlap, if that means – services providers communicating with each other while performing their respectful roles.**

HCBS Response: CMS is unclear regarding what the question is. If the question is can the service definitions overlap per Sec. 1902. [42 U.S.C. 1396a] (a) A State plan for medical assistance must—

(30)(A) provide such methods and procedures relating to the utilization of, and the payment for, care and services available under the plan (including but not limited to utilization review plans as provided for in section 1903(i)(4)) as may be necessary to safeguard against unnecessary utilization of such care and services and to assure that payments are consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area;" Therefore, states must ensure that there is no duplication of Medicaid services/duplication of payment for Medicaid services.

8. Understanding in many states, including Maryland, case managers and service coordinators are employees of the state, and support brokers are employees of the participant, can support brokers provide the following services when requested by the participant and their team:

a. Ensure the participant's home maintenance, including food and supply inventories? **It is unclear what this "ensuring the participant's home maintenance" means in this context. Additional explanation is needed.**

b. Manage the participant's employee schedules? **Under self-direction, the individual or the individual's representative should manage the schedules.**

c. Schedule participant's healthcare and medical-related appointments? **This seems to be beyond the scope of a support broker. This is something that a case manager could do.**

d. Manage the participant's other daily needs, including health and safety needs? **This is a direct service and beyond the scope of a support broker.**
e. Ensure the participant's support services are functioning effectively and efficiently? **Varies – based on the Medicaid authority**
f. Assume administrative responsibilities, including approving and submitting staff time sheets, vendor payments (other than their own), tracking budgets, and suggest proper fund allocation? Varies – based on the Medicaid authority. **Some of these activities fall under Financial Management Services.**
g. Assure proper plan administration and timely submission of paperwork? **Varies – based on the Medicaid authority**

HCBS Response: The employer of the service provider is immaterial to the answer. The service definition in the specific approved 1915(c) or 1915(i) document determines the answer to these questions.

9. Does CMS prohibit transportation reimbursement for non-employee family members who provide required specialized vehicles?

HCBS Response: CMS is unclear of the question being asked. However, clarifies that services are funded as specified in the approved 1915(c) waiver or 1915(i) benefit. States are not able to fund individuals who are not authorized providers of authorized services. In addition, services that are funded through HCBS programs must be provided to the individual.

10. Does CMS prohibit transportation reimbursement as a stand-alone service, including mileage used, under specific service categories like community development?

State Plan Response: Response for questions 9 & 10, Under state plan authority, beneficiaries and family members are eligible to receive mileage reimbursement for transporting the beneficiary to and from covered medical services, when mileage reimbursement is specifically covered in the state plan. For transportation to and from <u>non-medical</u> waiver services, the waiver must specify that transportation to and from the non-medical waiver services is a covered benefit and must also specify that mileage reimbursement is covered for beneficiaries and family members when traveling to and from waiver services.

HCBS Response: CMS is unclear regarding this question but offers the following information. If the state includes transportation as a stand-alone service it generally would not be for only one specific service category. Generally, if transportation is included in connection to a specific service category it is included as a component of the rate for that service.

11. Does CMS include individual or family homes as a setting for receiving "community" based services? **HCBS Response: Yes.**

a. If an individual is self-employed, a volunteer worker, or participating in recreational activities at their home utilizing support services, is the home considered a community setting or a facility? **It would be considered a community setting and the definition can be found with the Technical Guide**.

HCBS Response: The person's own home is considered a community setting.

Person Centered Planning needs to be at the forefront. If the person's preference is to receive his/her service in the larger community the services and providers should be aligned to honor that preference. Please note that a person receiving and spending all their time at home is not person-centered or community integrated, unless that is their preference.

b. Are these services considered personal habilitation, attendant services, community development, or individualized and integrated day services?

This would depend on the service definition.

State Plan Response: CMS Technical Guide, Appendix C-5 Home and Community Based Setting Requirements, starting at page 149, provides instruction and guidance regarding settings.

HCBS Response: CMS notes in response that the answer is dependent on how the services are defined in the approved 1915(c) waiver and how they are implemented. It could be any of these services or more than one service.

12. Does CMS prohibit the participant from being directly reimbursed for expenditures like transportation fees when in the community?

State Plan Response: Under state plan authority, beneficiaries and family members are eligible to receive mileage reimbursement for transporting the beneficiary to and from covered medical services, when mileage reimbursement is specifically covered in the state plan. For transportation to and from <u>non-medical</u> waiver services, the waiver must specify that transportation to and from the non-medical waiver services is a covered benefit and must also specify that mileage reimbursement is covered for beneficiaries and family members when traveling to and from waiver services.

HCBS Response: Except under specific and unique situations CMS funds the provider of the service. In 1915(c) or 1915(i) self-directed programs the individual may have budget authority but the payment goes to the provider of the service and not to the individual receiving service.

Documents for Review by the Maryland Self-Direction Study WG Subcommittee on CMS/Federal Policy Review/Analysis on Self-Direction

Reference Point #1:

- Letter from Representative Trone to CMS re: federal policy on key questions related to self-direction under Medicaid waiver programs (Attached as Separate Document)

- CMS responses to Trone's letter (Attached as Separate Document)

Reference Point #2:

Email correspondence between Shawn Terrell (Senior Policy Adviser, Administration for Community Living at the U.S. Department of Health and Human Services) and Kathryn Poisal (Technical Director for the HCBS 1915(c) Waiver Programs under the Office for Long Term Supports and Services, Disabled and Elderly Health Programs Group, Centers for Medicare and Medicaid Services) dated 8/12/2021. SUBJECT: Whether or not CMS has any policy regarding the allowance of overnight supports in Medicaid waiver programs for people who self-direct.

---------- Forwarded message ---------
From: **Terrell, Shawn (ACL)** <Shawn.Terrell@acl.hhs.gov>
Date: Fri, Aug 20, 2021 at 11:34 AM
Subject: FW: Self -direction question
To: Serena Lowe <ewolaneres@gmail.com>

Shawn Terrell, MS, MSW
Health Insurance Specialist
U.S. Department of Health and Human Services
Administration for Community Living
330 C Street, SW
Suite 1233B
Washington, DC 20201
202-205-0415
Shawn.terrell@acl.hhs.gov

From: Poisal, Kathryn J. (CMS/CMCS) <Kathryn.Poisal@cms.hhs.gov>
Sent: Thursday, August 12, 2021 3:12 PM
To: Terrell, Shawn (ACL) <Shawn.Terrell@acl.hhs.gov>
Subject: RE: Self -direction question

Hi Shawn,

Sorry for the delay in responding; I was out of the office on leave. There is not CMS policy or guidance that is specific to the use of overnight supports.
If you haven't already seen this, you may want to look at the FLSA rule on payment for workers on the DLT website under the homecare rule. Factsheets 22 and 23 at the below link provide an overview:
https://www.dol.gov/agencies/whd/compliance-assistance/toolkits/flsa
I am told that this is several years old but discusses how overnight workers should be paid in varied situations (live-in, outside workers, etc.).

I hope this is helpful and that you are doing well.

Kathy

From: Terrell, Shawn (ACL)
Sent: Wednesday, July 28, 2021 2:54 PM
To: Poisal, Kathryn J. (CMS/CMCS) <Kathryn.Poisal@cms.hhs.gov>
Subject: Self -direction question

Hi Kathy – I hope you are doing well.

I have a question re self-direction. Is there any specific policy or guidance regarding the use of overnight supports in SD?

Thanks in advance for any insight you can offer.

Shawn

Shawn Terrell, MS, MSW
Health Insurance Specialist
U.S. Department of Health and Human Services
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330 C Street, SW
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202-205-0415
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Reference Point #3:

In response to the original CMS response to Question #8 (looking at roles and duties of support brokers) in Rep. Trone's letter, ACL followed up with CMS' Central Headquarters with the following question:

> *"Are there any prohibitions or restrictions in federal policy on the duties of support brokers that states must abide by? If yes, please provide the list of these restrictions and the language/citation of where these are located in federal policy."*

See Email Communication below between Shawn Terrell and CMS leaders Kathryn Poisal (Technical Director, 1915(c) HCBS Waiver Programs) and Kenya Cantwell (Technical Director, 1915(k) Community First Choice State Plan Options). Dated 8/25/2021. SUBJECT: Parameters around Support Brokers

---------- Forwarded message ---------
From: **Terrell, Shawn (ACL)** <Shawn.Terrell@acl.hhs.gov>
Date: Wed, Aug 25, 2021 at 4:24 PM
Subject: Self Direction Qs
To: Serena Lowe <ewolaneres@gmail.com>

Hi Serena
Kenya and Kathy provided the following responses to the questions from MD. Happy to talk about it. The SB service definition seems to allow some latitude. Hope you are well.

Roles and Duties of a Support Broker under Self-Direction
"Are there any prohibitions or restrictions in federal policy on the duties of support brokers that states must abide by? If yes, please provide the list of these restrictions and the language/citation of where these are located in federal policy."

CMS Response: For 1915(c) waivers, the following CMS core service definition, guidance, and instructions for support brokerage services can be found on pages 175-176 of the Instructions, Technical Guide, and Review Criteria for 1915(c) waivers.

Information and Assistance in Support of Participant Direction (Supports Brokerage)
Core Service Definition
Service/function that assists the participant (or the participant's family or representative, as appropriate) in arranging for, directing and managing services. Serving as the agent of the participant or family, the service is available to assist in identifying immediate and long-term needs, developing options to meet those needs and accessing identified supports and services. Practical skills training is offered to enable families and participants to independently direct and manage waiver services. Examples of skills training include providing information on recruiting and hiring personal care workers, managing workers and providing information on effective communication and problem-solving. The service/function includes providing information to ensure that participants understand the responsibilities involved with directing

their services. The extent of the assistance furnished to the participant or family is specified in the service plan. This service does not duplicate other waiver services, including case management.

Instructions

Modify or supplement the core definition to accurately reflect the scope and nature of supports for participant direction furnished under the waiver

Guidance

- This service is limited to participants who direct some or all of their waiver services.
- As discussed in the instructions for Appendix E (Participant Direction of Services), the scope and nature of this service hinges on the type and nature of the opportunities for participant direct afforded by the waiver.
- Through this service, information may be provided to participant about:

- person centered planning and how it is applied;
- the range and scope of individual choices and options;
- the process for changing the plan of care and individual budget;
- the grievance process;
- risks and responsibilities of self-direction;
- free of choice of providers;
- individual rights;
- the reassessment and review schedules; and,
- such other subjects pertinent to the participant and/or family in managing and directing services.

Assistance may be provided to the participant with:

- defining goals, needs and preferences, identifying and accessing services, supports and resources;
- practical skills training (e.g., hiring, managing and terminating workers, problem solving, conflict resolution)
- development of risk management agreements;
- development of an emergency backup plan;
- recognizing and reporting critical events;
- independent advocacy, to assist in filing grievances and complaints when necessary; and,
- other areas related to managing services and supports.

- This service may include the performance of activities that nominally overlap the provision of case management services. In general, such overlap does not constitute duplicate provision of services. For example, a "support broker" may assist a participant during the development of a person-centered plan to ensure that the participant's needs and preferences are clearly understood even though a case manager is responsible for the development of the service plan. Duplicate provision of services generally only arises when exactly the same activity is performed and billed on behalf of a waiver participant. Where the possibility of duplicate provision of services exists,

the participant's service plan should clearly delineate responsibilities for the performance of activities.

Agenda for Self-Direction Workgroup

July 28, 2021: 1:00-2:50 p.m.

Roll Call/Introduction of Study WG Members

Melissa Bender (5 mins)

Opening Remarks & Overview of Meeting Objectives

Delegate Lewis Young (5 mins)

Meeting Focus: *Resetting the Vision for Self-Direction in Maryland*

- **Guest Presenters (45 mins)**
  - **Fundamentals of Self-Direction -- Federal Framework for Self-Direction (15 mins)**

    Shawn Terrell, Senior Policy Adviser, Administration for Community Living, U.S. Department of Health & Human Services
  - **Maryland's Journey with Self-Direction: Here and Now (15 mins each)**

    Patti Saylor – SDAN BOD and Heather Shek – MDH, Director of Governmental Affairs (Bernie Simons – MDH, Deputy Secretary of DDA (available for questions)
- **Interactive Discussion with the Workgroup and Presenters (15 mins)**

Updates from Previous Meeting (5 mins)

Status of MDH's Procurement/RFP for Self-Direction Fiscal Management Services - Heather Shek

Public Comment (15 mins)

Administrative Wrap-up (5 mins)

Review Self-Direction Study Group Scope/Schedule

Next Meeting – August 25th at 1pm, Zoom

Maryland Self-Direction Program Workgroup

Members:

The Honorable Karen Lewis Young, Chair

The Honorable Susan Lee

The Honorable Nicholaus Kipke

The Honorable Lisa Belcastro

The Honorable Heather Bagnall

The Honorable Harry Bhandari

The Honorable Kirill Reznik

The Honorable Geraldine Valentino-Smith

Alicia Wopat, SDAN

Serena Lowe, SDAN

Patti Saylor, SDAN

Esther Ward, MD Commission on Caregiving

Laura Howell, MACS

Rachel London, DD Council

Ken Capone, People on the Go

Megan Rusciano, Disability Rights Maryland

Ande Kolp, The Arc Maryland

Heather Shek, MDH

Deputy Secretary Bernard Simons, DDA

Staff

Kris Fair, Committee Secretary

Erin Hopwood, Committee Counsel

AGENDA

Wednesday, August 25, 2021, | 1:00 p.m.
Zoom

Welcome and Old Business

Roll Call | Kris Fair	1:00 – 1:05
Opening Remarks | Delegate Lewis Young	1:05 – 1:10
Follow-up from Prior Meeting: 1. Process for Addressing Questions 2. Updates/Progress on Self-Advocate Panel Delegate Lewis Young | General Workgroup	1:10 – 1:25

Addressing Operational Challenges in Self-Direction

Presumed Competence & Competency Testing | Serena	1:25 – 1:32
New Designated Representative Requirement | Alicia	1:32 – 1:39
Budget Allowance for House Manager/Admin | Ande	1:39 – 1:46
Access to Overnight Personal-Care Assistance | Megan	1:46 – 1:52
Hiring Family Members to Provide Supports | Esther	1:52 – 1:59
Allowances for Administration of Medications | Patti	1:59 – 2:06

Group Discussion and Wrap-Up

Public Comment	2:06 – 2:30
Action Items Review | Delegate Lewis Young	2:30 – 2:35

Next Meeting: Wednesday, September 29, 2021 | 1:00 p.m.

Minutes, DDA workgroup 7/28 at 1pm

Del Lewis Young – says she is seeing major issues surface

Presentation by Shawn Terrell – I have his powerpoint in an email

Presentation by Patti Saylor– she has seen what was once an innovative program, built on flexibility, she has seen the flexibilities dwindle, the process has become too complex to navigate – requires such advocacy and number of hours to make it work, it falls on who can navigate the system, have to hang in there to problem solve, sees an inequity on who is being told about sd and who can be successful with it. Shared her own story from 10 years ago – Ethan had down syndrome, needed 24 hour care, had a consistent coordinator and support broker – he had 20 hours a month of support brokage, was in an apartment – if he had this program now, he would have coordinator change often, he would have services through DDA AND MDH– (before was just DDA) = DDA and MDH have different requirements, can no longer have overnight staff, currently support broker capped at 4 hours unless push hard from the state for more – she says she would not be as successful now as she was then

Another story – another man with DS, 20 yo, highly functional, is insulin dependent, family waited over 13 months for approval of SD plan, mother had to retire early b/c no one available to provide supports, once plan approved had very rigid rules so parent has to be available all the time to manage his diabetes

Another story – worked with him for a long time, he lived in a nh but did not need to be there, he had a developmental disability, able to get him into his own apartment, at first did well in SD services, he began to age and had more typical middle age health issues, he had surgery and while in hospital, ended up in rehab facility for 13 months b/c could not go back to apartment b/c could not access overnight support, now he has to go to group home b/c cannot be in apartment b/c rules too rigid around the support he needs

Feels like DDA is shutting down innovation, feels there is an equity issue, only those who have someone who can fight for them have access to SD

KLY asked MDH for data broken down by demographics of those accessing SD – asked for this before next meeting

Heather Shek – MDH offers SD in several programs (attendant care, MD Vet directed HCBS, Community first choice, Family support community pathways waivers) SD started in 2005, with ind plus waivers for ind with DD, 41 indiv enrolled in first year, annual enrollment has grown by 21% = now have over 1,000 participants – Heather noted the large growth in participation, families get greater control, SD can manage their services, including being the employer and to control their allocated budget, they can identify goals, can hire and fire – MDH (CCS) provides guidance and services to individuals participating in SD, they also have advocacy specialists who provide technical assistance. Also have support brokers who are HR related, give initial orientation, develop staff policies, procedures, help with recruitment of potential staff, help the SD individual abide by state and federal law as employer, sb cannot make budgetary decisions, cannot hire or fire workers. FMS– are the fiscal intermediary, help with accounting and payroll functions, verifying that employees meet the necessary qualifications, facilitates employments, tax withholding and payments, monthly expenditure reports, important to accounting/auditing, FMS completes background checks of employees, also have the service providers. How the structure has changed over the years, most notable changes were in budget development

process – used to have to stay within established budget, based on a matrix score based on health and supervision needs – in 2020, MDH moved to person centered plan – based on assessed needs, unmet needs and cost detailed tool – establishes overall budget – goal is to ensure fair and equitable funding, participants use budget to establish plan – the pcps can be updated annually (participant no longer locked into initial budget as circumstances change) In January 2021, MDH moved to person centered plan and based on LTSS authorization form, required use of this form for SD ensures fair funding regardless of service model = went from 12 services to 27 service options – noting that service options are growing

FMS RFP update – July 2019, DDA audit finding that FMS vendors were from a no–bid RFP. June 2019, second RFP, MDH selected a vendor while being approved, COVID hit and vendor pulled their proposal. MDH issued new RFP in December 2020. Current RFP issued in May 2021 – updated RFP to comply with 2021 LTSS bill – have adjusted RFP in response to workgroup concerns, new proposal due date is Sept 2021 – 200 questions submitted on RFP – have answered the questions on EMMA

Heather – Appendix K waiver issue – emergency regulations = sec order ends Aug 15th, will continue authority until December 31st. Allows for retainer payments for 60 days. Waiting for AELR approval.

KLY – opened meeting to questions.

GVS – to Shawn, could HHS review Maryland's regulations to see if consistent with federal govt intention? Shawn, state could request technical assistance from CMS on regs, a challenge with vision is that it is not law. Shawn says a lot is state discretion. You can do a lot of things – for example, there is no prohibition on overnight assistance. GVS likes the idea of asking to technical assistance on a review from CMS.

GVS – to Heather (MDH) – we have limited time as a workgroup, suggests a conversation with Patti Saylor to address her concerns and give feedback on their concerns. GVS wants to know what is the unmet need? Would like to know for the next hearing.

Ande Kolp – to shawn – benchmark for sb? Maryland saw a significant reduction in hours for sb. He said it varies significantly – he said he would look into it.

Ande Kolp – to MDH– how much of approved budget can a family actually spend? Families are running into bureaucratic issues (heather will look into this)

Del Bhandari – to MDH – can we find a middle ground? Do you think program is less flexible, less patient centered. Heather – we can find a middle ground through workgroup. Thinks moving to LTSS will help, have added more services, thinks maybe feeling of less flexibility is b/c is not what people are used to. Wants to find out where perceived inflexibilities lie.

KLY would love to work out solutions through this workgroup and not have another bill.

Serena Lowe – to MDH, what about the issue of allowing the FMS to decide if family members can be paid, heather – can not answer right now, also wants written policy on reimbursement to the individual so can understand why Maryland is requiring it

Alicia Wopat – to Shawn, opinion on losing federal match b/c of HB318, what is the likelihood? Shawn says has not seen this, especially with HCBS, also would have to go through admin process, cutting off funding is a big deal,

Alicia to Patti – wanted her thoughts on Heather's take? Patti the reason families are advocating b/c having troubles. People entering SD b/c traditional services will not accept them b/c they cannot meet their needs. So people entering SD trough default many times.

KLY – recalled DDA saying HB318 could lead to loss of federal funds. To Shawn– as long as there is a separate FMS to ensure sb is not involved with approval of time sheets are we ok? Shawn thinks leg is consistent with expected role of the sb. KLY submitted a question to Cong. Trone to have him approach CMS for an opinion of this issue.

Public Comment – Menucha (she is a sb) the way presented by MDH to the way it is utilized. A possible solution is to alter timelines – system is frustrating – example approval of pcp can take anywhere from minutes to 4–6 weeks, wants to be able to hold DDA to timelines

Shared support Maryland – wants workgroup to add members with disabilities to the workgroup, wants more than 50% of workgroup to be these members – KLY wants MDH to do outreach to individuals who SD to determine user satisfaction – can help us end the debate – Menucha said DDA did do a survey and would like DDA to share these results

Meg Carter – question about overnight support, can MDH explain rationale for not authorizing? Also asked about truncating role of sb? Heather – overnight supports not completely eliminated, CMS says has to be a rehabilitative service –she will get more info from CMS – shawn said he could also get CMS' specific policy on overnight supports/what is meant by rehabilitation

KLY= themes – def of sb, overnight supports, role of family, direct reimbursement to individual, equity/disparity of receiving sd, making sd model more user friendly

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QUESTIONS, ANSWERS, AND COMMENTS FROM WORKGROUP

Question: "Does the material in this series of seminars apply to the disabled who were over age 26 when coming onto SSI, who are not on Maryland DDA? I have one disabled on Maryland DDA and one who started SSI at age 27, is not on Maryland DDA."

Answer: The Self Direction Act (H.B. 318) is focused on the parameters for the Maryland Department of Health to increase funding to assure certain recipients of services funded through the Developmental Disabilities Administration to receive HCBS under self-direction. The study group during the Summer Session is focused on addressing questions that arose during the previous legislative session related to specific provisions outlined in H.B. 318, as well as identifying areas that DDA's current self-direction option could be improved and strengthened either via changes in regulatory policy by DDA of as part of the legislation.

Comment: CCS's should receive more paid on-the-job training during regular working hours and not be given such large caseloads. We need better working conditions and higher wages for CCS's so they can stay longer and do better work. We should also consider hiring some self-advocates to help out doing some tasks for these organizations to lighten the burden and provide jobs for self-advocates. Anything from shredding paper to coding will help.

Maryland Self-Direction Program Workgroup

Members:

The Honorable Karen Lewis Young, Chair

The Honorable Susan Lee

The Honorable Nicholaus Kipke

The Honorable Lisa Belcastro

The Honorable Heather Bagnall

The Honorable Harry Bhandari

The Honorable Kirill Reznik

The Honorable Geraldine Valentino-Smith

Alicia Wopat, SDAN

Serena Lowe, SDAN

Patti Saylor, SDAN

Esther Ward, MD Commission on Caregiving

Laura Howell, MACS

Rachel London, DD Council

Ken Capone, People on the Go

Megan Rusciano, Disability Rights Maryland

Ande Kolp, The Arc Maryland

Heather Shek, MDH

Deputy Secretary Bernard Simons, DDA

Staff

Kris Fair, Committee Secretary

Erin Hopwood, Committee Counsel

AGENDA

Tuesday, September 28, 2021, | 1:00 p.m.
Zoom

Welcome and Old Business

Roll Call | Kris	1:00 – 1:05
Opening Remarks | Delegate Lewis Young	1:05 – 1:10
Follow-up from Prior Meeting: 1. Questions for MDH | Heather 2. Edits to Meeting Minutes | Erin	1:10 – 1:25

Updates from Subcommittees

Self-Direction Participants Subcommittee Report | Kris	1:25 – 1:50
CMS Review Subcommittee Report | Serena & Ande	1:50 – 2:15

Group Discussion and Wrap-Up

Public Comment	2:15 – 2:35
Action Items Review | Delegate Lewis Young	2:35 – 2:40

Next Meeting: Wednesday, October 27, 2021 | 1:00 p.m.

Acronyms	
ORGANIZATIONS	
ACL	Administration for Community Living
AIDD	Administration on Intellectual and Developmental Disabilities
AoD	Administration on Disabilities
ARC	The ARC of Maryland
CMS	Centers for Medicare and Medicaid Services
DDA	Developmental Disabilities Administration
DORS	Division of Rehabilitative Services
DRM	Disability Rights Maryland
HCBS	Home and Community Based Services
ILA	Independent Living Administration
MACS	Maryland Association of Community Services
MDH	Maryland Department of Health
MDOD	Maryland Department of Disabilities
MGA	Maryland General Assembly
OIDD	Office of Intellectual and Developmental Disabilities
CRMO - SDS	Central Maryland Regional Office - Self Directed Services
SRMO - SDS	Southern Maryland Regional Office - Self Directed Services
ESRO - SDS	Eastern Shore Regional Office - Self Directed Services
WMRO - SDS	Western Maryland Regional Office - Self Directed Services
PROGRAMS	
ADA	Americans with Disabilities Act
CFC	Community First Choice; personal care program which is part of the State Medical Plan; source of funding separate from DDA
GTYI	Governor's Transitioning Youth Initiative
HB 318	House Bill 318 - The Self Direction Act of 2021
IFDGS	Individual/Family Directed Goods and Services
IP&B	Individual Plan and Budget
PCP	Person Centered Plan
SUPPORTS	
ASD	Applied Self-Direction
CCS	Coordination of Community Services
DSP	Designated Support Professionals
DR	Designated Representative
FMS	Fiscal Management Services
LISS	Low Intensity Support Services
LTSS	Long Term Systems & Supports
SB	Support Brokers
SIS	Supports Intensity Scale – Formal assessment of support needs; completed every five years
OTHER	
COLA	Cost of Living Adjustment – usually awarded in each fiscal year by DDA budget approved by legislature
COMAR	Code of Maryland Regulations
DSAT	Detailed Service Authorization Tool which is part of the LTSS Maryland data system and PCP process
EVV	Electronic Visit Verification used for Personal Supports; is different from e-timekeepting offered by FMSes
HRST	Health Risk Screening Tool – Mandatory assessment tool - Must be completed at least once a year, usually before annual plan submitted to DDA for approval; score of 3 or more requires a nurse review
REM	Rare and Expensive Medical Conditions – source of funding separate from DDA

MEETING MINUTES

1. SELF DIRECTION WORKGROUP
    - 8-25-2021
2. SELF DIRECTION PARTICPANTS SUBCOMMITTEE
    - 9-15-2021
3. CMS AND FEDERAL POLICY REVIEW SUBCOMMITTEE
    - 9-17-2021

8/25/2021 DDA Workgroup minutes

1. Comments from Delegate Lewis Young
    a. Cannot change the composition of the workgroup to 50% participants. However, it will have two subcommittees:
        i. Self-direction participants
        ii. CMS and federal policy review
        iii. Contact Delegate Lewis Young's office if you want to participate. She would like to have legislators present on each committee.
    b. Delegate Lewis Young spoke with Secretary Schrader at MACo. She asked for more MDH representation.
        i. MDH sent Marlana Hutchinson from Medicaid
2. Comments and Answers from MDH representative Heather Shek
    a. MDH Updates: MDH updated the website and have a new handbook – she will send links, working on training modules for family members and participants, updating budget modification process, and hiring family as staff form, have been meeting with DD coalition – lessons learned from pandemic and unwinding process, meeting 1x weekly.
    b. Can MDH provide the written policy about reimbursement to the individual? CMS advised that reimbursement to participants is not allowed and not permitted under COMAR
    c. Can MDH share survey results? MDH did seek input for resuming day services, also sent a survey on core indicators. Results will be sent to the workgroup.
    d. She is going to format the data, but there are 1,696 participants – gave stats by region
    e. Why can't DDA provide money for rent? Comes from CMS = explicitly prohibited under CFR
    f. Provided answers about individuals selecting self–directed – would need to use Hilltop to get numbers on those choosing self–direction from the beginning of the program
    g. How does Maryland's self–direction compare to other states? She does not have this, but each state's self–direction program is different, so she does not feel it is valid.
    h. Why would DDA reduce support broker's hours and responsibilities? MDH feels they have clarified support brokers to minimize duplication with case managers.
    i. Why does DDA reduce representation by relatives? MDH disagrees; MDH allows relatives
    j. How much of an approved budget can a family spend? Heather said she missed that and will get back to the workgroup asap
3. Operational Challenges with Self–Direction
    a. Presumed competence and competency testing – wants clarity from state, there is no mandate of competency testing – in the recent FMS RFP– said competency testing would be the role of the FMS. This testing seems like another barrier and instead should consider what supports should be available. It feels punitive to put this in the FMS– it appears like a way to restrict participation in self–direction. It is discouraging to have FMS completing competency testing.
    b. New designated representative requirements – Alicia – Designated representatives, as DDA proposed, are antithetical to self-direction because one person determines the budget instead of the participant. DRs create unnecessary barriers. SDAN supports a

team approach, participant retains control of budget but could consult with their team and document meetings.

c. Budget allowance for house manager – new directions pilot worked b/c had several hours of support services to fill in gaps where ccs could not provide supports – such as setting staff schedules, help person understand budget, ccs' come and go, should allow individuals to have some admin support and would make self–directed services more successful
d. Overnight supports – Randy – overnight supports should be accessible; it is a critical service that allows individuals to stay in their homes. In July 2018, DDA modified the definition. Clients have lost awake overnight hours, which compromises their ability to remain at home. Disability Rights Maryland feels it violates federal law – it is a habilitative service, and supported living is not an equitable substitute.
e. Hiring family members to provide support – Esther (Md Commission on Caregiving) family members are consistent, DDA rules change very fast. Family caregivers stay whereas non–family caregivers only last a few years; therefore, family as caregivers is in the participant's best interest.
f. Allowances for medication administration – MBON sets regulations on how to provide medication – COMAR sets forth delegation of nursing tasks and is not updated often. Regs bind family as staff – have to take a 20-hour course, be overseen by a nurse, the nurse writes care plan every 45 days – is burdensome, overseeing nurses are hard to find. There are exemptions to the regulations (ex – foster care parents, child care centers, unpaid care are exempt) and thinks an exemption for an adult who lives with family is essential.
    i. Heather – MBON is statutorily separate – would have to go to the board to make changes. Also, MDH looks at requests for overnight supports on a case by case basis, not a blanket denial

4. Public Comment:
    a. Margaret Carter – heard DDA reopening waiver as a result of appendix K – thinks should consider some of the workgroup issues = such as overnight supports and make FMS a waiver service
    b. Carol Custer – SDAN not looking for a formal response from the committee, just some additional information for the workgroup
    c. Susan Goodman – support brokers, used to be independent, gave control to others, discouraged by this
    d. Barbara Reff's father – Had overnight staff and can only use wheelchair vans, also seems like regional differences in reimbursements, cited the many differences between group homes/self–direction. Thinks agencies are favored. Does not think DDA should make representative payee decisions.
5. Final workgroup comments:
    a. Patti Saylor – acknowledges that MBON is separate, MBON did form a workgroup – does not think MBON would do anything without the support of DDA
    b. Delegate Bagnall – mentioned unwinding, rise in cases might indicate the need to pivot again

c. Delegate Lewis Young – wants people to express interest in subcommittees in the next two days
d. Next meeting – Sept 29th – venue TBD, would like to meet in person but will watch data carefully

Meeting adjourned at 2:35 pm

MINUTES
Self-Direction Workgroup
Subcommittee of Self-Direction Participants
September 15, 2021 | 10:30 a.m. | Zoom

Attendees*: JP Shade, Carmen Hudlud, Mat Rice, Thomas, Robert, Sunny Cefarratti, Delegate Karen Lewis Young, Delegate Heather Bagnall, Kris Fair (Recorder, Delegate Lewis Young)

*Formal roll call was not taken. Names listed either spoke during the meeting identifying themselves or were recorded through the name on their zoom profile.

1. Welcome & Introductions – Delegate Lewis Young
2. Discussion of Key Topics

Support Brokers

- More support brokers. Coordination of Community Services (CCS) is not paid for, nor do they have the time to do the work.
- Specific users have not found a support broker that meshes with them and is educated about the resources available in their region. Thus, families are forced to become resource educators.
- 1 hour per week is only enough time to just do the paperwork. They are limited to 4 hours per month and limited to only helping with human resources. It is impossible to complete any actual tasks with such a limited schedule.
- Four hours a month might works for some individuals but in most cases it does not and should be left up to the individual practicing self-direction.
- Largely word of mouth. If you are well connected to the disability community, you can reach out and find recommended members.
    - Because not everyone has access to these word-of-mouth resources, this is a health equity issue.
- Challenges with and for support brokers:
    - Cannot identify when/how they train for the role
    - Are not paid for training or testing.
    - The reporting requirements placed on a support broker is extreme
    - Are not given enough hours to be productive
    - Are not given enough hours to encourage job seekers to become support brokers
    - Are not thoroughly vetted by DDA for quality and the needs of people practicing self-direction.
    - Participants and families do not have a voice about the parameters for support brokers.
    - Because of existing parameters, support brokers are not flexible with the support which goes against the spirit of self-direction.
- Some believe that DDA is pushing for counseling services instead of support brokers, a move they disagree with.

Designated Support Professionals (DSP)

- There is a shortage of DSPs.
- DSPs need to have varying skillsets. Different people need different DSPs.

- There is no harmonization between nursing facilities/programs and the DSP.
- There are needs that self-direction participants need that neither DSPs or Nurses provide leaving the gap to be filled by a family member.
- In some cases, telehealth with DSPs has helped assure access but has also led to a lack of direct connection.

Designated Representatives

- Designated representatives are seen to undercut the work of the family
- A single representative will take on all the liability of the individual practicing self-direction without proper compensation and protection.
- While recognized to streamline the decision-making process, this removes the autonomy of the person practicing self-direction for informed, supportive decision making.
- Designated representatives are antithetical to the spirit of self-direction.
- Designated representatives should be removed from the participant agreement.

Other

- Transportation fees versus reimbursement should be more flexible depending on the needs of the individual practicing self-direction. For some transportation would be better suited at a standard hourly rate. For others, transportation would be better calculated using a mileage reimbursement. By doing it this way, the state could potentially save money and make it easier for participants to find transportation services.
- The root challenges facing supports for self-direction are consistent: Recruitment, Retention, and Support.

3. Closing
    a. Subcommittee Report for Workgroup Needed By Wednesday, September 22.
        i. Kris will present the committee report.
    b. Next Meeting: Wednesday, October 13 | 10:30 a.m.

MINUTES
Self-Direction Workgroup
Subcommittee on CMS and Federal Policy Review
September 17, 2021 | 10:30 a.m. | Zoom

Attendees: Delegate Karen Lewis Young, Ande Kolp (ARC of Maryland), Serena Lowe (SDAN), Jacob Took (Delegate Bhandari), Kris Fair (Recorder and Delegate Lewis Young)

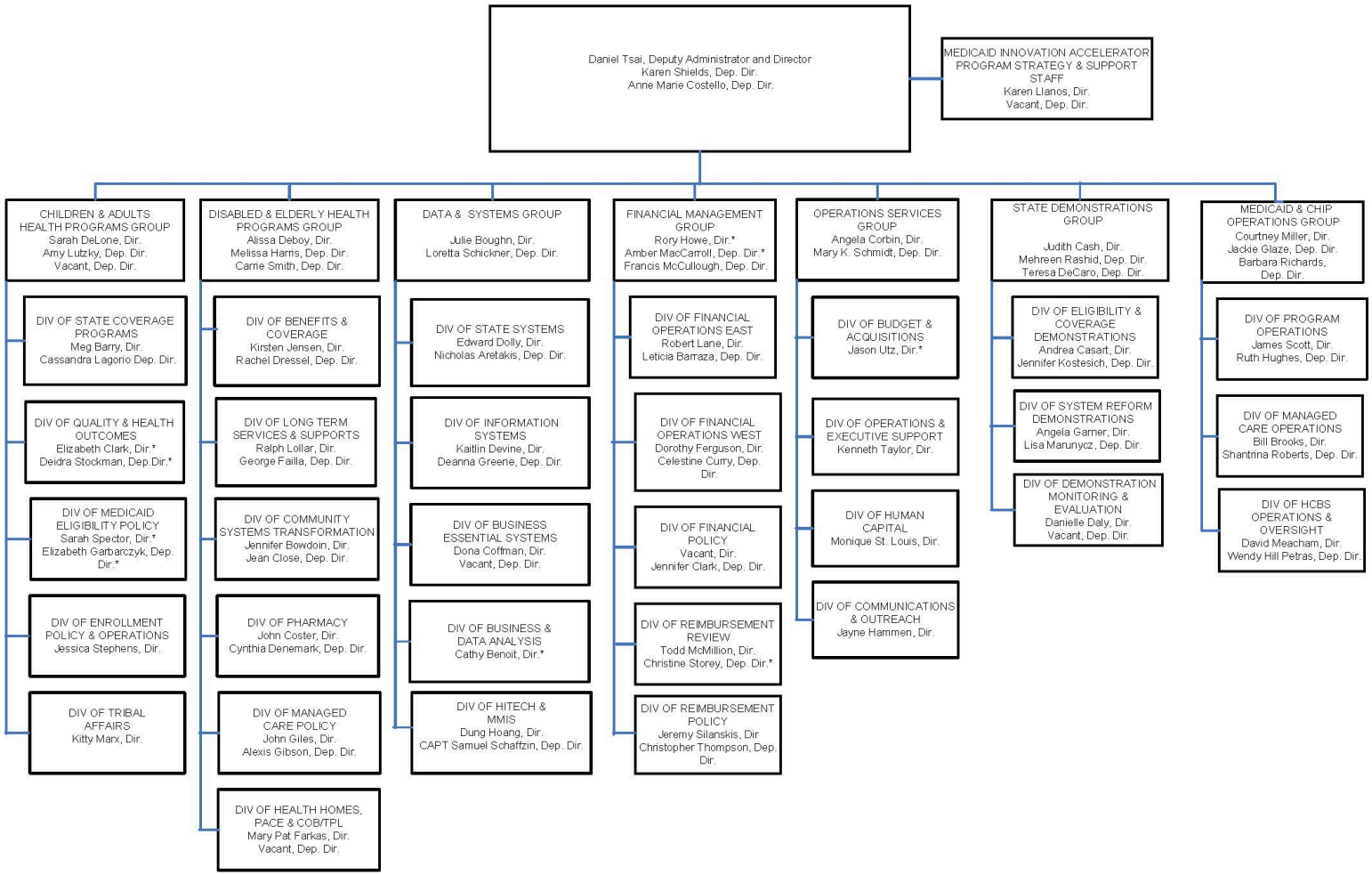
1. Welcome – Delegate Lewis Young
    a. Discussed the original fiscal note from HB 318
    b. Identifies three areas of contention: Support Brokers, Overnight Supports, and Fiscal Management Services.
2. Review of Communications/Information
    a. Congressman Trone's Letter to Centers for Medicare and Medicaid Services (CMS)
        i. Letter was sent in April to CMS from Congressman Trone
    b. CMS response to Congressman Trone's letter
        i. CMS response was sent in August.
        ii. Two Different organizations responded: Home and Community Based Services (HCBS) and State Plan.
        iii. 1915(c) program and 1915(k) community choice program.
3. Discussion of Key Topics
    a. Overnight Supports
        i. Personal supports need the waiver to be approved for family supports through 1915(c)
        ii. DDA has said these are not habilitative services
        iii. CMS says that maintaining health and safety is inherently habilitative thus DDA can approve.
        iv. If DDA includes that waiver through 1915(c), CMS will approve the cost.
        v. The cost sharing between the state and federal government would cost the same as the state is currently paying without the waiver.
    b. Support Brokers
        i. Support Brokers used to be able to do a lot more
        ii. Many folks cannot find a community provider. The support broker used to have a more expanded role, but it was cut to just 4 hours per month.
        iii. Its important to define the difference between Coordination of Community Services (CCS) and Support Brokers
    c. Questions the subcommittee are looking more closely.
        i. Question 3 clearly outlines habilitative supports.
        ii. Hold on discussions around FMS due to closing of the RFP.
        iii. Questions 7 & 8. Question 8 was taken directly to the program director. The answer they provided was clearer than the original answer.

        iv. Question 12 should also be placed on hold because responses are still unclear and somewhat contradictory.
4. Committee Homework
    a. Develop Chart of Policy Concerns that need to be address in workgroups final report.
    b. Cross Tabulate Current State Policies with Current Federal Policy Guidance
    c. Make Editable Document Available to Subcommittee.
    d. New Information Should Be Added as it Becomes Available.
5. Closing
    a. Subcommittee Report for Workgroup Needed by Wednesday, September 22.
        i. Serena and Ande will present to the workgroup.
    b. Next Meeting: Friday, October 15 | 10:30 a.m.

APPENDIX: CMS Department and Leadership Tree

DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR MEDICARE & MEDICAID SERVICES
CENTER FOR MEDICAID AND CHIP SERVICES

APPROVED LEADERSHIP
As of Sept 1, 2021
***Acting**



SUPPLEMENTS FOR SELF DIRECTION WORKGROUP - 9-28-2021

1. Congressman David Trone's Letter to the Centers for Medicaid Services
2. CMS Response Letter
3. Clarification Emails Between CMS Staff and Advocates

April 21, 2021

Sharon Graham, Regional Administrator
Philadelphia Office of Local Engagement and Administrative Staff
Centers for Medicare & Medicaid Services
801 Market Street, Suite 9400
Philadelphia, PA 19107-3134

Administrator Graham:

I am requesting information to understand better the federal requirements related to self-directed options for individuals with significant disabilities eligible to receive Medicaid-funded home and community-based services (HCBS). The purpose of my outreach is to seek clear guidance and clarification on specific questions related to what states are and are not allowed to do under Medicaid HCBS self-direction.

Maryland's self-direction option was initially a model for community inclusion and participant autonomy created over 15 years ago. It provided advocacy and oversight from involved professionals with intimate knowledge of the participant, and it saved the state an average of at least 25% over traditional programming. Self-Direction was also transparent. It was clear to participants and state administrators the parameters of the self-direction, including resource allocation and documentation. However, in the past five years, changes to the program have resulted in less choice and control for participants. Advocates feel that the original self-direction model of individualized, efficient, person-centered care is now more standardized, state-centered, and costly. Despite various discussions between advocates and State policymakers, the State's Developmental Disabilities Administration (DDA) remains steadfast that proposed changes and restrictions are now CMS requirements.

Additionally, some time ago, I believe DDA received a CMS notification that Medicaid funds could not be used for certain services not listed in the state's HCBS waiver. Instead of amending the HCBS waiver to include these services, DDA opted to prohibit resources under self-direction to pay for such services. Thus, I am seeking to clarify federal regulations.

Recently, Maryland Delegate Karen Lewis Young introduced legislation to protect and preserve self-direction and build consensus between administrators, self-direction participants, and their families. Recognizing CMS allows states broad latitude to implement HCBS Medicaid Waiver programs, it would be helpful if your department could answer the attached questions regarding CMS regulations.

CMS is the federal authority responsible for providing support and oversight of state Medicaid agencies and sub-operational entities. As a legislative summer study has begun researching these challenges, it is helpful to receive some clarity from your department. Thank you for your insights into this matter.

Sincerely,

David Trone, M.C.

Inquiry for administrative staff of Centers for Medicare and Medicaid Services

1. Has CMS ever reduced or withheld the federal medical assistance percentage (FMAP) to a state for incorrect implementation of a self-direction option or waiver service? If so, how often has this occurred, and under what circumstances?

2. Has CMS ever reduced or withheld FMAP to a state due to a review and determination of non-compliance of state statutes concerning the provision of Medicaid-financed HCBS? If so, how often has this occurred, and under what circumstances?

3. How does CMS define and interpret "habilitative supports"?

    a. Does habilitative services include supervision of an individual to maintain health and safety and the performance of personal care supports?
    b. Does CMS prohibit the use of habilitative services for overnight supports under self-direction?
    c. Does CMS prohibit the use of personal care supports at night that are not considered habilitative in nature?
    d. Does CMS prohibit an individual from exercising employer authority for overnight supports delivered in their home or family home? If so, under what conditions?
    e. Can states prohibit individuals from hiring Direct Support Professionals of their choice to provide personal care supports at night, requiring the individual to use a provider agency?
    f. Does CMS believe this limitation would violate the HCBS settings rule because it restricts the choice of professionals providing the service?

4. Should Medicaid-funded HCBS states offer more than one fiscal management service (FMS) for individuals who opt for self-direction services?

5. Are states allowed to restrict or prevent individuals eligible for HCBS from pursuing self-direction?

6. Does CMS require that recipients maintain a documented hourly schedule?

7. Does CMS prohibit incidental overlap between the support brokers, case managers, or service coordinators?

8. Understanding in many states, including Maryland, case managers and service coordinators are employees of the state, and support brokers are employees of the participant, can support brokers provide the following services when requested by the participant and their team:

    a. Ensure the participant's home maintenance, including food and supply inventories?
    b. Manage the participant's employee schedules?
    c. Schedule participant's healthcare and medical-related appointments?
    d. Manage the participant's other daily needs, including health and safety needs?
    e. Ensure the participant's support services are functioning effectively and efficiently?

f. Assume administrative responsibilities, including approving and submitting staff timesheets, vendor payments (other than their own), tracking budgets, and suggest proper fund allocation?

g. Assure proper plan administration and timely submission of paperwork?

9. Does CMS prohibit transportation reimbursement for non-employee family members who provide required specialized vehicles?

10. Does CMS prohibit transportation reimbursement as a stand-alone service, including mileage used, under specific service categories like community development?

11. Does CMS include individual or family homes as a setting for receiving "community" based services?

a. If an individual is self-employed, a volunteer worker, or participating in recreational activities at their home utilizing support services, is the home considered a community setting or a facility?

b. Are these services considered personal habilitation, attendant services, community development, or individualized and integrated day services?

12. Does CMS prohibit the participant from being directly reimbursed for expenditures like transportation fees when in the community?

Inquiry for administrative staff of Centers for Medicare and Medicaid Services

1. Has CMS ever reduced or withheld the federal medical assistance percentage (FMAP) to a state for incorrect implementation of a self-direction option or waiver service? If so, how often has this occurred, and under what circumstances?

2. Has CMS ever reduced or withheld FMAP to a state due to a review and determination of non-compliance of state statutes concerning the provision of Medicaid-financed HCBS? If so, how often has this occurred, and under what circumstances?

Response to questions 1 & 2, there were no recent deferrals or disallowances related to HCBS. However, we did issue two disallowances in 2015 and 2014 for OIG audit related issues for the following.

1. **Maryland Claimed Unallowable Medicaid Costs For Residential Habilitation Add-On Services Under Its Community Pathways Waiver Program, Report Number A-03-13-00202, dated June 29, 2015 for $34,155,857 FFP.**
2. **Maryland Claimed Costs For Unallowable Room And Board And Other Residential Habilitation Costs Under Its Community Pathways Waiver Program, Report Number A-03-12-00203, dated September 2013, for $20,627,705 FFP.**

3. How does CMS define and interpret "habilitative supports"?

a. Does habilitative services include supervision of an individual to maintain health and safety and the performance of personal care supports? **HCBS Response: Yes, per Section 1915(c)(5)(A)**

b. Does CMS prohibit the use of habilitative services for overnight supports under self-direction? **HCBS Response: No, not under 1915(c) waivers or 1915(i) State plan HCBS. However, a state may choose to do so in their 1915(c) or 1915(i) programs.**

c. Does CMS prohibit the use of personal care supports at night that are not considered habilitative in nature? **HCBS Response: No, not under 1915(c) waivers or 1915(i) State plan HCBS. However, a state may choose to do so in their 1915(c) or 1915(i) programs.**

d. Does CMS prohibit an individual from exercising employer authority for overnight supports delivered in their home or family home? If so, under what conditions? **HCBS Response: This is not prohibited under 1915(c) waivers or 1915(i) State plan HCBS. However, a state may choose to do so in their 1915(c) or 1915(i) programs.**

e. Can states prohibit individuals from hiring Direct Support Professionals of their choice to provide personal care supports at night, requiring the individual to use a provider agency? **HCBS Response: States select the option to permit individuals to self-direct services and specify the conditions under which this can happen (including setting standards for service providers) in the individual 1915(c) program or 1915(i) benefit. States are permitted to operate 1915(c) waivers and 1915(i) benefits along with concurrent managed care authorities in order to limit the pool of providers in a manner that meets the requirements of the managed care authority.**

f. Does CMS believe this limitation would violate the HCBS settings rule because it restricts the choice of professionals providing the service? **HCBS Response: No, there is not requirement for states to select a self-directed service delivery option in the HCBS settings rule.**

State Plan Response: **CMS views habilitative services as those services that assist an individual to acquire skills for the first time or maintain skills. CMS allows states to cover habilitative services under the preventive services benefit at 42 CFR 440.130(c).**

HCBS Response: Per Section 1915(c) of the Social Security Act pasted here: (5) For purposes of paragraph (4)(B), the term "habilitation services"—
(A) means services designed to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings; and
(B) includes (except as provided in subparagraph (C)) prevocational, educational, and supported employment services; but
(C) does not include—
(i) special education and related services (as such terms are defined in section 602 of the Individuals with Disabilities Education Act[236] (20 U.S.C. 1401)) which otherwise are available to the individual through a local educational agency; and
(ii) vocational rehabilitation services which otherwise are available to the individual through a program funded under section 110 of the Rehabilitation Act of 1973[237] (29 U.S.C. 730).

4. Should Medicaid-funded HCBS states offer more than one fiscal management service (FMS) for individuals who opt for self-direction services?

State Plan Response: It is unclear if the question is asking about the number of FMS providers or the type of FMS offered. This answer may be different if CMS receives further clarification. This depends on the Medicaid Authority used. The 1915(j) authority requires that FMS is an administrative activity. States may limit the number of providers of administrative activities. Section 1915(k) allows a state to choose to provide the service as an administrative or a medical service. If the activity is provided as a medical service, then the state must adhere to free choice of provider requirements, and may not limit the number of qualified providers who can provide the service.

HCBS Response: For 1915(c) HCBS waivers, it depends on how FMS is provided in the approved waiver. If FMS is included as a waiver service, providers may not be limited. Individuals must be offered choice of providers unless there is an approved concurrent authority that would allow the state to limit choice of providers. If FMS is provided as an administrative activity, providers may be limited and individuals are not afforded choice of providers.

5. Are states allowed to restrict or prevent individuals eligible for HCBS from pursuing self-direction?

State Plan Response: All Medicaid self-direction authorities are considered an optional Medicaid benefit or service delivery option. As such, states are not required to make optional benefits or service delivery options available to Medicaid beneficiaries.

HCBS Response: Yes, self-direction is not a mandatory requirement but rather an option that states may elect in their 1915(c) waivers or 1915(i) benefit. We note that CMS strongly encourages the self-direction option.

6. Does CMS require that recipients maintain a documented hourly schedule?

State Plan Response: States must develop a plan of care, and or conduct a needs assessment that feeds into a services plan. The needs assessment and services plan must explain the number of

hours a person is authorized to receive. The beneficiary should have flexibility to decided when the services they receive are provided.

Section 12006(a) of the 21st Century Cures Act requires states to implement electronic visit verification of all personal care services. EVV systems must verify:

- **Type of service performed;**
- **Individual receiving the service;**
- **Date of the service;**
- **Location of service delivery;**
- **Individual providing the service;**
- **Time the service begins and ends.**

A schedule could be used in conjunction with an EVV system.

HCBS Response: No, states specify the process for verifying and authorizing payment for services.

7. Does CMS prohibit incidental overlap between the support brokers, case managers, or service coordinators?

State Plan Response: **States should prevent duplication of payment for all Medicaid services. However, there is no prohibition on incidental overlap, if that means – services providers communicating with each other while performing their respectful roles.**

HCBS Response: CMS is unclear regarding what the question is. If the question is can the service definitions overlap per Sec. 1902. [42 U.S.C. 1396a] (a) A State plan for medical assistance must—

(30)(A) provide such methods and procedures relating to the utilization of, and the payment for, care and services available under the plan (including but not limited to utilization review plans as provided for in section 1903(i)(4)) as may be necessary to safeguard against unnecessary utilization of such care and services and to assure that payments are consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area;" Therefore, states must ensure that there is no duplication of Medicaid services/duplication of payment for Medicaid services.

8. Understanding in many states, including Maryland, case managers and service coordinators are employees of the state, and support brokers are employees of the participant, can support brokers provide the following services when requested by the participant and their team:

a. Ensure the participant's home maintenance, including food and supply inventories? **It is unclear what this "ensuring the participant's home maintenance" means in this context. Additional explanation is needed.**

b. Manage the participant's employee schedules? **Under self-direction, the individual or the individual's representative should manage the schedules.**

c. Schedule participant's healthcare and medical-related appointments? **This seems to be beyond the scope of a support broker. This is something that a case manager could do.**

d. Manage the participant's other daily needs, including health and safety needs? **This is a direct service and beyond the scope of a support broker.**
e. Ensure the participant's support services are functioning effectively and efficiently? **Varies – based on the Medicaid authority**
f. Assume administrative responsibilities, including approving and submitting staff time sheets, vendor payments (other than their own), tracking budgets, and suggest proper fund allocation? Varies – based on the Medicaid authority. **Some of these activities fall under Financial Management Services.**
g. Assure proper plan administration and timely submission of paperwork? **Varies – based on the Medicaid authority**

HCBS Response: The employer of the service provider is immaterial to the answer. The service definition in the specific approved 1915(c) or 1915(i) document determines the answer to these questions.

9. Does CMS prohibit transportation reimbursement for non-employee family members who provide required specialized vehicles?

HCBS Response: CMS is unclear of the question being asked. However, clarifies that services are funded as specified in the approved 1915(c) waiver or 1915(i) benefit. States are not able to fund individuals who are not authorized providers of authorized services. In addition, services that are funded through HCBS programs must be provided to the individual.

10. Does CMS prohibit transportation reimbursement as a stand-alone service, including mileage used, under specific service categories like community development?

State Plan Response: Response for questions 9 & 10, Under state plan authority, beneficiaries and family members are eligible to receive mileage reimbursement for transporting the beneficiary to and from covered medical services, when mileage reimbursement is specifically covered in the state plan. For transportation to and from <u>non-medical</u> waiver services, the waiver must specify that transportation to and from the non-medical waiver services is a covered benefit and must also specify that mileage reimbursement is covered for beneficiaries and family members when traveling to and from waiver services.

HCBS Response: CMS is unclear regarding this question but offers the following information. If the state includes transportation as a stand-alone service it generally would not be for only one specific service category. Generally, if transportation is included in connection to a specific service category it is included as a component of the rate for that service.

11. Does CMS include individual or family homes as a setting for receiving "community" based services? **HCBS Response: Yes.**

a. If an individual is self-employed, a volunteer worker, or participating in recreational activities at their home utilizing support services, is the home considered a community setting or a facility? **It would be considered a community setting and the definition can be found with the Technical Guide**.

HCBS Response: The person's own home is considered a community setting.

Person Centered Planning needs to be at the forefront. If the person's preference is to receive his/her service in the larger community the services and providers should be aligned to honor that preference. Please note that a person receiving and spending all their time at home is not person-centered or community integrated, unless that is their preference.

b. Are these services considered personal habilitation, attendant services, community development, or individualized and integrated day services?

This would depend on the service definition.

State Plan Response: CMS Technical Guide, Appendix C-5 Home and Community Based Setting Requirements, starting at page 149, provides instruction and guidance regarding settings.

HCBS Response: CMS notes in response that the answer is dependent on how the services are defined in the approved 1915(c) waiver and how they are implemented. It could be any of these services or more than one service.

12. Does CMS prohibit the participant from being directly reimbursed for expenditures like transportation fees when in the community?

State Plan Response: Under state plan authority, beneficiaries and family members are eligible to receive mileage reimbursement for transporting the beneficiary to and from covered medical services, when mileage reimbursement is specifically covered in the state plan. For transportation to and from <u>non-medical</u> waiver services, the waiver must specify that transportation to and from the non-medical waiver services is a covered benefit and must also specify that mileage reimbursement is covered for beneficiaries and family members when traveling to and from waiver services.

HCBS Response: Except under specific and unique situations CMS funds the provider of the service. In 1915(c) or 1915(i) self-directed programs the individual may have budget authority but the payment goes to the provider of the service and not to the individual receiving service.

Documents for Review by the Maryland Self-Direction Study WG Subcommittee on CMS/Federal Policy Review/Analysis on Self-Direction

Reference Point #1:

- Letter from Representative Trone to CMS re: federal policy on key questions related to self-direction under Medicaid waiver programs (Attached as Separate Document)

- CMS responses to Trone's letter (Attached as Separate Document)

Reference Point #2:

Email correspondence between Shawn Terrell (Senior Policy Adviser, Administration for Community Living at the U.S. Department of Health and Human Services) and Kathryn Poisal (Technical Director for the HCBS 1915(c) Waiver Programs under the Office for Long Term Supports and Services, Disabled and Elderly Health Programs Group, Centers for Medicare and Medicaid Services) dated 8/12/2021. SUBJECT: Whether or not CMS has any policy regarding the allowance of overnight supports in Medicaid waiver programs for people who self-direct.

---------- Forwarded message ---------
From: **Terrell, Shawn (ACL)** <Shawn.Terrell@acl.hhs.gov>
Date: Fri, Aug 20, 2021 at 11:34 AM
Subject: FW: Self -direction question
To: Serena Lowe <ewolaneres@gmail.com>

Shawn Terrell, MS, MSW
Health Insurance Specialist
U.S. Department of Health and Human Services
Administration for Community Living
330 C Street, SW
Suite 1233B
Washington, DC 20201
202-205-0415
Shawn.terrell@acl.hhs.gov

From: Poisal, Kathryn J. (CMS/CMCS) <Kathryn.Poisal@cms.hhs.gov>
Sent: Thursday, August 12, 2021 3:12 PM
To: Terrell, Shawn (ACL) <Shawn.Terrell@acl.hhs.gov>
Subject: RE: Self -direction question

Hi Shawn,

Sorry for the delay in responding; I was out of the office on leave. There is not CMS policy or guidance that is specific to the use of overnight supports.
If you haven't already seen this, you may want to look at the FLSA rule on payment for workers on the DLT website under the homecare rule. Factsheets 22 and 23 at the below link provide an overview:
https://www.dol.gov/agencies/whd/compliance-assistance/toolkits/flsa
I am told that this is several years old but discusses how overnight workers should be paid in varied situations (live-in, outside workers, etc.).

I hope this is helpful and that you are doing well.

Kathy

From: Terrell, Shawn (ACL)
Sent: Wednesday, July 28, 2021 2:54 PM
To: Poisal, Kathryn J. (CMS/CMCS) <Kathryn.Poisal@cms.hhs.gov>
Subject: Self -direction question

Hi Kathy – I hope you are doing well.

I have a question re self-direction. Is there any specific policy or guidance regarding the use of overnight supports in SD?

Thanks in advance for any insight you can offer.

Shawn

Shawn Terrell, MS, MSW
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Reference Point #3:

In response to the original CMS response to Question #8 (looking at roles and duties of support brokers) in Rep. Trone's letter, ACL followed up with CMS' Central Headquarters with the following question:

> *"Are there any prohibitions or restrictions in federal policy on the duties of support brokers that states must abide by? If yes, please provide the list of these restrictions and the language/citation of where these are located in federal policy."*

See Email Communication below between Shawn Terrell and CMS leaders Kathryn Poisal (Technical Director, 1915(c) HCBS Waiver Programs) and Kenya Cantwell (Technical Director, 1915(k) Community First Choice State Plan Options). Dated 8/25/2021. SUBJECT: Parameters around Support Brokers

---------- Forwarded message ---------
From: **Terrell, Shawn (ACL)** <Shawn.Terrell@acl.hhs.gov>
Date: Wed, Aug 25, 2021 at 4:24 PM
Subject: Self Direction Qs
To: Serena Lowe <ewolaneres@gmail.com>

Hi Serena
Kenya and Kathy provided the following responses to the questions from MD. Happy to talk about it. The SB service definition seems to allow some latitude. Hope you are well.

Roles and Duties of a Support Broker under Self-Direction
"Are there any prohibitions or restrictions in federal policy on the duties of support brokers that states must abide by? If yes, please provide the list of these restrictions and the language/citation of where these are located in federal policy."

CMS Response: For 1915(c) waivers, the following CMS core service definition, guidance, and instructions for support brokerage services can be found on pages 175-176 of the Instructions, Technical Guide, and Review Criteria for 1915(c) waivers.

Information and Assistance in Support of Participant Direction (Supports Brokerage)
Core Service Definition
Service/function that assists the participant (or the participant's family or representative, as appropriate) in arranging for, directing and managing services. Serving as the agent of the participant or family, the service is available to assist in identifying immediate and long-term needs, developing options to meet those needs and accessing identified supports and services. Practical skills training is offered to enable families and participants to independently direct and manage waiver services. Examples of skills training include providing information on recruiting and hiring personal care workers, managing workers and providing information on effective communication and problem-solving. The service/function includes providing information to ensure that participants understand the responsibilities involved with directing

their services. The extent of the assistance furnished to the participant or family is specified in the service plan. This service does not duplicate other waiver services, including case management.

Instructions

Modify or supplement the core definition to accurately reflect the scope and nature of supports for participant direction furnished under the waiver

Guidance

- This service is limited to participants who direct some or all of their waiver services.
- As discussed in the instructions for Appendix E (Participant Direction of Services), the scope and nature of this service hinges on the type and nature of the opportunities for participant direct afforded by the waiver.
- Through this service, information may be provided to participant about:

- person centered planning and how it is applied;
- the range and scope of individual choices and options;
- the process for changing the plan of care and individual budget;
- the grievance process;
- risks and responsibilities of self-direction;
- free of choice of providers;
- individual rights;
- the reassessment and review schedules; and,
- such other subjects pertinent to the participant and/or family in managing and directing services.

Assistance may be provided to the participant with:

- defining goals, needs and preferences, identifying and accessing services, supports and resources;
- practical skills training (e.g., hiring, managing and terminating workers, problem solving, conflict resolution)
- development of risk management agreements;
- development of an emergency backup plan;
- recognizing and reporting critical events;
- independent advocacy, to assist in filing grievances and complaints when necessary; and,
- other areas related to managing services and supports.

- This service may include the performance of activities that nominally overlap the provision of case management services. In general, such overlap does not constitute duplicate provision of services. For example, a “support broker” may assist a participant during the development of a person-centered plan to ensure that the participant’s needs and preferences are clearly understood even though a case manager is responsible for the development of the service plan. Duplicate provision of services generally only arises when exactly the same activity is performed and billed on behalf of a waiver participant. Where the possibility of duplicate provision of services exists,

the participant's service plan should clearly delineate responsibilities for the performance of activities.

Maryland Self-Direction Program Workgroup

Members:

The Honorable Karen Lewis Young, Chair

The Honorable Susan Lee

The Honorable Nicholaus Kipke

The Honorable Lisa Belcastro

The Honorable Heather Bagnall

The Honorable Harry Bhandari

The Honorable Kirill Reznik

The Honorable Geraldine Valentino-Smith

Alicia Wopat, SDAN

Serena Lowe, SDAN

Patti Saylor, SDAN

Esther Ward, MD Commission on Caregiving

Laura Howell, MACS

Rachel London, DD Council

Ken Capone, People on the Go

Megan Rusciano, Disability Rights Maryland

Ande Kolp, The Arc Maryland

Heather Shek, MDH

Deputy Secretary Bernard Simons, DDA

Staff

Kris Fair, Committee Secretary

Erin Hopwood, Committee Counsel

AGENDA

Wednesday October 27, 2021, | 1:00 p.m.
Zoom

Welcome and Old Business

Roll Call | Kris	1:00 – 1:05
Opening Remarks | Delegate Lewis Young	1:05 – 1:10
Follow-up from Prior Meeting: 1. Follow up on last meeting MDH | Heather 2. Review Prior Meeting Minutes | Erin	1:10 – 1:25

Special Presentation

Reviewing Roles of Support Brokers & CCS | Panel 1. Support Broker 2. Former MD State CCS 3. Family Member	1:25 – 1:45

Updates from Subcommittees

Self-Direction Participants Report | Mat Rice	1:45 – 1:55
CMS Review Report | Jacob Took	1:55 – 2:15

Group Discussion and Wrap-Up

Public Comment	2:15 – 2:35
Action Items Review | Delegate Lewis Young	2:35 – 2:40

Next Meeting: Wednesday, November 24, 2021 | 1:00 p.m.

9/28 minutes – DDA workgroup – 1pm

Opening Remarks Delegate Lewis Young– provided a history of the mission of the workgroup. She explained that the workgroup has formed two subworkgroups: Provider Issues and CMS

Heather Shek – provided an overview of findings from MDH (she will provide written copy to the workgroup)

- Included information on enrollment and how many people using self–directed model over the years
- Information on % of budget that an individual spends (around 85%)
- Information on survey results

Delegate Lewis Young (KLY) to Heather – why do you think more people to not chose self–direction?

Heather – MDH has heard that it may be confusing for families on how to access

KLY has noticed many minority users, there is a health inequity issue if they are not getting the services they need

KLY asked if there were any additions/changes to the minutes

Serena Lowe/SDAN/Consultant and Ande Kolp Arc of Maryland–presented CMS subworkgroup report

Explained 1915(c) waivers

Had slide presentation which will be provided to the workgroup

FMAP issue

Overnight supports – are these restricted by CMS? They are restricted under Community First Choice by MDH as a habilitative services. Provided CMS definition of habilitative services.

Provided questions from Rep Trone to CMS regarding overnight supports and CMS answers

Support brokers and whether there are federal restrictions – shared CMS guidance on support brokers

Presentation included miscellaneous questions to CMS

Included summary of subworkgroup findings related to what MDH can do regarding services and CMS. Legislation may be necessary to require MDH to alter waiver.

KLY asked if DDA would comment on the presentation at next month's meeting.

Delegate Valentino Smith– asked about family member reimbursement. Did CMS clarify? Serena – overnight services, individual can hire whoever they want, have not asked the direct question whether can reimburse under federal law b/c you can. It's just that not all states allow it.

Delegate Bagnall – asked Serena to see if other states offer additional services to families to navigate the self direction system. Serena – she can gather promising practices in other states

Senator Lee staff – requested info on the states that do not allow reimbursement to families (when/why?) Serena – may be hard to find out why

KLY – from states with more robust programs, is there a cost benefit available?

Report from Self Direction participant subworkgroup

Mat Rice – ARC of Maryland

Provided minutes from the subworkgroup meeting on September 15, 2021 (Erin get from Kris)

Four hour minimum from support broker is of concern,

Mat uses self–directed services, he feels having a designated representative goes against the intent of self–directed services

Mileage reimbursement – affects ability to recruit

Public Comment

Susan Goodman Question for KLY – possibility for legislative route? KLY – hoping to have enough consensus to not have to use legislation, but there is always that possibility.

Alarice – represents brokers – 75% of her clients are not indigenous to US or have communication needs – she has shared with DDA the need for a diversity initiative, She wanted to make workgroup aware of the issue

Rob Stone – his mother spoke acting as support provider, Rob is on participant workgroup, issue of non–alignment of 1915(c) programs – Rob is in multiple programs (REM and Self Direction) – He would like workgroup to find out how many people are in similar situation. He is having difficulty getting nursing needs met.

Irene Souada – also discussed issue of CFC and REM. Low reimbursement through CRC vs. DDA. This makes it hard to recruit staff.

Karenna – parent, son in REM, nursing shortage issue, she has to take care of her son's overnight needs.

Karen Blanchard– advocate parent, adult son with autism, moved to Maryland during pandemic, thought she would get the same services that she got in Florida

KLY – plan for next three months

October 27 meeting– focus on recommendations from subworkgroups, comments from DDA on today's comments

November – wants presentation to workgroup on recommendations

December – hopes to have consensus on final report from workgroup.

Oct 13 – 10:30 am, participant subcommittee meeting

Oct 15 – 10:30am,CMS subworkgroup meeting

Meeting concluded – 2:35pm

Matrix of Policy Questions, Current Federal/State Policy, and Policy Reform Options

TOPIC	Policy Questions/Issues	Current Federal Guidance (if any)	Current MD State Policy/Program Challenges	Policy Reform Strategies/Options
Overnight Supports under Self-Direction	Can the State of Maryland cover personal care services overnight irrespective of HCBS authority?	CMS does not prohibit nor require States to pay for personal care and/or habilitative services overnight.	Individuals under self-direction are being denied reimbursement for overnight services.	State policy should provide overnight supports.
	If yes, should the individuals be required to go through a provider agency to receive overnight supports?	CMS permits States to allow individuals to exercising employer authority under self—direction for overnight supports delivered in their home or family home. States are allowed to establish their own policies for whether and how they will reimburse for overnight supports.	Because the Maryland DDA has disallowed coverage of overnight supports through their waivers, for those who have received approval for overnight personal care services, the State of Maryland is paying for these with state-only funds rather than drawing down the federal match via 1915(c) waiver.	Clarify by statute and/or policy guidance (i.e. waiver or regulation) that personal care/habilitative services can be covered overnight, and include through the waiver this service so that state of Maryland can receive the federal match to support payment of such services.
	Can a person of the individual participant's choosing be hired directly by the individual to provide such supports?	CMS permits States to allow individuals to exercise employer authority under self—direction for overnight supports delivered in their home or family home. States are allowed to establish their own policies for whether and how they will reimburse for overnight supports.	Individuals have reported being told by their CCS that DDA won't cover overnight supports unless they go through a provider agency. While participants under self-direction can stay in their own home, if they are told they have to go through a provider agency to receive overnight supports, then the provider is the one controlling/hiring staff who support them 128 hours each week. Additionally, some participants have reported being encouraged to move to a provider owned or controlled residential setting as opposed to remaining in their own home or in a family home if they require overnight supports.	Clarify in the waiver that individuals under self-direction have the option of exercising employer authority to hire individuals or a provider of their choosing to provide the service.
	If yes, should there be any restrictions around this in terms of the types of supports needed or the individual(s) providing the supports?	States are not required to establish restrictions on who provides such services.	State has allowed people to hire family members or other personnel for overnight supports, but State-only funding is being used (the State is currently not drawing down the federal match).	Once overnight supports are deemed necessary, no restrictions should be placed on a participant in terms of exercising their hiring authority to retain the person(s) they desire to provide the service.

Matrix of Policy Questions, Current Federal/State Policy, and Policy Reform Options

TOPIC	Policy Questions/Issues	Current Federal Guidance (if any)	Current MD State Policy/Program Challenges	Policy Reform Strategies/Option
Accessing and Utilizing Support Brokers	Should all individuals under self-direction be offered a support broker, and what should the requirements be to educate and counsel individuals and families on this option?	There is no prohibition on States to offer support broker services under their Medicaid HCBS 1915(c) waiver authorities.	The information/education to individuals and families on support brokers is limited/varies, and as a result, many individuals and families do not know how to access support brokers.	Authorize and fund additional training and SB information & referral process for all individual participants under self-direction (current and future) on an annual basis as part of the S-D planning process.
	What specific duties should participants under self-direction be allowed to hire a support broker to perform?	For 1915(c) waivers, the following CMS core service definition, guidance, and instructions for support brokerage services can be found on pages 175-176 of the Instructions, Technical Guide, and Review Criteria for 1915(c) waivers.[1] States should prevent duplication of payment for all Medicaid services. However, there is no prohibition on incidental overlap, if that means – service providers communicating with each other while performing their respective roles.	Several duties/activities that SBs used to assist individuals with under self-direction have now be delegated to CCS, who lack the expertise, competencies, or bandwidth to absorb. This creates additional problems as well in that as state CCS, are beholden to the best interests of the state, whereas SBs are beholden to the best interests of the individual participants in self-direction.	Rescind policy changes that resulted in transference of SB duties from CCS back to support brokers to allow for a more proportional balance in terms of level of effort and alignment of talents/skills among the two categories of support professionals. Allow SBs to provide any duties allowed under federal regulation (see Footnote 1) if an individual chooses to be supported by the SB for any of these activities.
	Should there be a cap on the number of hours an individual can receive in support broker services, and if so, what should that be?		DDA decreased the maximum number of hours self-directed participants can access assistance from support brokers to 4 hours/month.	Update policies to allow individuals under self-direction to utilize SBs for up to 40 hours/month based on the individual needs of each participant. DDA may authorize more hours beyond 40/month if deemed necessary for the participant.

[1] Through this service, information may be provided to a participant about: person centered planning and how it is applied; the range and scope of individual choices and options; the process for changing the plan of care and individual budget; the grievance process; risks and responsibilities of self-direction; free of choice of providers; individual rights; the reassessment and review of schedules; and, such other subjects pertinent to the participant and/or family in managing and directing services. Assistance may be provided by a support broker to the participant with: defining goals, needs and preferences, identifying and accessing services, supports and resources; practical skills training (e.g., hiring, managing and terminating workers, problem solving, conflict resolution); development of risk management agreements; development of an emergency backup plan; recognizing and reporting critical events; independent advocacy, to assist in filing grievances and complaints when necessary; and, other areas related to managing services and supports. This service may include the performance of activities that nominally overlap the provision of case management services. In general, such overlap does not constitute duplicate provision of services. For example, a "support broker" may assist a participant during the development of a person-centered plan to ensure that the participant's needs and preferences are clearly understood even though a case manager is responsible for the development of the service plan.

	Should DDA also allow for the reimbursement under self-direction of someone to support participants who need assistance with the daily management of service coordination and trouble-shooting when plans change or problems arise in real-time?	There is no prohibition in federal regulation restricting states from reimbursing for these services, so long as there is a documenting of services rendered and a clear delineation between the roles, tasks and duties performed of each member of an individual's team. States should prevent duplication of payment for all Medicaid services. However, there is no prohibition on incidental overlap, if that means – service providers communicating with each other while performing their respective roles.	Beyond the need for additional/expanded access to support brokers, participants under self-direction often need someone to support the daily management and logistical coordination of activities in real time across various paid staff and the individual. These are activities that fall well outside the realm of the CCS, support broker, or paid staff. Under a traditional provider model, the costs associated with these tasks are built in as administrative fees within service rates. But there is no corresponding line-item in individual budgets under self-direction.	Create an allowable expense or service for supporting the daily logistical coordination and management of the individual's services, activities and options in real-time.

Matrix of Policy Questions, Current Federal/State Policy, and Policy Reform Options

TOPIC	Policy Questions/Issues	Current Federal Guidance (if any)	Current MD State Policy/Program Challenges	Policy Reform Strategies/Options
Designated Representative	What is the intent behind having a Designated Representative (DR)?	Current federal law allows for the appointment of a designated representative, as well as promotes the availability of supported decision-making for participants receiving federally-funded HCBS.	The intent of the DR is to allow individuals who have a legal guardian that is also a paid support person to select someone else beyond the legal guardian to support the designation of services. The purpose is to prevent financial conflicts of interest in determining the services an individual needs and who should provide them outside the context of paid family staff. If the DR is a family member, no other family member including the DR can serve as paid staff. Current state policy is unclear regarding the legal obligations or duties of the DR. Waiver language suggests this role should be non-legal in nature. This is also an unpaid role. This lack of clarity greatly impedes participants' access to willing DR supports.	Transition the forms and process to one that is focused on a team-oriented, person-centered supported decision making process, allowing participants to identify individual(s) who they wish to support them in making decisions in specific areas of their life, and make sure these preferences are included in any participant agreement.
	Should individuals be required to have a DR, and if so, under what conditions? Should individuals be allowed to choose whoever they want to be a DR? What if any restrictions should apply?	Federal regulation does not require participants under self-direction to have a DR.	State of Maryland is going to release a new Self-Directed Participant Agreement in the near future. Some individuals would have to select a DR in order to sign the agreement.	Individual participants should not be required to select a DR, but have several options (a DR, a support broker, or a team of people in their lives that will help them make key decisions via a supported decision-making model). Participants should not be constrained in these options or in who they select in terms of the DR, the support broker, or their supported decision-making team.
	Can support brokers address issues that appointing a DR is attempting to resolve around potential conflicts of interest when paid family members are involved in a person's service plan under self-direction?	The guidance related to the parameters a support broker may be used do not preclude a support broker from monitoring the designation of services and identifying areas of potential conflicts of interest to the participant (and state).	Support brokers are required to report any potential coercion of participants or financial conflicts of interest to DDA.	In instances where individual participants under self-direction are receiving services from paid family member(s), require the individual to select a support broker or DR to address areas of potential conflict of interest, depending on what is in the best interests of the individual.

Matrix of Policy Questions, Current Federal/State Policy, and Policy Reform Options

TOPIC	Policy Questions/Issues	Current Federal Guidance (if any)	Current MD State Policy/Program Challenges	Policy Reform Strategies/Options
FMS Roles & Scope	How should FMS vendors be selected?	If FMS is provided as an administrative activity, providers may be limited and individuals not afforded a choice of providers. But the determination of how many FMS providers under an administrative activity is up to the state and is not regulated by any federal standards or restrictions.	State is currently vetting bids submitted as part of the most recent Request For Proposals released in 2021. The evaluative criteria for selecting vendors was vague in the RFP.	Establish clear criteria to assure vendors have strong knowledge base in the provision of HCBS and self-direction.
	Should individuals participating in self-direction have a choice in FMS vendors?	Federal regulations do not require a limitation of FMS providers under any situation. For 1915(c) HCBS waivers, it depends on how FMS is provided in the approved waiver as to whether a State can limit choice of providers. • If FMS is included as a waiver service, providers may not be limited. Individuals must be offered choice of providers unless there is an approved concurrent authority that would allow the state to limit choice of providers. • If FMS is provided as an administrative activity, providers may be limited and individuals not afforded a choice of providers. But the determination of how many FMS providers under an administrative activity is up to the state and is not regulated by any federal standards or restrictions.	MDH has indicated that it will select between 2-10 FMS vendors, but the state has not clarified whether participants will be assigned a vendor or can choose their vendor. Additionally, it is unclear what, if any, recourse participants have if they are unhappy with their FMS vendor and wish to use a different vendor.	Require multiple vendors in all future bidding processes. Also, establish a clear process for individuals under self-direction to be educated on the FMS options, to choose the FMS vendor they prefer, and to be able to switch FMS vendors if they are unhappy with the initial vendor they chose.
	Should FMS vendors be required to assess the appropriateness of a participant paying a family member to provide services?	Federal regulations do not require States to have FMS vendors assess the appropriateness of a participant paying a family member to provide services.	Scope of FMS RFP stated vendors are required to have a process in place for determining appropriateness of a paid family member relationship, and to perform competency evaluations on self-direction participants.	Remove from scope duties involving evaluation of the appropriateness of paid family relationships.
	Should FMS vendors be expected to conduct competency evaluations to determine whether an eligible HCBS participant can engage in self-direction?	Self-Direction, when offered by States within HCBS authorities/ programs, should be available to all individuals regardless of age, disability, diagnosis, functional limitations, cognitive status, sex, sexual orientation, race, ethnicity, physical characteristics, national origin, religion, and other such factors.	There is no state policy currently authorizing the evaluation of individuals as a condition of self-direction by FMS providers.	Remove from scope duties involving evaluation of competency of participants to engage in self-direction and reaffirm that anyone can self-direct with the right supports.

Maryland Self-Direction Program Workgroup

Members:

The Honorable Karen Lewis Young, Chair

The Honorable Susan Lee

The Honorable Nicholaus Kipke

The Honorable Lisa Belcastro

The Honorable Heather Bagnall

The Honorable Harry Bhandari

The Honorable Kirill Reznik

The Honorable Geraldine Valentino-Smith

Alicia Wopat, SDAN

Serena Lowe, SDAN

Patti Saylor, SDAN

Esther Ward, MD Commission on Caregiving

Laura Howell, MACS

Rachel London, DD Council

Ken Capone, People on the Go

Megan Rusciano, Disability Rights Maryland

Ande Kolp, The Arc Maryland

Heather Shek, MDH

Deputy Secretary Bernard Simons, DDA

Staff

Kris Fair, Committee Secretary

Erin Hopwood, Committee Counsel

AGENDA

Wednesday November 24, 2021, | 1:00 p.m.
Zoom

Welcome and Old Business

Opening Remarks | Delegate Lewis Young	1:00 – 1:10

Review of Recommendations

Review of Recommendations	1:10 – 2:00

Wrap Up

Public Comment	2:00 – 2:25
Action Items Review | Delegate Lewis Young	2:25 – 2:30

Next Meeting: Wednesday, December 29, 2021 | 1:00 p.m.

1.) CCS members will fully orient new and current participants about self-direction. This is a component of person-centered planning process.
    a. Potential Actionable Items: Video explaining self-direction, checklist for the CCS to follow that they have explained the program, yearly check-in, and reiteration of the self-direction option.
2.) Expand and Assure Access to Support Brokers for all individuals under Self-Direction by:
    a. Offering a Support Broker to all participants as part of the counseling/information session on self-direction and as part of their annual person-centered planning process.
    b. Expanding the definition of "Support Broker Services" to include any allowable activities as contained in the CMS core service definition, guidance, and instructions for support brokerage services can be found on pages 175-176 of the Instructions, Technical Guide, and Review Criteria for 1915(c) waivers.
    c. Create a similar service for CFC and CFAS HCBS authorities.
    d. Allowing participants to utilize an individual choice model for support broker services that is no greater than 40 hours/month (or more, if approved on an individualized, case-by-case basis).
3.) Amend all existing HCBS state authorities to allow participants under self-direction to:
    a. Self-direct overnight supports
    b. Hire Family as staff
    c. Choose their FMS vendor from three or more options.
4.) Allow participants under self-direction the option of choosing a Designated/Authorized Representative, Support Broker, or a team of individuals under a supported decision-making model to support them in directing services under self-direction.
5.) With consideration for administrative needs of a person utilizing self-direction, assure parity and transparency in the rates and reimbursement of services provided under self-direction and traditional provider services.
6.) Restore flexibility with definition of "individual goods and services":
    a. Equipment
    b. Therapies
    c. Technologies
    d. Transportation
    e. Miscellaneous Expenses
7.) MDH will provide a report to the Maryland General Assembly annually showing they have properly audited their self-direction program as a progress report of the key provisions of the workgroups recommendations/legislation. This provision would sunset after three years.

PLACE IN THE REPORT NOT IN THE RECOMMENDATIONS. Refrain from requiring any participant in any of the state's HCBS authorities from having to demonstrate competency or suitability (either by completing a competency examination or evaluation) to participate in self-direction.

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AGENDA

Wednesday, December 29, 2021, | 1:00 p.m.
Zoom

Welcome and Old Business

Opening Remarks | Delegate Lewis Young	1:00 – 1:05
Discussion of SDAN Recommendations | SDAN	1:05 – 1:35
Conversation with MDH | Delegate Lewis Young	1:35 – 2:05

Group Discussion and Wrap-Up

Public Comment	2:05 – 2:25
Action Items Review | Delegate Lewis Young	2:25 – 2:30

Thank You!

Recommendations Review List			
#	Theme	Goal	Action Items
1	CCS	CCS Orientation and Continuing Education Requirements	Training materials (flyers, videos), signoff that SDS program was offered, yearly followup with participants to reiterate self direction options.
2	SUPPORT BROKERS	Expanding the Support Broker Role	SB option being offered at each information session. Expand the definition of SB services to allow many of services to be perfomed by the SB if participant chooses to assign tasks to them as previously offered.
3		Expanding SB Hours	SB hours increased up to 40 hours.
4		Expand SB Options	Create similar services for CFC and CFAS.
5		Required SB for Participants Hiring Family	Require a support broker to be hired if the participant hires a family member or guardian as paid staff to assure oversight.
5	OVERNIGHT SUPPORTS	Increase Overnight Support Options	Allow participants option to use personal supports for overnight supports, which will then make full employer authority available for the entire day instead of using supported living which takes it away for 128 hours/week. Current waiver definitions may already allow this at no cost to the State.
6		Remove Overnigh Support Hour Limit	Remove 82 hour limit on Community Pathways Waiver (CPW).
7		Update CPW for Overnight Supports	DDA amends the CPW regarding overnight supports to allow Medicaid federal matching funds. Experts have reported could be done under the current definition of Personal Support.
8	COMPETENCY	Remove All References to Competency Assessments	Assuring individuals seeking to participate in self direction are allowed to do so without undergoing competentcy assessments by any agency including in the FMS RFP
9	FMS	Expand Fiscal Management Service (FMS) Options to At Least Three	Require any Request for Proposal provide three viable FMS provider options to self direction participants.
10	PARTICIPANT CENTERED SUPPORTS	Participant Selection of Person Center Planning Supports	Options include Designated/Authorized Representative, Support Broker, or a team of individuals. Specifically, the SB role should be the coordinator for ensuring the program/plan is followed.
11		Parity and Transparency in Rates and Reimbursements for Services.	Paticipants can access their plans and budgets on an online platorm. Assure parity between Self Direction supports and traditional providers. This program assists inviduals who do not have family who are able to provide free services for the participant.
12		Defintion of Individual and Family Directed Goods and Services Expanded to Include More Flexibility	Allow for the participant to utlitize funding for equipment, increased therapies, new technologies, transportation, and other miscellenaous expenses as allowed and envisioned by CMS.
13		Remove Budget Cap for IFDGS.	Remove the $5000 cap on IFDGS. Allow participant to identify financial need on an annual basis. Money that most SDS participants have already existing in their savings account.
14		Increase Transportation Options	Expand transportation to allow for coverage of milage to owners of vehicles who are not paid staff and mileage reimbursement for non-employee owners of vehicles used by particpants for related activities
15	Follow Up After Workgroup	Annual Report to the Maryland General Assemble	Report will outline the number of self direction particpants and the progress of key provisions of this workgroup

SDAN

Self-Directed Advocacy Network of Maryland, Inc.

Participant Choice and Control of Services

RECOMMENDATIONS TO SUMMER STUDY WORKGROUP HR318 of 2021

Maryland's original self-direction program, New Directions, was initiated in 2005 as a unique DDA/CMS waiver. A cost-effective national model, it embodied the spirit of CMS guidelines, stressing person-centeredness and participant choice and control of services. The primary goal of these recommendations is to restore aspects of self-direction which have been lost or diluted since 2014 when MDH dissolved New Directions into the Community Pathways waiver, a provider-centered model. The second goal of these recommendations is to achieve greater equity by ensuring that people in disadvantaged communities and those who lack robust family supports can also access and successfully utilize self-direction. As the study group heard from numerous public witnesses and members of the study group, many of these individuals are now effectively shut out from self-direction. It is also SDAN's request that these recommendations be included in comprehensive legislation and subsequent regulations that restores and then maintains both flexibility and access to Self-Direction (S-D) embodied in Maryland's original vision, while retaining its well-documented cost-savings.

Overnight Supports (ONS) and Personal Supports (PS)

The Issue:
In the 2018 waiver renewal to CMS, DDA eliminated coverage of overnight supports (OS) for people who self-direct via the state's Community Pathways Waiver (CPW). DDA then began to require self-directing participants with an established need for overnight supports (ONS) to accept *Supported Living Services* from a provider-managed agency. This new policy evaporated the self-directed participant's employer authority and ability to choose their own employees for all but 40 hours of day-time hours each week. Furthermore, it prohibited even agency-provided ONS for people living in their family homes.

Implications of Current State Policy:
The Supported Living requirement has forced people under self-direction with an established need for ONS into a more costly, more restrictive, and less person-centered service (i.e., requiring individuals to utilize an agency, who then has control over staffing and schedules 128-hours per week). It is particularly devastating to people who live with aging parents who can no longer provide gratuitous ONS. It also actively discourages people who want to live independently in their own homes from doing so, coercing them into living in provider-owned or controlled group settings.

In fact, this new requirement has been so controversial and devastating that due to an outpouring of advocate opposition, DDA has started granting exemptions on a case-by-case basis. However, this is only occurring for people who have the support and knowledge of how to successfully get an exemption, and when an exemption is granted, DDA is funding ONS for self-directed participants with "state-only" money. This stop-gap strategy presents two problems. First, it limits access to employer authority for ONS only to people who can successfully navigate DDA's complicated and overly bureaucratic exception/appeal process. Second, it prevents the state from accessing the federal match for ONS. This is particularly maddening as it is leaving potentially millions of dollars in federal match on the table unnecessarily, as SDAN and Disability Rights Maryland believe that DDA's definition of personal support services under the current waiver and CMS' allowance of overnight supports under self-direction actually allows Maryland to go ahead and cover these ONS costs for self-direction participants now without any additional changes to the waiver.

Recommendation:
Require DDA to reinstate full employer authority for all personal supports to self-directed participants—including those with an established need for ONS (including but not limited to those living independently or in their family homes). Additionally, require DDA to amend the CPW with this change so as to reap the benefits of Medicaid federal matching funds. Finally require DDA to remove the 82-hour limits on personal supports under the current CPW waiver and instead base allowable personal supports on individual need.

Competency Assessments, Designated Representatives (DR) or Authorized Representative

The Issue:
Since 2016, DDA representatives have publicly stated that some individuals may not have the capacity to direct their own services. The competency question has been reflected in many DDA policies and documents, including requirements outlined under the most recent Request for Proposals (RFP) for fiscal management services (FMS) that requires vendors to administer a competency examination for certain self-direction participants receiving Medicaid HCBS. This requirement initially included both DDA and CPAS and CFC programs. SDAN's advocacy helped to remove this requirement for the DDA population ONLY, but we believe it is inappropriate for anyone who received these services. DDA's planning program has also previously required Annual Plan documents that have communicated the need for an "authorized" or "designated representative" as a condition of self-direction even though DDA has maintained that it is not a requirement. Under such documents, if guardians or family members are listed as the authorized or designated representative, then any other immediate family member is prevented from serving as paid staff to the participant under self-direction.

Implications of Current State Policy:
Federal CMS guidelines for self-direction *presume competence* for all participants and do *not* require states to administer competency tests or to assign authorized or designated representatives.[1] The state's drive to assign such a representative has broad legal consequences. It not only robs the participant of both employer and budget authorities (the control and choice centerpieces of self-direction), but also undermines the very foundation of self-direction as reflected in CMS's original guidelines and in its 2014 Final Rule on Home and Community Based Services. It also creates brand new legal conundrums which ripple throughout the self-directed person-centered plan.

This policy has already negatively affected people who self-direct as DDA prohibits people with DRs or Authorized Representatives who are family members from hiring *any* family member to work. Many participants include family members as just one aspect of their paid support staff. Since the inception of self-direction at the national level, the ability to hire family as staff has been a well-documented key to successful participant centered plans. This importance of paid supports from family members has been especially evident since the Covid crisis.

Recommendation:
Eliminate competency assessments in any form from all DDA policies and allow the participant to retain both budget and employer authority as envisioned in Maryland's original *New Directions* waiver.

When participants need or request assistance with specific aspects of their person-centered plan, allow team members to be identified to help implement the participant's wishes by assisting them with the tasks by which the participant has specifically requested assistance. And, when family members work as staff, require conflict-free oversight and assistance from a third-party support broker.

[1] Section 2502(a) of the Affordable Care Act affirms that when offered within programs receiving federal funds through the U.S. Department of Health and Human Services, Self-Direction should be available to all individuals regardless of age, disability, diagnosis, functional limitations, cognitive status, sex, sexual orientation, race, ethnicity, physical characteristics, national origin, religion, and other such factors.

Support Broker (SB)

The Issue:

In its 2018 waiver renewal to CMS, DDA opted to eliminate the requirement that participants use a support broker and made other changes that limited the role, functions, and availability of Support Brokers to waiver participants under self-direction. The new SB definition limited the duties of Support Brokers to primarily human resource functions role and prevent the performing of numerous tasks or activities that CMS has deemed appropriate for support brokering.[2] This policy represented a significant departure from Maryland's original vision for self-direction where the support broker functioned as the participant's primary professional advocate and played key roles from inception to plan development and implementation in an advisory/consultant capacity (but never as the decision maker).

DDA has now allocated the majority of duties that were previously undertaken by a support broker to Coordinators of Community Services (CCS). SDAN feels that this violates the "conflict-free" imperative of CCS agencies since they can now bill for services previously supplied by professional support brokers. CCSes often lack the expertise, knowledge, or capacity to absorb these additional duties given their already large caseloads and professional responsibilities. Additionally, as contractors of the state, they are beholden to represent the best interests of the state, which are not always in alignment with the participant. In the past, having a Support Broker was mandatory, and DDA required Support Brokers to provide *at least* four hours each month of oversight and assistance and allowed participants to use up to 20 hours per month in support broker services before additional approval from DDA was needed. Now, Support Brokers are "optional" and officially *limited* to four hours each month.

[2] In its Instructions, Technical Guide, and Review Criteria for 1915(c) waivers, CMS offers the following core definition for support broker services: "Service/function that assists the participant (or the participant's family or representative, as appropriate) in arranging for, directing and managing services. Serving as the agent of the participant or family, the service is available to assist in identifying immediate and long-term needs, developing options to meet those needs and accessing identified supports and services. Practical skills training is offered to enable families and participants to independently direct and manage waiver services. Examples of skills training include providing information on recruiting and hiring personal care workers, managing workers and providing information on effective communication and problemsolving. The service/function includes providing information to ensure that participants understand the responsibilities involved with directing their services. The extent of the assistance furnished to the participant or family is specified in the service plan. This service does not duplicate other waiver services, including case management." As discussed in the instructions for Appendix E (Participant Direction of Services), **the scope and nature of this service hinges on the type and nature of the opportunities for participant-direct afforded by the waiver.** Through this service, information may be provided to a participant about: person centered planning and how it is applied; the range and scope of individual choices and options; the process for changing the plan of care and individual budget; the grievance process; risks and responsibilities of self-direction; free of choice of providers; individual rights; the reassessment and review of schedules; and, such other subjects pertinent to the participant and/or family in managing and directing services. Assistance may be provided to the participant with: defining goals, needs and preferences, identifying and accessing services, supports and resources; practical skills training (e.g., hiring, managing and terminating workers, problem solving, conflict resolution); development of risk management agreements; development of an emergency backup plan; recognizing and reporting critical events; independent advocacy, to assist in filing grievances and complaints when necessary; and, other areas related to managing services and supports. This service may include the performance of activities that nominally overlap the provision of case management services. In general, such overlap does not constitute duplicate provision of services. For example, a "support broker" may assist a participant during the development of a person-centered plan to ensure that the participant's needs and preferences are clearly understood even though a case manager is responsible for the development of the service plan. Duplicate provision of services generally only arises when exactly the same activity is performed and billed on behalf of a waiver participant. Where the possibility of duplicate provision of services exists, the participant's service plan should clearly delineate responsibilities for the performance of activities.

Implications of Current State Policy:
Professional Support Brokers specialize in self-direction and bring specific knowledge about strategies and resources to the participant-centered team. Because there is now no requirement to use a support broker, many new self-direction participants are unaware that they can access a knowledgeable and professional advocate who works just for them. Furthermore, many CCSes are unfamiliar with the rules of self-direction and lack the knowledge they need to assist with designing an initial plan and budget and seeing it through the arduous approval process. Therefore, many participants are not getting the support they need, and many self-direction applicants are now having to wait months or years to transition into self-direction.

Another implication of eliminating the support broker requirement is that when family members work as staff, the participant team may now lack a professional advocate who can assist with quality assurance and staff oversight.

In addition to the various testimony presented by Support Brokers, participants, and family members about the critical importance of support broker services in assuring participants' successful experience with self-direction, SDAN also conducted an informal survey of Support Brokers about DDA policy changes in their roles. We found that for participants with strong family support networks, the new four-hour limit may (but not always) suffice. However, when participants lack that network or have extensive needs like 24/7 support or come from disadvantaged communities, or have a language barrier, they likely require more than four hours of assistance a month from a qualified, knowledgeable support broker. This is especially true for people who are living on their own, who may require significant oversight to ensure their health and safety. In many cases, requests for additional hours in support broker services have been routinely denied by DDA.

Recommendations:
Ensuring adequate services from professional Support Brokers promotes both equity and access. SDAN would like to see any legislative package include: an allowance of up to 40 hours of support broker services a month for those with an assessed need; a restoration of allowable duties under the state's support broker services definition to include all activities permitted by CMS; and a requirement that a third-party support broker be selected by a participant under self-direction whenever a family member and/or guardian serves as paid staff to the individual in order to assure proper oversight and quality assurance as well as reduce conflicts of interest.

Improved Capacity and Quality of CCS, Support Broker, Participants, and Advocates

The Issue
CCS are overburdened with high caseloads (working with individuals in both traditional provider models and self-direction), and often lack the specific expertise or qualifications to get into any level of depth with individual participants on complexities that arise in self-direction. There is a high turnover rate, which often leaves participants without a steady, consistent, knowledgeable, and reliable source of information. Many individuals have had two or more CCS in one year, and many currently have an "emergency-only" CCS assigned to them due to staffing shortages at several of the CCS agencies. In the past, Support Brokers were trained to be experts in self-direction and to serve as the primary professional advocate and to help the participant with the "nuts and bolts" of self-direction.

Recommendation:
The State needs to invest, in partnership with advocates and stakeholders, in more significant training for all CCSes on self-direction and for professional SBs. Proper training on policies, resources and roles will result in improved access to self-direction for transitioning youth, for people who lack strong family supports, and for people who come from disadvantaged communities. Additionally, any future state legislation on self-direction should include designated funds for participants under self-direction to incorporate into their annual budgets to pay for ongoing training of direct support professionals or other care personnel. The investments will result in improved access to self-direction, and will result in more functional and truly person-centered plans and higher quality service provision.

Transportation

The Issue:
Most people in self-direction go to and from their activities in their employee's vehicle, and those employees are directly reimbursed for their mileage. However, some people with severe mobility restrictions require a specialized van, typically supplied by the family, in order to access their communities. DDA's waivers do not allow for mileage reimbursement to owners of the vehicle, including family, who are not also an employee.

Implications for Current Policy:
Owners of vehicles who are not paid staff but who supply expensive vehicles to support their loved ones in accessing the community are unable to recover the mileage costs—something other participants do not face.

Recommendation:
Expand coverage of transportation services to allow for coverage of mileage to owners of vehicles who are not paid staff but are supporting participants under self-direction in legislation and through amendment to the DDA waivers to allow for mileage reimbursement to non-employee owners of vehicles used by the participant for plan goals and activities.

Individual and Family Directed Goods and Services (IFDGS)[3]

The Issue:
DDA now limits participants to $5,000 per year that can be used towards Individual-Directed Family Goods and Services (IFDGS). Funds for these services must come from direct "savings", which are calculated by comparing the self-directed budget to the same services that are available in similar provider-managed plans. In addition to setting an arbitrary limit on IDFGS without taking into consideration the diverse needs of individual participants under self-direction, DDA also strictly limits the types of services that are funded in this category. This policy represents another significant departure from Maryland's original vision that allowed participants to generate the customized goods and services they needed – while remaining within the total figure allowed by their budget and within the types of activities allowed under federal CMS guidelines.

Implications of Current State Policy:
This new policy has vastly diminished the participant's ability to customize their supports. Like other states, Maryland allowed participants to be reimbursed for an array of services and expenses that are required to fully live, work, participate and thrive in one's community. Such examples include laundry services, fees, materials and equipment associated with college courses or community classes; child care; internet access and assistive technology; emotional therapies; summer camps; etc.

Recommendation:
Restore flexibility in IFDGS according to the spirit of Maryland's original vision and CMS guidelines. Remove the $5,000 cap and instead set a limit based on assessed individual needs in the person-centered planning process (to be re-evaluated annually). Allow participants to identify IFDGS needs in their person-centered plans—so long as they stay within the budget they would have received in a provider-based model.

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[3] In its Instructions, Technical Guide, and Review Criteria for 1915(c) waivers, page 172, CMS offers the following core definition for IFDGS: *Individual Directed Goods and Services are services, equipment or supplies not otherwise provided through this waiver or through the Medicaid state plan that address an identified need in the service plan (including improving and maintaining the participant's opportunities for full membership in the community) and meet the following requirements: the item or service would decrease the need for other Medicaid services; AND/OR promote inclusion in the community; AND/OR increase the participant's safety in the home environment; AND, the participant does not have the funds to purchase the item or service or the item or service is not available through another source. Individual Directed Goods and Services are purchased from the participant-directed budget. Experimental or prohibited treatments are excluded. Individual Directed Goods and Services must be documented in the service plan.*

Transparency in the Person-Centered Planning Processes

The Issue:
The new LTSS (Long-Term Services and Supports computer system) format makes it difficult for individuals and their family advocates to participate in the process as they were previously able to under the *New Directions* waiver. Some CCSes present participants with pre-written plans, which are only loosely based on the actual needs, goals, and strengths of the participant. Many participants are not properly educated or informed by CCSes of their rights to a more person-centered process, and may not know that they can ask for more supports when needed. In addition, since participants and Support Brokers lack access to the LTSS platform, they are unable to address problems or inaccuracies reflected in the person's plan within the system or track the plan over time.

Implications of Current State Policy:
Plans for participants are now often generic and systems-oriented, as opposed to reflecting person-centered goals and preferences informed by evidence-based practice. Additionally, due to significant caseloads and burden on CCSes, participants often endure excessive delays in getting approved for self-direction and for needed waiver services.

Recommendation:
Allow participants to access their plans and budgets on the LTSS platform in order to ensure it accurately reflects team discussions and to track its progress. This will improve communication between all team members, reduce wait times and lead to more effective person-centered plans.

Parity between Provider-Managed Services and Self-Directed Services

The Issue:
In 2021 DDA began calculating self-directed budgets on the basis of provider-managed services. For the first time ever, self-directed budgets demonstrate what the person would be allocated had they chosen provider-managed services. And, in the majority of cases, the actual budget submitted by the participant and/or participant's team under self-direction amounts to less than the total amount authorized by the State.

From this parity rate, however, traditional providers are able to pay oversight supports, such as a house manager, program director, etc. No such option currently exists in self-direction despite the need for these positions when there no gratuitous supports available. Self-direction also has the need for overhead expenses, such as internet access for submitting timesheets with no option to include that expense in a budget.

Recommendation:
We applaud DDA for this new parity of budgets, but we strongly recommend that those in self-direction be able to access all service supports (manager positions, overhead) in the same manner as traditional providers. We further recommend that parity remain an essential feature of self-direction and be incorporated into any legislative package in order to preserve this much-needed and long overdue policy in future Administrations.

Nursing

Introduction:
Individuals who self-direct may require Nursing Support Services as part of their Person Centered Plan. The DDA current Medicaid waiver allows for two types Nursing Support Services in Self-Direction: Nursing Consultation, and Nursing Case Management/Delegation.

The regulatory bodies affecting Nursing Support Services include but are not limited to:

- **Maryland Nurse Practice Act (MBON) COMAR 10.09 & 10.27**
  Standards for Nursing Practice and Nursing Delegation
- ***DDA Regulations COMAR 10.22***
  Historically written for DDA licensed provider agency programs
- **Occupational Safety Health Act (OSHA) Regulations**
  Applies to licensed settings such as DDA licensed provider agency programs
- **Office of Health Care Quality (OHCQ)**
  Applies to licensed settings such as DDA licensed provider agency programs

The Issue:
Individuals self-directing their services and their families will tell you they experience some of these regulations as restrictive, inflexible, and not person-centered, thus creating barriers to community inclusion. It appears these regulations do not take into account the unique setting of self-directed services where the individual is the employer, Nursing Support Services are contracted and delivered in the individual's home, and the individual's home is not a DDA licensed provider agency. We agree regulations are necessary to maintain the health and safety of all individuals, but they should be applicable to the setting and needs of the participant.

Recommendations:
We recommend the Maryland Department of Health convene a workgroup to examine the current MBON and DDA regulations and policies, including the curriculum for Certified Medical Technicians (MTTP), to determine the impact on participants who self-direct their supports. Recommendations for regulatory and policy changes will be made to the legislature, MBON, and DDA.

Workgroup Goals:

- Develop recommendations allowing maximum flexibility and control of one's services, while maintaining health and safety standards and full community participation.
- MDH/DDA to assure the capacity of DDA-approved Registered Nurse Case Managers to meet the needs of participants in Self-Direction.
- MDH/DDA to assure the availability and accessibility of Certified Medication Training (MTTP) for staff working for individuals who self-direct.

- MDH/DDA to assure the MTTP curriculum does not solely focus on Nursing Supports in traditional agency-based services but accurately and positively represents Nursing Support Services in Self-Directed Services.
- MDH/DDA to assure the ongoing nursing education currently provided to DDA-approved Registered Nurses include application of Nursing Support Services in Self-Direction and not solely those focused on traditional agency-based settings.

The workgroup should consist of a minimum of:

- three individuals who self-direct their DDA services and who have received Nursing Support Services for three or more years
- three nurses who have provided Nursing Support Services for five or more years to people who self-direct
- A representative from the DD Coalition
- A representative from Disability Rights Maryland
- Applicable state agency representatives