SB868_AdrianKorzeniewicz_fav.pdf

Uploaded by: Adrian Korzeniewicz

Position: FAV

SB868
Adrian Korzeniewicz
Maryland Down Syndrome Advocacy Coalition
Favorable

I strongly support SB868, the Self-direction Act.

I receive Medicaid waiver services through a self-directed program. This means I have the ability to determine my life: I determine my direction, I choose goals and motivations, I choose my ambitions, and who I love, where I live, where I work, how I spend my time.

Just like you.

I believe self-determination is benifical for individuals with disabilities to be fully included in making all their choices. If you are not at the table, then you are not making choices for yourself. Individuals with disabilities can tell their team what they need and what they want. We want to be self-determined, to be at the table, to take leadership of our lives.

With Self-directed services, I have a team that includes my support broker, the Coordinator of Community Services, an Advocate, Job coaches, mentors, and my Supervisor at work (sometimes). With these people on my team, I can be fully included in a leadership role. This means I can choose how I plan to use my services, I can develop goals I want to see achieved, and I can understand what needs to be improved.

I develop my plan by doing these four things.

1. Going over the budget
2. Reflecting on last year's goals
3. Tweaking last year's plan to create a new plan
4. And adding new goals when necessary.

My self-directed budget provides job coaching, developing independence, and other employment and community skills. My services allow me to be involved in the community with peers with and without disabilities, to stay fit and to be healthy, and to use public transportation so I can be more independent in the community.

I strongly feel that individuals with disabilities should have the same right to self-determination as anybody else– because they have a voice that says "Let me do it. I have the ability. I have the voice. Support me but let me lead."

Equality and Accessiblity 03082022 - Alarice Vidal

Uploaded by: Alarice Vidale de Palacios
Position: FAV

Tuesday, March 8, 2022

Consulta Life Coaching and Support Brokerage
2 Wisconsin Circle, #700
Chevy Chase, Maryland 20815

Distinguished Ladies and Gentlemen:

My name is Alarice Vidale the Palacios

- I am certified support broker
- I have 7 years' experience providing services to adults and their families in self direction
- I am the parent of a specially enabled individual, who is a participant in DDA's self-directed waiver.

My agency, Consulta has represented and advocated for over 100 families and their stakeholders in Self Direction. Consulta currently provides active brokerage service to 60 participants, their family members and their support providers. Consulta has active cases in all four (4) regions where DDA has offices.

Since our inception, our business niche has been to represent families whose origins were not of the United Stated. This is because, I being an Afro-Latina, of Caribbean descent by way of South America, understand the challenges faced when attempting to access forms of social services.

Here we are, years later and the result is; we are a solid organization that represent many individuals with multicultural backgrounds and varying degrees of financial status. Over the last three years we've have observed increasing variation in the self-directed service delivery model.

Specifically access of services by individuals and their families of cultural and racial groups. The lack of access we noted were simple barriers:

1) lack of information or inconsistencies in the information provided.
2) poor follow up to waiver questions, discouraging responses to families seeking hope
3) lack of qualified DDA agents (CCS), who failed to thoroughly understand the programs
4) straight deterrence in the form of steering families away from self-directed services
5) Language - the universal connector - although DDA has translation services many families still miss an opportunity to connect because the DDA agent (CCS) does not access the translation services in order to take a 15 minute conversation and share the services with the family.

The aforementioned, is mild compared to what we have been witnessing recently. Consulta has had several cases where the families have been approved for self-directed services and the funding package has taken months to be received by the fiscal management service. The most recent case of this involved a family from Pakistan whose package was approved in October 2021, however their funding package was not loaded until January 25, 2022.

Equality and the accessibility of services are further driven apart by the functionality of the DDA regional offices (WMRO, SMRO, ERO, CMRO), which all fail to have a minimum standard of cohesive operation. Simply put each regional office oscillates in a different direction resulting in prolonged access or even denial of services to qualified individuals.

My agency has done the work. We can provide the numbers and if you were to ask, we would be able to provide you with the names. In the state of Maryland families, government officials and communities on a whole, must continue to strive for families to be able to access information about all DDA waivers and services. We must continue to strive to be certain that all regional offices of DDA are aligned and are providing equal services. We must strive to create an eligibility and verification process that does not hinder or injects large amounts of time into a participant's plan and budget. Such uncoordinated practices result in high denial of services to the prospect who is in dire needs of these services.

DDA, as an organization needs to define a strategy which will allow for equal accessibility and diversity support for all families.

Respectfully,

Alarice R.A. Vidale de Palacios (her, she)
Executive Broker and Certified Victim's Advocate
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(888) 339-3556 (24-hour line and fax)
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March 7, 2022

Senator Pamela Beidle

Senate Finance Committee

SB 868- Developmental Disabilities Administration – Self–Directed Services (Self–Direction Act of 2022)

Position: Favorable

I, Alexandra Hunter, Family member and Advocate for my sister-in-law, a SD participant, would like to register my support for SB868.

To restore and maintain flexibility and access to Self-Direction while retaining cost savings.

Self-Direction is an evolving program with changing needs as families and DDA figure out what services are needed to meet the Participants daily needs. Self-Direction has changed over the last 6-7 years by DDA eliminating and/or not approving certain services even though they are allowed in traditional services. The emerging need of Operation/ House Manager positions that have already been proven as a need in traditional services, should be accessible to the SD participant as well. For example, The ARC, Bello Machre and other Provider Agencies are allowed to have the aforementioned position, it is equally important to have it available to the SD Participants to ensure their daily needs are met as well. It will not be an additional cost and would remove a mountain of stress caused to the participants and their families.

Family members should not be tasked to handle staff call-outs, schedule changes, times-sheets and mileage sheet processing, ensuring hiring and termination paperwork is completed correctly before they have to send it to the FMS, (just to name a few tasks), while they are at their own 40-hour jobs. If the government (DDA) makes Family members assume the mentioned tasks than the family member should have the option to be paid staff; especially since Family members have full time or part time jobs to support themselves to pay their rent or mortgage and other living expenses. That is one of the many reasons “The Self- Direction Services Act of 2022” (HB1020/SB868) is so important to pass, it would allow the employer authority flexibility to adjust staffing needs as well as restore Support Broker roles.

Please vote to recommend passage of this bill out of committee. As a family member of someone with a developmental disability and who is a SD Participant, I ask for your uncompromising support of our loved ones right to choose the types and intensity of supports and services they receive, so that they have control over how they want to live their own life.

Thank you!

Alexandra Hunter

SB868testimony2022.pdf

Uploaded by: Alicia Wopat

Position: FAV

Support of SB868
The Self Direction Act of 2022

My heartfelt thanks to you for your attention to this bill.
My name is Alicia Wopat. I am a member of the work group, on the SDAN board and proud parent of a self-direction participant.

This bill seeks a return to the flexible and person-centered Self Direction program envisioned when MD created it in 2005. It seeks to provide equity by codifying policies and allowing additional CMS approved services. It will allow families to set up a program for when they are unable to provide gratis services for their adult children.

DDA tells us that an approved budget for a participant using the DDA formula is earmarked for that individual for the fiscal year.

BUT some of these dollars cannot be accessed due to arbitrary caps or a choice to exclude needed CMS waiver services. This bill seeks to allow ACCESSS NOT MORE MONEY.

There is nothing new in this bill. Nothing that advocates and stakeholders haven't told the administration time after time and for years.

MDH had a seat at the table during the House Summer Study. The chair expressed her desire to resolve the issues. At the conclusion, MDH expressed appreciation of the opportunity to continue to work together. No resolutions. It is interesting to note that there were no MDH objections to the recommendations of the summer study which formed the basis of this bill.

You may hear from MDH that they have agreed to some of the items the bill seeks. That isn't wrong and we are grateful. These concessions have come after years of advocacy and many policies we appeared to win came back in the following year or with a new policy clarification. This bill codifies important policies and services important to the people who self-direct and protects them through future administrations because we have seen what has been given can be taken away. In other words, we had it, we lost it and we need it back.
Highlight of two items in the bill:

Missing Services Right now, many parents and siblings of self-direction participants assume an unpaid role of manager, i.e., making sure staff are scheduled and hiring substitutes when needed, or being the substitute themselves.

They also have responsibility for the home where the individual lives. For example, ensuring bills are paid, that the home has the needed supplies, that medical and other necessary appointments are made and kept, etc.

When families are no longer able to provide these supports gratis; this bill ensures the ability of the individual to hire staff to provide these supports out of the program funding that is earmarked for them. Again, access not additional cost.

I am not alone in having a recurring nightmare that my son, who needs 24/7 care won't be truly cared for. Perhaps it is hard for everyone to relate to having a child with intellectual and/or developmental disabilities but we all have parents and can imagine what would happen to them in their most frail moments…what would they do without someone to ensure their needs are met?

This same provision/service would also allow the funds to pay for administrative supports, such as office equipment or the internet, so the individual can communicate with his CCS and/or support broker and maintain online connections to their community.

Transparency
Close to 10% of the plans and budgets haven't yet been approved for the fiscal year.
We hear from our membership that one of the reasons for these delays is that the participant is left out of the process after signing the plan.

Participants have no mechanism to see if the plan was submitted or received by DDA, They cannot see if there were questions, or if those questions were answered in a timely and correct manner. In other words, the person at the center of plan is left in the dark not knowing the source the delay.

This bill stipulates transparency through access to the tracking system the administration uses and fits into Governor Hogan's commitment to transparency.

I humbly ask for your favorable vote.

Alicia M. Wopat
SDAN Board Member
Proud parent of an adult in the self-direction program

SB868(1).pdf

Uploaded by: Beth Wiseman

Position: FAV

TESTIMONY IN FAVOR OF SENATE BILL 868

Developmental Disabilities Administration – Self-Directed Services

(Self-Direction Act of 2022)

As an advocate for seniors and people with a disability, this Bill had special significance to me, not as an advocate, but personally.

Two people in my family had problems with their sons. Both wanted to keep their sons at home to care for them and protect them, regardless of the advice they were given.

One mother finally succumbed to the pressure and let her son, now 35, be placed. He is a highly productive person, achieving what his mother could never have predicted.

The other son is still at home, now 45, completely non-productive, completely non-functional, and costing taxpayers money.

It is easy to see how beneficial, strengthening this program will be.

I trust you will agree and give this Bill a favorable vote.

Thank you.

Beth Wiseman

1216 Glenback Avenue

Pikesville, Maryland 21208

410-484-6866

SB868_caseyhuether_fav.pdf
Uploaded by: Catherine Huether
Position: FAV

March 7, 2022

Senator Justin Ready
Senate Finance Committee
SB 868- Developmental Disabilities Administration – Self–Directed Services (Self–Direction Act of 2022)

Position: Favorable

I would like to register my support for HB1020/SB868.

This bill has three simple goals. It gives greater equity and access to appropriate services for self directed participants, restores flexibility that was taken away by DDA and presumes competence of the individuals who the program is designed to serve. Everything in this bill complies with CMS rules/regulations ensuring the federal match. Current DDA policies forfeit matching funds unnecessarily. There is no additional cost to the state or county required by passage of this bill.

We have a team that supports my daughter in her decisions on what she needs and how to spend her budget for services to meet those needs. I've helped her hire staff who take her shopping, out to exercise, visit with friends and volunteer for meals on wheels delivery. She has plans to get a job once we know it's really safe from Covid. She's working hard to become more independent because I will not be around forever. It comforts me to know her support system will be set when I'm gone.

Please vote to recommend passage of this bill out of committee. As the mother of someone with a developmental disability, I ask for your uncompromising support of her right to choose the types and intensity of supports and services she receives, so that she has control over how she wants to live her own life, just like the rest of us.

Thank you,

Casey Huether

SB0868_Self–Direction_Act_MLC_FAV.pdf

Uploaded by: Cecilia Plante

Position: FAV

MARYLAND
LEGISLATIVE
COALITION

TESTIMONY FOR SB0868
Developmental Disabilities Administration – Self–Directed Services (Self–Direction Act of 2022)

Bill Sponsor: Senator Lee
Committee: Finance
Organization Submitting: Maryland Legislative Coalition
Person Submitting: Cecilia Plante, co-chair
Position: FAVORABLE

I am submitting this testimony in favor of SB0868 on behalf of the Maryland Legislative Coalition. The Maryland Legislative Coalition is an association of activists - individuals and grassroots groups in every district in the state. We are unpaid citizen lobbyists and our Coalition supports well over 30,000 members.

There are groups of people in Maryland who are not truly in control of their own lives. For anyone who is not able to control their own independence, we have facilities and personnel who do that for them. But, even with the best intentions in the world (which some have and others do not), we cannot adequately determine what is best for another person. This is especially true for those individuals with Intellectual/Developmental Disabilities.

The goal for those individuals should always be to allow them to become independent members of society. The more choices that they are able to make, and the more control they have over their own lives, the more integrated they can be in society. This bill attempts to bring back to the Self-direction waiver the goal of independence.

Self-direction allows individuals with Intellectual/Developmental Disabilities choice and control over their Medicaid waiver services, including choosing the staff that support them (employer authority) and deciding how their budget will be spent (budget authority) so that they can tailor their daily activities to meet their own needs and interests, rather than receiving services from an agency which determines their schedules and activities. Since 2005 when Maryland instituted its first Self-direction waiver, individual choice, control, and flexibility have been whittled down. This bill seeks to reinstate the lost equity and flexibility in Self Direction and to ensure that all people are eligible for self-direction with supports if needed. For example, it requires better training for case managers, reinstates self-directed overnight supports (which have been taken away), and removes competency requirements in favor of team support.

Our members believe that everyone should be able to control their own lives – not have them controlled by others. We strongly support this bill and recommend a **FAVORABLE** report in committee.

SB868-jacksonc-fav.pdf

Uploaded by: COLETTE JACKSON

Position: FAV

March 7, 2022

Senate Finance Committee
SB 868- Developmental Disabilities Administration – Self–Directed Services (Self–Direction Act of 2022)

and

Health and Government Operations Committee
HB 1020- Developmental Disabilities Administration – Self–Directed Services (Self–Direction Act of 2022)

Position: Favorable

I would like to register our support for HB1020/SB868.

My Regina has a developmental disability and has been in DDA services since 2004. She has been in the Self-Directed Services program since 2007. I support all of those items proposed:

1. Case managers (CCS-es) will be better trained in self-direction and will fully orient new and current participants about self-direction annually (PCP).
2. Reinstate Support Broker roles and increase hours available where needed.
3. Reinstate Self-Directed Overnight Supports (this waiver service removed in 2018)
4. No Prohibition to Having Family as Staff per CMS rules
5. Transparency in Person Centered Planning (PCP) – ability to track
6. Mileage Reimbursement for Specialized Vehicles
7. Remove Competency Requirements in Favor of Team Support
8. Parity in Budgets/Services – SD doesn't have all needed services
9. Individual Family Directed Goods & Services (IFDGS) to be more flexible per needs
10. Progress Report to Legislature Annually – 3 years

Please vote to recommend passage of this bill out of committee. As a family member of someone with a developmental disability, I ask for your uncompromising support of our right to choose the types and intensity of supports and services we receive, so that we have control over how we want to live our own lives.

Thank you!

Colette Jackson
Proud Mom of Regina Maria Jackson
Registered Voter
9202 Old Frederick Road, Ellicott City, MD 21042
Howard County, Maryland
Email Address: Peace4all515@yahoo.com

Regina Maria Jackson, SDS Participant

CHL Testimony Senate.pdf

Uploaded by: Genevieve Houston-Ludlam
Position: FAV

Finance Committee

SB868- Developmental Disabilities Administration – Self–Directed Services (Self–Direction Act of 2022)

Position: Favorable

My husband Mark, my daughter Carmen and I would like to register our support for HB1020/SB868.

Meet Carmen Houston-Ludlam, a 24 year-old young lady with Down Syndrome. Carmen has been self-directing her services since she transitioned from school-based services to adult services in 2019.

Carmen is a swimmer, a cheerleader, a ballroom dancer, a snowboarder, a fashionista, a ventriloquist and a ukulele player. She has a job at MOD Pizza in Dunkirk, MD which she loves. And they love her. She is able to live her full, fabulous life because she is able to tailor her services to her individual needs and desires through the self-direction option for HCBS services in Maryland. The same kind of flexible and tailor-made life that YOU are able to choose for yourselves.

What's more, self-direction is cost effective. Carmen only uses about 65% of her allocated budget- the amount that a provider would charge to provide more rigid, one-size-fits-all services to her.

Unfortunately, the DDA has been systematically reducing flexibility in self-directed services since 2016. The Self-Direction Act of 2022 codifies and protects certain freedoms and flexibilities that should be there- freedoms and flexibilities that are completely consistent with CMS rules and which provide excellent services to people with I/DD while maintaining cost savings to the State of Maryland. There are three provisions in the bill that are especially important to Carmen and her family.

1. ***The removal of competency Requirements in Favor of Team Support.*** We are believers in a trusted team surrounding Carmen to make sure that she is able to live her best life. This approach is really how we all live- we all have accountants, lawyers, tax preparers, investment advisors, etc. to help us make decisions. Why should someone with an intellectual disability be forced to give up all their decisionmaking ability because they can't independently do all those things? And this approach is also more sustainable, given that so many caregivers for people with I/DD are aging and won't be around forever. We need to jettison the entire concept of "competency" from DDA policies and instead be consistent with current thinking regarding disability rights, which is allowing the individual with I/DD make decisions about their life with the support of a trusted team.
2. ***No Prohibition to Having Family as Staff***. If we have learned anything from the COVID-19 pandemic, it is that the lives of people with I/DD are particularly susceptible to upset when things go south. When Carmen's staff person was not able to come into our house to support Carmen, guess who stepped up to the plate? Her family. This happened in households all over the State. Some people had to quit their jobs to support their loved ones with I/DD. Having a permanent understanding of the important roles that Family plays in supporting people with I/DD is critical. We are always the staff of last resort- let's celebrate that instead of trying to stamp it out!! This has been a constant fight with the DDA for years.
3. ***Reinstate Support Broker Roles and increase hours where needed***. I have already expressed how important having Family available to support Carmen is, but what happens when we are no longer around to advocate for/with her? We need to be able to access people who understand the

rules and regulations surrounding Self-directed Medicaid Waiver Services, and that person is the Support Broker. Right now, because mama-bear is around, we don't even use the 4 hours of Support Broker services that we have allocated in her plan. Once family support isn't around, she will need more than 4 hours to make sure all the paperwork is done, and done properly. Some people with intense needs have been flatly denied any more than 4 hours. This service needs to be allocated on an as-needed basis, not an artificial cap of 4 hours. And once family support is not there, we can't have people with I/DD having to fight the DDA to get what they legitimately need. Please raise the cap of "argument-free" hours to cover what is needed by so many people.

Here is the bottom line:

- **NOTHING in this bill causes the state to lose federal matching dollars.**
- **EVERYTHING in this bill complies with CMS rules/regulations ensuring federal match.**
- **Policy changes can be addressed with current allocations - no increase in cost.**
- **SD services are generally less expensive than traditional provider managed services.**

Our family has watched in frustration as the past two attempts to codify these freedoms into law were torpedoed by ridiculous fiscal notes provided by Maryland Department of Health. Please don't let the MDH fool you- they are using big, frightening, UNSUPPORTED numbers to avoid legislative oversight. They have succeeded twice. Don't let them get away with it!!

Please vote to recommend passage of this bill out of committee. Let Carmen and those like her live her best life- a life of her choosing- while saving the State of Maryland money.

Genevieve Houston-Ludlam, Ph.D.

SB868_heathernewcomb_fav.pdf

Uploaded by: heather newcomb

Position: FAV

SB868 The Self Direction ACT

Heather Newcomb
Favorable

Maryland Senate,

I am reaching out to you to encourage you to vote in support of SB868/HB1020 The Self-Directed Services Act of 2022. If passed this act will maintain and restore support services to individuals with intellectual and developmental disabilities that are tailored to meet their needs, like my daughter Hanna. The Self-Directed Services Act allows participants to have choice and control over their Medicaid waiver services and how their budget is spent while fully adhering to all applicable laws and rules/regulations set forth by CMS.

The Self-Directed Services Act personally helps, my daughter Hanna, maintain the flexibility of allowing her to continue to choose family as staff to supply her support services. This flexibility of staff choice is crucial for her due to her profound disabilities and medical fragility. Another reason this act is so important to us is that it restores the reinstatement of the Self-Directed Overnight Support Service. This support service was removed from the waiver in 2018. The Overnight Support Service is essential for the health and safety of the participants who meet the need for this service.

It has taken me years to navigate and advocate for services for my daughter. Having services available that are flexible and can be tailored to meet the needs of the participant result in a more positive outcome. The Self-Directed Service Act of 2022 supports this flexibility, and in most cases, provides a less expensive outcome for the state of Maryland.

Passing HB1020/SB868 The Self-Directed Services Act of 2022 helps all Maryland intellectual and developmentally disabled persons who choose to self direct their services.

Sincerely,
Heather Newcomb for participant Hanna Newcomb

SB868_jameycohen_fav.pdf

Uploaded by: Jamey Cohen

Position: FAV

March 7, 2022

Senate Finance Committee
SB 868- Developmental Disabilities Administration – Self–Directed Services (Self–Direction Act of 2022)

Position: Favorable

We would like to register our support for SB868. While all of the stipulations in the bill are important, we would like to emphasize two of the stipulations that we feel are most critical. They are: 1) No prohibition to having family as staff per CMS rules, and 2) Remove competency requirements in favor of team support.

It would be a travesty to not allow parents (and other family members) to be hired as staff. Simply put, the family are the individuals that care most about the participant's happiness and wellbeing. They are also the individuals who know the participants the best and understand their needs, wishes, and health conditions.

We are the parents of Caden Cohen, 21, who is profoundly autistic and is completely non-verbal. He also has epilepsy and thus suffers from seizures. We can communicate with him and understand him better than anyone else. We can also identify signs that a seizure may be occurring and act promptly to keep him safe.

There are so many sacrifices involved in raising and caring for children with disabilities. And with adult children that have aged out of their school program, parents often find the available adult programs to be substandard. In order to provide the highest level of care that their children deserve, parents often have to give up their career to provide these services themselves. It would be unjust to not allow parents (and other family members) to be hired as staff.

Regarding the competency stipulation, it would add an unnecessary and unjust burden to require a competency requirement of the self-directed participant. In many cases, like ours, our son is unable to make his own decisions due to his level of ability and thus 'prove competency'. It should be up to his parents and his support team to decide if the self-directed program is appropriate.

Thank you for considering our testimony and please vote to recommend passage of this bill out of committee.

Very respectfully,

Jamey Cohen

Stacey L. Cohen

Jamey and Stacey Cohen

SB 868_jeanweller_fav.pdf

Uploaded by: Jean Weller

Position: FAV

IN SUPPORT OF SB 868 The Self Direction Act of 2022
Written Testimony by Jean J. Weller

Favorable

My son Paul Weller has been a participant in Self-Directed Services since its inception. He was born premature and injured at birth by an incompetent 1st year Resident. He was diagnosed with multiple disabilities including Cerebral Palsy(x4), Cortical Visual Impairment, Mild Intellectual challenges, and Auditory Processing difficulties. He is now 39 years old, very verbal, and uses a power wheelchair to get around. He developed Type I Diabetes in 2006 and has REM nursing 12 hours/day because he is not able to manage his Insulin Pump or care for himself physically. Still, he loves to go out into the Community every day and wants to entertain people by telling Jokes. However, Paul has an anxiety disorder which can become acute in crowded areas where there are a lot of children. If he goes to the Mall, he needs to sit in a quiet area. He needs Personal Support to manage his Diabetes diet for his meals, drive him to his various Dr.'s appointments and therapies and outings, and to be there for Personal Care when one of our nurses doesn't show up which happens fairly often. There is no duplication of services.

Paul takes PT every week and Counseling. He goes to Spirit Club, where his exercises his upper extremities to increase his strength in using his walker. He and his nurse and his Direct Support Professional shop for groceries every week. Paul volunteers a few hours a week at his Support Broker's office preparing folders, making the coffee, and shredding documents but then, again not where there are crowds or noisy children. He also loves to go to church. (see attached profile of Paul)! When DDA created the new Waiver in 2020, it decided that it would **no longer reimburse** Self-Directed Service participants for their mileage used during their approved daily activities **if** they used their medically necessary personal accessible vans owned by their parents!

Participants like Paul cannot safely ride in standard vehicles because they require the seating assistance of a specially designed wheelchair which requires an accessible van often purchased by the families at great expense. However, DDA will reimburse an employee who uses his or her own vehicle to transport those SDS participants who do not require accessible vans for Transportation! This is discrimination against those participants who have more physical challenges because they need accessible transportation. Of course, DDA provides accessible transportation for all participants in their Traditional Group facilities.

DDA was very unresponsive to questions about those in SDS who needed accessible transportation. They have refused to allow transportation funds to be allocated to reimburse parents even when it was medically necessary for the participant's safety and well-being. DDA tried to force applicants for new Fiscal Management Services to agree that they would evaluate participants to see if they were "competent enough" to be able to "self-direct", suggesting that a participant with fewer intellectual abilities might be excluded from Self-Directed Services. Not one FMS applicant was willing to evaluate participants. DDA has proven that it has no understanding of Self-Directed Services' main premise that "all participants can be successful in Self-Direction if they are provided with the necessary supports."

Please pass HB 1020 out of Committee, so DDA cannot continue to reduce the choices and services that Self-Directed Services was created to provide for the best Self-Determination that all persons with Intellectual and Developmental Disabilities deserve.

SDAN
Self-Directed Advocacy Network of Maryland, Inc.

I Support SB 868

The Self-Direction Act of 2022

Hi! My name is Paul Weller. I am 39 yrs. old and I live with my Mom and our two dogs. I have been in Self-Directed Services since 2006. Since I have many physical challenges and need lots of supports, I wanted to live with my Mom and Dad (d. 2016) and be able to choose who will be my Support Personnel and decide how I want to spend my days. Having Diabetes and not being able to give myself insulin made it necessary to have a Nurse as well to care for those needs and to help me stay healthy. I need more hours for my Support Broker when we need to hire new Employees. He helps me a lot in my program.

Choice and Control Matter
Matter to Me!

My interview with the Baltimore Sun about my Fused Glass art

Self-Direction is important to me because…
It's My Life.

I have had many exciting experiences in Self-Directed Services. In 2010, I began making Fused Glass with the help of my Personal Support Staff. I love to be creative! I participated in Musicals as a part of "New Horizons", a Community Theater Group for adults with disabilities. Recently, I began an exercise program at "Spirit Club". I am learning to tell jokes and want to entertain people and make them laugh. I tell one joke every Sunday evening at our church Fellowship on Zoom. So far they are a "Hit".

DDA decided two years ago that they would no longer reimburse Mileage for those who have to ride in an Accessible Van, due to their physical disabilities. They continue to try to limit the services and activities, even though SDS is the most cost-effective program in DDA. I love my Support Broker, but we rarely get together because DDA will only let him work 4 hours /month.

Support the Self-Direction Act of 2022

Paul M. Weller
10869 Hilltop Lane
Columbia, MD 21044
443-812-5030

SB0868_JenevaStone_fav.pdf

Uploaded by: Jeneva Stone

Position: FAV

Jeneva Stone: 4415 Highland Ave., Bethesda MD 20814 (D-16)
Testimony on SB0868, Senate Finance Committee **(favorable)**

I am urging you to pass SB0868 out of committee with a favorable rating. I am the parent of Robert Stone, a self-directed participant in Montgomery County. **Rob has complex medical needs, so self-direction was the only program that truly allowed him the full community access he deserves**.

Rob transitioned from high school wanting to be an advocate, an artist, and a writer. I am proud to say he has achieved all three of those goals! He has his own website, has testified multiple times in Annapolis on disability rights issues, and has been active with health care issues at the federal level through his work with Little Lobbyists, a family-led organization advocating for the health care of children with complex medical needs & disabilities.

I am 57 years old, and Rob's dad (my husband) is 60. Rob depends on self-direction's flexibility and commitment to choice. **However, self-direction is still subject to the DDA's internal rulemaking authority**. I have worked with the DDA on Rob's services since 2005 (when Rob had an ISS grant), and **my family has surfed through over 16 years of rules and services changed by the DDA with little or no notice**.

These rule changes have affected Rob's ability to purchase equipment, hire certain types of staff, and have access to his community. **The DDA makes internal rule changes with little input from the community it serves. We then have to go through the onerous process of speaking through our children's case manager intermediaries (CCS)**, providing more documentation (often previously provided), and making yet another argument for our child's right to certain services. In many cases, these requests are denied.

As I said, I'm 57 now, and I can, for the time being, continue to fight these **basic service battles** with Rob, but at some point, I will not.

If you pass SB0868, and it becomes law this session, Rob will be able to count on basic parameters in self-direction without my having to intervene. The DDA will have no choice because these will become law, no longer subject to their internal processes.

Our community needs certainty and predictability in self-direction. We need better training for the CCS.

Furthermore, the number of people choosing self-direction is increasing exponentially with every passing year. I advocate with 4 different disability organizations, and have a seat on 2 commissions that deal with disability-related issues. As I have become more visible, friends and friends of friends are contacting me regularly—either wanting to know more about how to do self-direction or to check with me to see if what their child's case managers (CCS) are telling them is accurate. **So, clearly, better training on self-direction for CCS is important!** And that is in this bill.

All of these new self-directed participants need certainty and predictability as well. In a recent public meeting, I heard an MCPS official say that about 1/3 of transitioning youth are those with complex medical needs—and that group has been choosing self-direction more and more because many traditional providers are not open to them. **Recent estimates of self-directed participants in Montgomery County show that the program has increased by up to 20% or more over the last few years**.

As I speak to parents of those who choose self-direction, I am hearing that this is related to the family's wishes to ensure that their children remain members of their communities, pursuing their own passions. Self-direction is what opens doors for many of those with I/DD.

You can look at it this way: **The success of the federal IDEA has raised expectations about what those with I/DD can do after school ends. Maryland's services for those with I/DD need to keep apace of what our community wants. The DDA has to balance too many competing factors to ever guarantee certainty and predictability in self-direction. It's time for the legislature to ensure that our families have that going forward**.

Thank you.

SB0868_LISA COHEN_FAV.pdf
Uploaded by: Lisa Cohen
Position: FAV

STATEMENT FOR THE RECORD BY LISA COHEN

IN SUPPORT OF (FAVORABLE)

SB0868 – THE SELF DIRECTION ACT

My name is Lisa Cohen and I am writing in support of The Self Direction Act - HB1020 & SB0868. I am requesting favorable consideration of this legislation.

By way of introduction, I am the mother of three children and currently reside with my husband in Montgomery County. I am a lifelong Marylander and my family on both sides has lived in Maryland for generations. I am writing on behalf of my 24-year-old son Michael.

Michael is severely handicapped. His diagnosis is very complex and includes: intellectual disability, chromosomal anomaly, seizure disorder, sleep disorder, cerebral cortical dysgenesis, spastic quadriplegic cerebral palsy and speech/language impairment. Put simply, Michael's is unable to walk, talk or provide for himself in any way. He is 100% dependent on support from a caregiver in order to eat, bath, move, and toilet. He experiences seizures and currently takes 4 anti-seizure medications twice daily. Over the past few years, Michael's overall seizure activity has increased. His gran mal seizures can occur with little or no warning through-out the day as well as during overnight hours while sleeping. During seizures Michael's breathing often becomes interrupted causing cyanosis and requiring airway maintenance. Michael has a fifth emergency medication to use when he has more than three seizures in a day or when he stops breathing and becomes cyanotic

Early on, my husband and I decided that Michael would remain at home with us. We have committed our lives to providing him a loving and caring home so that despite the pain and difficulty he experiences each day he knows that he is in a safe place with people who love him. While we are convinced, we made the right decision, it has been a difficult journey for our entire family. There is no part of our lives that hasn't been impacted - we haven't been able to take family vacations, we have lived with medical emergencies and we have made professional sacrifices.

We are lucky to live in Montgomery County. Until his 21st birthday, Michael spent his weekdays in a school-based program managed by the Montgomery County Public School System. Notwithstanding the love and care he received daily from the teachers and aides during those weekdays, it was up to us to either pay out of pocket for or provide in home care when he was not in school. After he turned 21, we selected the self-directed program through Maryland Developmental Disabilities Administration (DDA). We choose this route because as we considered facility-based day programs I found my visits to those programs usually resulted in my crying after the visit. Seeing the conditions of many of these facilities - places where the most vulnerable of our society spend their days reduced me to tears and strengthened my resolve that we would find a way to keep Michael at home and create opportunities that enable him to experience community learning. We know that there are many other families in Maryland taking a similar journey - families that are willing to sacrifice much to experience a brief smile or a hug from a child who didn't ask to be born with disabilities or life altering medical conditions. I hope that as you consider and debate this Bill, you do so thinking about these families, who despite the tremendous support of the wonderful people at DDA, struggle each day simply just to keep their heads above water.

One provision of this Bill that I ask for you to support is that pertaining to overnight personal support. For years we have tried to get respite care and overnight support so we could get a night’s sleep or take a few days of vacation with our other children. It simply hasn't been available. For years we took Michael with us on vacation. But now - his medical situation does not allow for that. Currently, we care for Michael overnight. My husband John and I have slept with a baby monitor for twenty-four years. Most nights, Michael will make noises, awaken, need to be re-positioned or he can even have seizures. Some nights he wakes up hungry and needs to be fed and other nights he will require toileting or he will urinate in his bed. There have been occasions where we are awakened by him having a seizure and in those instances, we need to run to his room to care for him. I can't begin to explain the level of exhaustion that we feel. We have had to raise our other children and work while never getting a good night’s sleep. Michael has always had erratic sleep patterns. Having night-time personal support would change our lives particularly as we age. My husband turned 60 and I just turned 57.

Facilitating family as staff is another important aspect of this Bill. Michael receives Community Learning and Personal Support services from the Maryland Developmental Disabilities Administration as part of the Self-Directed Program. And while we are grateful for the support provided by the program, it still falls on my husband and I to provide considerable care for Michael during parts of the day and all nighttime hours. My husband works full-time and also provides care to Michael. So in addition to being his loving parents, we are also his staff. Currently, there is ambiguity regarding whether family members can serve as staff. The ambiguity has resulted in inconsistent guidance from support brokers and even DDA. The section of this Bill that clearly states that family members can serve as staff, would end confusion, simplify the process and allow families who are doing the work for their adult children to be compensated.

Being the parents of a severely disabled child has been a long and difficult road for our family and we have worked very hard to keep our family intact. We realize there will be those who say that these are simply the cards that have been dealt and it is our responsibility to care for our child - or that this isn't an issue that impacts a majority of Marylanders. To those people I say this. While I may just be a Mom living in this great state, I have always been taught and have always believed that the role of government is to protect all of society - and that includes our most vulnerable who didn't choose or ask to be born with their disability or medical condition. There are too many families in this state that are struggling on this journey alone. The provisions of this Bill may seem to some unnecessary or insignificant, but to Michael and others like him, they can be life changing.

We love Michael very much and want him to remain in the self-directed program so that we can ensure he lives his best life. We are asking for your support of this Bill which will help make that a reality.

Thank you for your consideration,

Lisa Cohen

SB 868- Hollander Fav.pdf

Uploaded by: Marla Hollander
Position: FAV

Senate Finance Committee
SB 868- Developmental Disabilities Administration – Self–Directed Services (Self–Direction Act of 2022)

Favorable Support for HB1020/SB868.

Self-direction allows an individual with intellectual/developmental disabilities, like our son Ben, have choice and control of their Medicaid waiver services, including choosing the staff that supports them and how their budget is spent so their daily activities meet their own needs and interests. We submit this testimony on behalf of Ben who is a non-verbal 17-year old with autism, intellectual disability and seizure disorder.

Ben, with our support, has recently moved from the DDA traditional service model to self-direction under the family supports waiver. We moved to self-direction because we were not able to secure supports from traditional venders for more than 2 years. Traditional providers didn't have staff or interest in supporting Ben. We were approved for self-direction this January and Ben has been able hire 2 amazing staff who get Ben. Ben's staff provide amazing support that is driven by Ben's unique needs. Just as important, as we learned more about self-direction, we are relieved that Ben, with the support of his team now has the opportunity to make choices on how he lives his life. However, as you look under the hood of Maryland's self-direction model there are many aspects that need to be fixed. Many of which are addressed in HB1020/SB868. For instance, for several years, there has not been the ability for self-directed clients to access overnight supports – with the only option for people who need overnight supports is to be in a traditional group home model which limits choice. While Ben and other young adults with disabilities don't need overnight supports now, they will most certainly need them when their primary caregivers (their parents) have died. While DDA recently announced – just a few days ago on 3/4/22 – that the Maryland Department of Health has agreed to add overnight supports as a component of personal supports under self-direction, the announcement is not a guarantee that these supports will be available in perpetuity. The Department of Health has taken away this support and others in the past. As such, it is extremely important that these foundational supports be documented in legislation and cannot be changed by new administrative leadership in the future. Ben and other self-directed individuals should be able to continue to have guaranteed choice and control over their Medicaid waiver services as is the case in many other states. IHB1020/SB868 – the Self Directed Services Act, addresses this and many of other existing problems with how self-directed services are currently administered in Maryland.

Lastly, this legislation does not come with a price tag. It is cost neutral.

As family members of someone with a developmental disability, we ask for your uncompromising support of the right to choose the types and intensity of supports and services that are received. **Please vote to recommend passage of this bill, HB1020, out of committee.**

Marla Hollander and Peter Katz
D18: Kensington, MD 20895

Ben and his self-directed caregiving team: Choice and Control make the good Life Possible!

If the SB868/HB1020 the Self-Direction Act becomes law, it will:

- provide training and materials on self-directed services be to CCSes;
- require CCSes to annually inform waiver all participants of their right to self–direct;
- confirm the ability of participants to hire family as staff according to federal guidelines;
- restore self-directed Awake Overnight Supports for all those with a documented need;
- keep participants updated on the status of their PCP (person centered plan) throughout the creation, revision, and approval process;
- reinstate support broker role and hours;
- reimburse wheelchair-accessible and other modified vehicle owners to for mileage when the participant is a passenger, regardless of who is driving;
- remove competency requirements and provide for team support of participants;
- establish parity between self-directed and traditional services so participants in self-direction have equal access to the services they need;
- increase flexibility in Individual Family Directed Goods & Services (IFDGS)

SB868_GablerFamily_fav.pdf

Uploaded by: Martha Gabler

Position: FAV

March 7, 2022

Senate Finance Committee
Maryland General Assembly
Annapolis, MD

RE: SB868_GablerFamily_fav DDA – Self–Directed Services (Self–Direction Act of 2022)

Dear Respected Committee Members:

Thank you for this opportunity to comment on SB868. We live in Silver Spring, MD and have a 25-year old son, Douglas, who has severe autism and is profoundly nonverbal. He will need supported housing and intensive care for the rest of his life.

Douglas receives Self-Directed Services from the DDA. We strongly support SB868 and the comments provided by the Self-Directed Advocacy Network (SDAN). I would like to provide details on two items that are important for Douglas:

Reinstate Support Broker roles and increase hours available where needed

Under the original conceptualization of Self-Directed Services, Support Brokers were supposed to help participants find appropriate activities in the community, as well as take a lead role in recruiting, hiring, training, and managing staff. Support Brokers were supposed to be active partners for the participant and the family. Under the current system, we have only 4 hours per month of Support Broker services, and the role of the Support Broker has been down-graded to helping out with initial staff hiring and shuffling paperwork; it is a shadow of what it was supposed to be. Douglas needs a strong, well-informed Support Broker to serve as a real partner in setting up his activities and managing the staff who take care of him.

Restore self-directed Awake Overnight Supports

Douglas has severe autism and he is prone to Self-Injurious behaviors (punching himself in the face and biting his hands until they bleed). These are horrible and traumatic behaviors which can erupt at any time of the day or night. For this reason, Douglas needs access to Awake Overnight Support staff – people who are trained in the use of Positive Behavioral Supports to de-escalate and manage rhis terrible condition.

Please vote to recommend passage of this bill out of committee. Thank you.

Sincerely,

Martha Gabler

Martha Gabler
Mother and Legal Guardian of Douglas Gabler

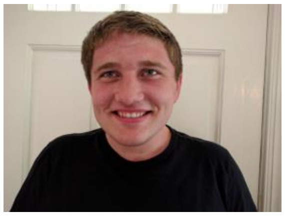
10125 Markham St.
Silver Spring, MD 2090
emgabler@verizon.net

Self-Directed Advocacy Network of Maryland, Inc.,
a 501(c)(3) nonprofit supporting
Participant Choice and Control of Services

All About Me

My name is Douglas Gabler. I am 25 years old. I have severe autism and am nonverbal. I Self-Direct my Medicaid Waiver Support Services. Because of the severity of my autism, being nonverbal, and having Self-Injurious and repetitive behaviors, I will need 24-hour supervision and care for the rest of my life. I especially need skilled behavioral supports: people who understand Operant Conditioning and Positive Reinforcement. I cannot tell people what is bothering me, or whether I am sick or in pain. The people who take care of me have to learn to read my body language and know how to use intensive positive behavioral supports to help me. For these reasons, I need to Self-Direct my services. Despite the severity of my autism, I love being around people and going

Choice, Continuity of Services,
and Positive Reinforcement
Matter to Me!



Self-Direction is important to me because…

- I can hire the right people to work with me; it takes a special person to cope with a guy like me who screams, bites his hands till they bleed, and punches his head -- seemingly out of the blue.
- I can choose how to spend my days and weekends.
- I can train my staff about the best ways to support my behavioral needs.
- I can make changes to my program and staff.
- I can spend my days doing the physical activities that I love (doing chores at a riding stable, hiking, swimming, boating, and ice skating) and hopefully, being around the people I love, and who accept me -- despite the severe autism.

Douglas Gabler
10125 Markham St.
Silver Spring, MD 20901
Home: 301-681-2716
Email:
emgabler@verizon.net

SB868_owenlinville_fav.pdf

Uploaded by: Owen Linville

Position: FAV

I support HB1020 and SB868

Developmental Disabilities Administration -- Self-Directed Services

My Self-Directed Life

Self-Direction is important to me because it supports me to be as independent as possible.

Self-Direction has changed my life as I work in a childcare program and go to community college.

Self-Direction allows me to be out in the community going to church, playing in a bell choir, and being a member of a drama club.

Because of **Self-Direction** I can have reliable transportation to community activities, including training my assistance dog, Belle.

*My family and I support the **Self-Direction Act** because **Choice and Control** make the "Good Life" possible.*

My family and I support the **Self-Direction Act** because it will:

- **C**reate a strong Advisory Council to re-establish the principles of self-direction and DDA accountability
- **A**llow participants to continue to include family members as support staff
- **R**estore the participants' right to choose a support broker as their professional advocate
- **E**nsure participant choice and control of all services
- **M**andate that *anyone* eligible for DDA services can self-direct

For more information visit: MarylandSDS.org

Owen Linville
7290 Ridge Road
Marriottsville, MD 21104
Owen.linville2@gmail.com
District 9A

SB868_pammiller_fav.pdf

Uploaded by: PAMELA MILLER

Position: FAV

Support of HB1020 & SB868 – The Self-Direction Act
Developmental Disabilities Administration – Self-Directed Services
Written Testimony 3/7/22
Favorable

Pamela R. Miller, Ed.D., mother of a young adult in self-direction
7290 Ridge Road, Marriottsville, MD 21104
Pamiller8@gmail.com
443-562-9945
District 9A

As the mother of a son receiving self-directed services, I am in support of the Self-Direction Act. This unique service delivery model (one of many within the Developmental Disabilities Administration) supports adults with intellectual and developmental disabilities to be as independent as possible within their homes and communities by allowing them to choose how they spend their day, choose how they participate in their community, and choose who they spend time with.

For my son this means he has transportation and support to work at an after-school program in our community, to attend community college, to train his assistance dog, to play in a community bell choir, to participate in a parks and recreation drama club, and to teach Sunday School at a local church. It also means that he receives the physical support he needs at home with dressing and personal hygiene as well as meal preparation, laundry, and grocery shopping. My son's goal is to live in his own apartment with supports. Self-direction currently assists him to focus on the specific skills he needs to be more independent so he can reach this goal.

Historically, self-direction has saved the state money while providing remarkable outcomes for people with developmental disabilities, including my son. **HB1020 & SB868 will preserve that.** Other critical components of the Self-Direction Act will:

- provide training and materials on self-directed services to be shared with participants and their families;
- confirm the ability of participants to hire family as staff according to federal guidelines;
- restore self-directed Awake Overnight Supports for all those with a documented need;
- keep participants updated on the status of their PCP (person centered plan) throughout the creation, revision, and approval process;
- reinstate support broker role and hours;
- reimburse wheelchair-accessible and other modified vehicle owners to for mileage when the participant is a passenger, regardless of who is driving;
- remove competency requirements and provide for team support of participants;
- establish parity between self-directed and traditional services so participants in self-direction have equal access to the services they need;
- increase flexibility in Individual Family Directed Goods & Services (IFDGS).

For more information visit MarylandSDS.org

Thank you for your support!

SB0868 Support 03082022.pdf

Uploaded by: Patricia Saylor

Position: FAV

<Date>3/8/22

Senate Finance Committee
SB 0868Developmental Disabilities Administration – Self–Directed Services (Self–Direction Act of 2022)
Senator Lee – Sponsor

Position: Favorable

My name is Patti Saylor, I am a nurse who has been providing Nursing Support Services to people with disabilities and their families since the inception of Self Directed Services sixteen years ago. I have worked for over two hundred customers during that time.

I joined the Board of The Self Directed Advocacy Network of Maryland several years ago when it became obvious my customers were seeing their services become less flexible and they were being given less choice and control over those services. Some services were even eliminated after being provided for years (overnight personal supports).

I was also a member of the Summer Legislative Workgroup this past year who's recommendation lay the foundation for this legislation.

I am writing in support for HB1020/SB868

Individuals with disabilities and their families have better lives when they have choice and control over a flexible set of services based on their individual needs. Given a budget frame work of an annual allocated amount the individual and/or family can make choices best for them.

The intent of this legislation is to increase flexibility and access while remaining fiscally responsible and budget neutral.

Please read the recommendations of the Summer Legislative Workgroup and pass this legislation out of Committee.

Thank you!

Patti Saylor RNMS CMDN

SB868_FAV_PathfindersforAutism .pdf

Uploaded by: Rebecca Rienzi

Position: FAV

PATHFINDERS FOR AUTISM

SENATE BILL 868
Developmental Disabilities Administration: Self–Directed Services Act
March 8, 2022
POSITION: FAVORABLE

To Chair Kelley and the Senate Finance Committee:

Pathfinders for Autism (PFA) is Maryland's largest autism organization dedicated to helping individuals, parents, and professionals find resources, support, and training while working to increase the awareness of autism spectrum disorders. We accomplish this through a variety of programs and services, all of which are offered FREE of charge. Last year our programs directly served 20,000 Maryland residents.

PFA supports Senate Bill 868 to require the Developmental Disabilities Administration to: provide Coordinators of Community Services with better training in self-direction and require them to fully orient new and current participants about self-direction annually; to reinstate Support Broker roles and increase hours available where needed; to reinstate Self-Directed Overnight Supports that were removed in 2018; to remove the prohibition to having family as staff; offer transparency in Person Centered Planning (PCP) with the ability to track; provide mileage reimbursement for specialized vehicles; remove competency requirements in favor of team support; ensure parity in budgets/services; allow for Individual Family Directed Goods & Services (IFDGS) to be more flexible per the individual's need; and to provide a progress report to the Legislature every 3 years,

According to the Developmental Disability Administration (DDA) website, people with developmental disabilities have the right to direct their lives and services. They acknowledge that self-directed services provide people with disabilities the basic human right to determine what makes a good day for them, if they want to live with others and with whom, decide what participating in the community means to them, and to decide who they want to spend time with. DDA states that these factors are the foundation of Person-Centered planning, with the goal of ensuring that people receive services to support them to have the life that they choose. Yet, DDA's policies create barriers to the Self-Directed model that are in direct opposition to what the agency claims to be fundamental rights of all people.

At is heart, the Bill addresses long standing issues of equity within DDA's Self-Directed Services model ensuring that people in disadvantaged communities, with language barriers, and without robust family supports and resources may also access Self-Directed services. Additionally, it respects an individual's fundamental right and ability to direct their services (with supports when needed) in order to live the life they choose. The Bill restores the flexibility that has been lost due to DDA's past changes. It remains in compliance with CMS rules ensuring federal matching dollars. Additionally, the changes can be achieved with no increase to current budget allocations.

I respectfully ask that you vote in favor of SB868. For more information, please contact Rebecca Rienzi, Executive Director, Pathfinders for Autism at 443-330-5370, ext. 101 or rrienzi@pfamd.org.

2022-Bill-My-Story-RobertSheinberg-Final.pdf

Uploaded by: Reda Sheinberg

Position: FAV

SDAN
Self-Directed Advocacy Network of Maryland, Inc.

I Support HB1020/SB868

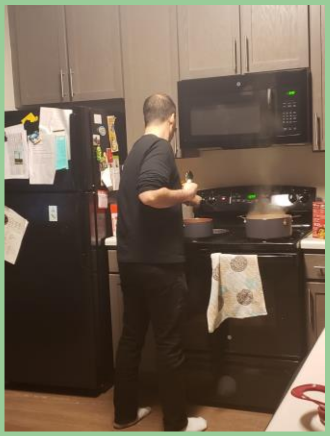
The Self-Direction Act

Robert

Our son Robert has been a self-advocate with self-directed services since 2008. The continuation of Self-Direction is very important and we strongly support the Self-Directed Services Act of 2022: We support goals as worked on with Self-Directed Advocacy Network of Maryland (SDAN).

1)To achieve greater equity by ensuring that people in disadvantaged communities, those with
language barriers and those who lack robust family supports can also access SD
2) To restore and maintain flexibility and access to SD while retaining cost-savings
3) To ensure that anyone be deemed capable of self-directing with the needed supports

Choice and Control Matter
Matter to Me!



Self-Direction is important to me because I choose my direct support staff with my team support. My staff helps me do daily living chores in my own apartment community, do chores in the community, as well as successfully continue my part-time job at Goodwill. Self-directed services allow me to hire my own vendor, Integrated Living Opportunities, a creative non-profit. ILO Staff help me thrive integrated in my community in my own place, make friends with other self-advocates in the ILO program, work on health and wellness goals, and help learn cooking and cleaning skills needed to live on my own. I am working with ILO in helping me develop supports I will need long term to continue on my own when my parents are not available.

Reda and Marc Sheinberg
501 King Farm Blvd, Apt 101
Rockville, MD 20850
Reda.sheinberg@gmail.com

SB868_redasheinberg_fav.pdf

Uploaded by: Reda Sheinberg

Position: FAV

Monday, March 7, 2022

Senate Finance Committee
SB 868- Developmental Disabilities Administration – Self–Directed Services (Self–Direction Act of 2022)

Position: Favorable

We would like to register our support for SB868 and Self-Directed Advocacy Network (SDAN) Goals.

Goals:
- To achieve greater equity by ensuring that people in disadvantaged communities, those with language barriers and those who lack robust family supports can also access SD
- To restore and maintain flexibility and access to SD while retaining cost-savings
- To ensure that anyone be deemed capable of self-directing with the needed supports

My son, Robert, has been thriving on the Self-Directed Services (SD) since 2008. Robert tried 3 years of support from 2 traditional provider unsuccessfully from 2005 to 2008. The first traditional provider dropped Robert without warning at one of the most difficult periods of his life. Self-Directed Services has allowed Robert to grow at his own pace and not have to fit into the limitations of provider-based services. Because of the flexibility of Self-Direction, Robert is able to work his part-time job at Goodwill with ongoing supports as needed, gain in independence in community related chores, and live in his own apartment. Self-Directed services were especially important during the COVID pandemic as he could make choices based on his own needs and still safely work and have normal interactions with his family and staff while still practicing safety protocols.

Please vote to recommend passage of this bill out of committee. As a parent of our son, Robert, with a developmental disability, I ask for your uncompromising support of our right to choose the types and intensity of supports and services we receive, so that we have control over how we want to live our own lives.

Thank you!

Reda Sheinberg

SB0868_RobertStone_fav2.pdf
Uploaded by: Robert Stone
Position: FAV

Robert Stone, 4415 Highland Ave., Bethesda MD 20814

Testimony to the Senate Finance Committee on SB0868 (Favorable)

I support the Self-Direction Act of 2022 (SB0868) because I am a participant in the DDA's self-directed services option through the Community Pathways waiver. Self-direction is giving me control of my own life and letting me make the choices I want.

I am a 2018 graduate of Walt Whitman High School in Bethesda. When I transitioned, I wanted to be an advocate, a writer, and an artist. None of the traditional programs would let me do all of those things, so I chose self-direction.

It is 2022, and I am now an artist with my own website where I sell prints of my artwork on canvas, on household items like coffee mugs and notebooks. I take art classes at VisArts, at Upcounty Community Resources, and at Montgomery College.

I also write poetry, and am taking private music lessons where I am setting my poems to music. After the pandemic, I hope I can find a place where I can perform them.

I am also interested in music and science, and am taking classes on those subjects.

I am a graduate of Maryland's Partners in Policymaking program, which I took through The Arc of Maryland. I advocate with The Arc, with Little Lobbyists and with the Self-Directed Action Network on disability rights and health care. I've met many Maryland lawmakers, including local, state and federal representatives. They are all very nice.

I am asking you to pass SB0868 because self-direction participants like me need the same guarantees that those who are in traditional services have. We need to know that we will have access to overnight supports when we need them, that we will have access to House Managers when we need them. We need to know that we can always hire our family as staff when needed.

While the DDA has done a good job of meeting my needs, I need to know that I can expect the same access to my services every year, that I will have the same access to funds every year. That as my mom and dad get older, they will know that I can live the same life I'm living now. I need to know that my competency to choose my own path in life will always be respected, and that I will be able to rely on people I choose to assist me with my choices.

The DDA can always change the rules on me. If you pass this legislation, the DDA will not be able to change the rules set out in this bill. These will stay the same. I will know, and my friends will know, and the other kids graduating from high school will know how self-direction works, what they can expect, and that they will be respected.

Thank you.

SB868_SerenaLowe_fav.pdf
Uploaded by: Serena Lowe
Position: FAV

Written & Oral Testimony to the Senate Finance Committee

Submitted by:	**Serena Lowe Former Consultant, Self-Direction Advocacy Network** **2803 Flagmaker Drive, Falls Church, VA 22042**
Regarding:	**SB 868 – Developmental Disabilities Administration – Self–Directed Services (Self–Direction Act of 2022)**
Position:	**Favorable**
Date:	**March 7, 2022**

My name is Serena Lowe[1], and I would like to offer my strong support in favor of the Self-Direction Act of 2022[2] (SB 868). From 2015-2019 I served as a Senior Policy Adviser to the Administration for Community Living[3] within the U.S. Department of Health and Human Services. In this role, I was ACL's primary liaison to the Home & Community Based Services (HCBS) Implementation Team of the Disabled and Elderly Health Programs Group within the Centers for Medicaid and CHIP Services at the Centers for Medicare and Medicaid Services. In this capacity, I provided technical assistance to all fifty states and the District of Columbia in the implementation of the federal regulation governing the provision of Medicaid-funded home and community based services.

Published in January of 2014, the federal Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers[4] established for the first time a set of criteria to assure that qualifying individuals with disabilities, mental illness, and older adults have access to an array of services in settings that are integrated in and supports access to the greater community; provides opportunities to work in competitive, integrated employment, engage in community life and control personal resources; optimizes individual initiative, autonomy, independent in making life choice; ensures individuals receives services in the community to the same degree of access as individuals not receiving Medicaid HCBS; ensures rights of privacy, respect, and freedom from coercion and restraint; and facilitates individual choice regarding services and supports and who provides them.

Later in that same year, in October 2014, CMS issued guidance[5] on the Implementation of Section 2402(a) of the Affordable Care Act[6], which outlined standards for Person-Centered Planning and Self-Direction in Home and Community-Based Services Programs. This section of the Affordable Care Act requires the Secretary of the U.S. Department of Health and Human Services to ensure that all states receiving federal funds develop service systems that are responsive to the needs and choices of beneficiaries receiving home and community-based long-term services (HCBS), maximize independence and self-direction, provide support coordination to assist with a community- supported life, and achieve a more consistent and coordinated

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[1] https://www.linkedin.com/in/serenalowe/

[2] https://trackbill.com/bill/maryland-senate-bill-868-developmental-disabilities-administration-self-directed-services-self-direction-act-of-2022/2220516/

[3] https://acl.gov/

[4] https://www.federalregister.gov/documents/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider

[5] https://acl.gov/sites/default/files/news%202016-10/2402-a-Guidance.pdf

[6] https://www.hhs.gov/sites/default/files/ppacacon.pdf

approach to the administration of policies and procedures across public programs providing HCBS.

The subsequent guidance on Section 2402(a) issued by CMS requires that self-direction programs be aligned with the HCBS Final Rule requirements and based on a person-centered plan. SD, when offered within programs, must also be made available to all eligible individuals regardless of age, disability, diagnosis, functional limitations, cognitive status, sex, sexual orientation, race, ethnicity, physical characteristics, national origin, religion, and other such factors. Individuals thus must have access to information and counseling and information on self-direction through a variety of sources as needed or desired, so they can make an informed decision when choosing a SD service delivery model. Additionally, when representatives are required, they must be freely chosen when circumstances permit.

Given the strong synergy between self-direction and the provision of Medicaid-funded HCBS, I and my colleagues at ACL and CMS also spent a great deal of time supporting states to use their various statutory authorities to expand and improve self-direction programs as a pathway to assuring strong implementation of the federal HCBS regulation. Individuals and their families should have access to the technical supports and flexibility needed to successfully engage in self-directing their Medicaid HCBS resources to assure they get what they need to live, work, and thrive in the greater community. Self-direction is not only a tool for assuring that people have the opportunity to receive services in the most integrated setting (a primary aim outlined in Title II of the Americans with Disabilities Act[7] and subsequently the landmark U.S. Supreme Court decision *Olmstead v. L.C.*[8]), but also to addressing critical labor shortages among the direct care workforce as we have witnessed during the global COVID-19 pandemic by allowing individuals through self-direction to hire family members as a way of assuring they continued to receive services necessary for avoiding institutionalization.

In 2021, I served as a technical consultant to the Self-Direction Advocacy Network of Maryland, and during this time was a member of the Maryland General Assembly's Workgroup to Review and Recommend Policies for the Maryland Self-Direction Program.

The purpose of the Workgroup, which met monthly over the course of seven months (from June-December of 2021), was to determine whether changes in the state's self-direction program for Medicaid HCBS since its inception in 2005 had become too administratively burdensome and had impeded the ability of individuals and families from accessing the supports and services they needed to obtain optimal independence and community integration. The Workgroup was charged with reviewing and understanding the self-direction model for participant-led healthcare; determining if program accessibility and flexibility has decreased; identifying and collating the needs and gaps for individuals practicing self-direction; and investigating financial concerns by reviewing existing CMS waivers for participants.

In its deliberations, the Workgroup determined that the introduction of various policy changes over the years had the effect of creating unnecessary administrative burdens on individuals and

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[7] https://www.eeoc.gov/americans-disabilities-act-1990-original-text

[8] https://www.law.cornell.edu/supct/html/98-536.ZS.html

families, as did restrictions on the use of self-direction resources that inhibit an individual's ability to get the level of supports required to live in one's own home or with family. For example, new rules were implemented that prevented individuals from receiving overnight supports for personal care or habilitative reasons unless they agreed to forgo hiring their own staff and agreed to go through a provider agency. Requiring participants to relinquish their ability to choose the individuals they would like to have provide the overnight supports in their home is the antithesis of self-direction. In another example, the state's diluted support broker services greatly limited self-direction as a feasible option for individuals who lack the natural supports or technical expertise to manage the various administrative complexities involved with self-direction. By limiting access to support brokers, whose sole purpose is to advocate for the individual participant, significant inequities persist in who truly can access and successfully participate in the state's self-direction HCBS option.

The Workgroup issued nine recommendations to provide greater access and flexibility to self-direction participants, which have been incorporated into the Self Direction Act of 2022 (Senate Bill 868)[9]:

- Require DDA to reinstate full employer authority for all personal supports to self-directed participants, to include individuals who have an established need for overnight supports and/or those living independently or in their family homes.
- Restore support brokers' responsibilities to match guidelines; allow for individuals to receive up to 40 hours of support broker services a month; and require a third-party support broker to be hired in any self-direction case where the individual hires a family member or guardian as paid staff in order to address any conflicts of interest and assure the fiscal integrity of the program.
- Invest in increased training for the Coordinator of Community Services to include proper policies, resources, and roles and strategies for working with transitioning youth, individuals without strong family supports, and historically disadvantaged communities.
- Expand coverage of transportation services to allow for mileage coverage to owners of vehicles who are not paid staff but are supporting participants under self-direction.
- Expand coverage of transportation services to allow for mileage reimbursement to nonemployee owners of vehicles used by the participant for plan goals and activities; create more flexibility with Individual and Family Directed Goods and Services; remove the five-thousand-dollar cap on IFDGS and instead base the determination on individual needs.
- Eliminate competency assessment in any form from all DDA policies and proposals.
- Ensure self-direction plans and budgets are easily accessible to individuals and their support teams by allow access to the Long-Term Services and Supports Computer System (LTSS).

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[9] https://trackbill.com/bill/maryland-senate-bill-868-developmental-disabilities-administration-self-directed-services-self-direction-act-of-2022/2220516/

- Enshrine in regulation the parity in budgets and compensation for individuals participating in the self-direction program, so they align with the budgets and compensation for individuals utilizing a provider-managed program.
- Require the Developmental Disability Administration (DDA)[10] to provide an annual update for three years to the Maryland General Assembly outlining its implementation and relevant outcomes of the Workgroup's recommendations.

Passage of the Self-Direction Act of 2022 would help streamline administrative burdens, assure parity between services that are provider-managed and those that are self-directed, and assure a balance between optimal participant flexibility and fiscal integrity. The implementation of the Workgroup's recommendations that are embedded in the Self-Direction Act will increase access and result in the successful use of self-direction as a viable option for individuals eligible for Medicaid-funded HCBS. Additionally, the provisions of Senate Bill 868 are consistent with federal policy and would assure stronger alignment of the state's HCBS self-direction option with the federal HCBS regulation and subsequent guidance related to Section 2402(a) of the Affordable Care Act.

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[10] https://health.maryland.gov/dda/Pages/home.aspx

SB868_suekleit_fav.pdf
Uploaded by: Susan Kleit
Position: FAV

March 7, 2022

Health and Government Operations Committee
SB868- Developmental Disabilities Administration – Self–Directed Services (Self–Direction Act of 2022)

Position: Favorable

I would like to register my support for SB868.

Please vote to recommend passage of this bill out of committee. As the legal guardian for someone with a developmental disability, I ask for your uncompromising support of their right to choose the types and intensity of supports and services they receive, so that they and their team can control how they live their life. More specifically, Self-Direction supports would enable this individual to access a more targeted vocational training program, thus reaching the goal of self-sufficiency sooner than later.

This young man below, Paul, seeks to learn a meaningful and productive set of skills to obtain a job, a real job that pays real taxes and contributes to the economy. With Self-Direction supports, Paul and his team can target his time and resources to learning specific skills to get a job that otherwise is not available to him.

Thank you!

Sue Kleit, guardian for Paul Kleit

Figure 1 Here I am at Hot Breads Bakery & Cafe, learning food prep skills

Appendix_Self Direction Workgroup_2021.pdf

Uploaded by: Susan Lee

Position: FAV

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

Annapolis, Maryland
March, 2022

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Karen Lewis Young
Legislative District 3A
Frederick County

Health and Government
Operations Committee

Subcommittees

Government Operations
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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 <u>not</u> 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 non-medical 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.

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

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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-timekeeping 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.

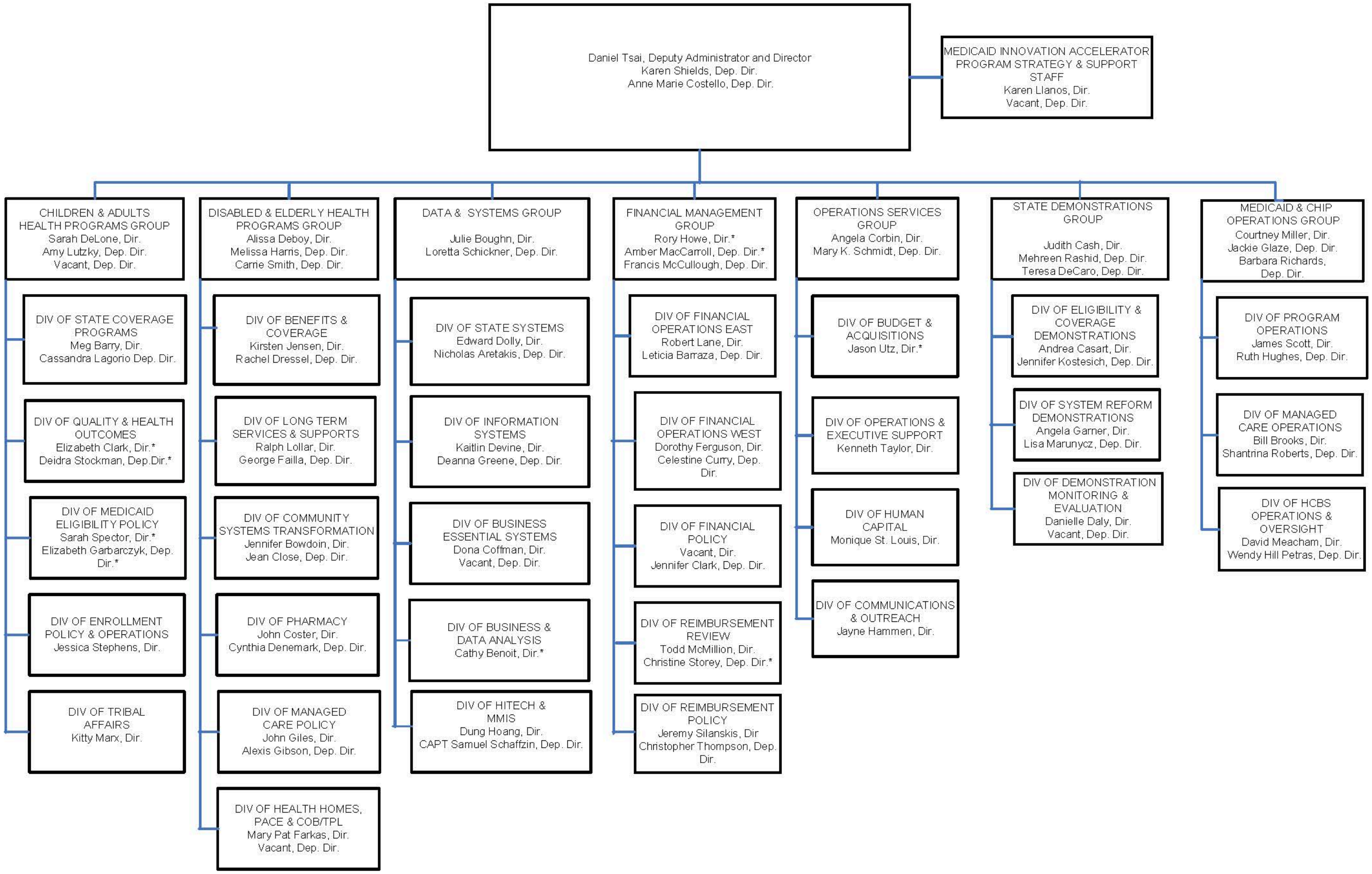
        iv. Question 12 should also be placed on hold because responses are still unclear and somewhat contradictory.

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**



Daniel Tsai, Deputy Administrator and Director
Karen Shields, Dep. Dir.
Anne Marie Costello, Dep. Dir.

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Karen Llanos, Dir.
Vacant, Dep. Dir.

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Amy Lutzky, Dep. Dir.
Vacant, Dep. Dir.

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  Meg Barry, Dir.
  Cassandra Lagorio Dep. Dir.
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  Vacant, Dep. Dir.
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  Celestine Curry, Dep. Dir.
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- DIV OF HCBS OPERATIONS & OVERSIGHT
  David Meacham, Dir.
  Wendy Hill Petras, Dep. Dir.

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 non-medical 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 non-medical 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
Administration for Community Living
330 C Street, SW
Suite 1233B
Washington, DC 20201
202-205-0415
Shawn.terrell@acl.hhs.gov

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: 1:10 – 1:25

1. Follow up on last meeting MDH | Heather
2. Review Prior Meeting Minutes | Erin

Special Presentation

Reviewing Roles of Support Brokers & CCS | Panel 1:25 – 1:45

1. Support Broker
2. Former MD State CCS
3. Family Member

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.

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[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

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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 <u>not</u> 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.

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[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.

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[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

SB0868/383220/1

AMENDMENTS
PREPARED
BY THE
DEPT. OF LEGISLATIVE
SERVICES

04 MAR 22
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BY: Senator Lee
(To be offered in the Finance Committee)

AMENDMENTS TO SENATE BILL 868
(First Reading File Bill)

AMENDMENT NO. 1

On page 1, in line 7, strike "self–directed services" and substitute "all models of services available to the recipient".

AMENDMENT NO. 2

On page 3 in line 24, on page 4 in line 6, on page 8 in line 19, and page 9 in line 30, in each instance, strike "**FAMILY**" and substitute "**AND FAMILY–DIRECTED**".

On page 3, in line 25, strike "**THERAPIES, TRANSPORTATION**" and substitute "**ACTIVITIES**"; and in line 28, after "**PLAN**" insert "**OF SERVICE**".

On page 4, in line 3, strike "**A**" and substitute "**ANOTHER**"; in line 7, strike "**ANY OTHER**" and substitute "**ALL**"; and in the same line, strike "**UNDER**" and substitute "**BY REGULATIONS ADOPTED OR**".

On page 5, in line 10, after "**PERSON–CENTERED**" insert "**PLAN OF SERVICE**"; in the same line, after "**SERVICES**" insert "**AND SUPPORTS**"; strike in their entirety lines 11 through 14, inclusive, and substitute:

"**(1) IS DEVELOPED WITH A FOCUS ON THE INDIVIDUAL HAVING CONTROL OVER THE SERVICES AND SUPPORTS;**

(2) ENSURES THAT THE INDIVIDUAL AND ANY OTHER PERSON SELECTED BY THE INDIVIDUAL IS THE PRIMARY CONTRIBUTOR TO THE GOALS OR OUTCOMES IDENTIFIED IN THE PLAN;

(3) IDENTIFIES AND ADDRESSES, TO THE EXTENT PRACTICABLE:

(I) THE INDIVIDUAL'S PREFERENCES AND INTERESTS RELATED TO ACHIEVING THE INDIVIDUAL'S DESIRED LIFESTYLE; AND

(II) THE SUPPORTS REQUIRED TO ACHIEVE THE INDIVIDUAL'S DESIRED LIFESTYLE AND PROVIDED IN A MANNER THAT ENABLES THE INDIVIDUAL TO HAVE CONTROL OVER THE INDIVIDUAL'S DAILY LIFE AND MAINTAINS THE INDIVIDUAL'S HEALTH AND WELFARE; AND

(4) ALIGNS SERVICES AND SUPPORTS TO ENSURE THAT THE INDIVIDUAL HAS ACCESS TO THE FULL BENEFITS OF COMMUNITY LIVING IN A MANNER THAT EMPHASIZES THE INDIVIDUAL'S QUALITY OF LIFE, WELL–BEING, AND INFORMED CHOICE.";

and in line 30, after "**SUPPORTS**" insert "**CHOSEN BY THE PARTICIPANT OR THE PARTICIPANT'S REPRESENTATIVE**".

On page 6, in line 1, strike "**FURTHERS**" and substitute "**:**

1. FURTHERS";

in lines 2 and 3, strike "**WITH DISABILITIES, REGARDLESS OF THE PHYSICAL OR INTELLECTUAL CAPACITY OF THE INDIVIDUALS,**" and substitute "**AND THEIR REPRESENTATIVES, AS APPLICABLE,**"; in lines 4 and 5, strike "**THROUGH CONTROL OVER RECEIPT OF, AND FUNDING FOR, SUPPORT SERVICES**" and substitute "**BY CHOOSING AND CONTROLLING THE DELIVERY OF WAIVER SERVICES, WHO PROVIDES THE SERVICES, AND HOW SERVICES ARE PROVIDED; AND**

2. RECOGNIZES THAT ALL INDIVIDUALS HAVE THE CAPACITY TO MAKE CHOICES AND MAY BE SUPPORTED IN MAKING CHOICES";

in line 9, strike "**AND**"; in the same line, after "**SUPERVISE**" insert "**, AND DISMISS**"; in the same line, strike "**INDIVIDUALS**" and substitute "**EMPLOYEES AND VENDORS**"; in line 12, after "**SPENT**" insert "**WITHIN THE TOTAL APPROVED ANNUAL BUDGET**"; and in line 18, after "**IMPROVE**" insert "**THE INDIVIDUAL'S**".

On page 7, in lines 4 and 5, strike "**ADVOCATES ON BEHALF OF AND AS DIRECTED BY**" and substitute "**WORKS AT THE DIRECTION OF AND FOR THE BENEFIT OF**"; in line 9, after "**RECEIVES**" insert "**, INCLUDING DECISIONS RELATED TO PERSONNEL REQUIREMENTS AND RESOURCES NEEDED TO MEET THE REQUIREMENTS**"; in line 11, strike "**BEST SUITED**"; and in line 12, after "**INDIVIDUAL**" insert "**AND AS AUTHORIZED BY REGULATIONS ADOPTED OR GUIDANCE ISSUED BY THE FEDERAL CENTERS FOR MEDICARE AND MEDICAID SERVICES UNDER § 1915(C) OF THE SOCIAL SECURITY ACT**".

On page 8, in line 3, after the first "**SERVICES**" insert "**SPECIFICALLY**"; in the same line, after "**ON**" insert "**THE**"; in the same line, after the second "**SERVICES**" insert "**MODEL OF RECEIVING SERVICES**"; in line 4, after "**SERVICES**" insert "**, PROCEDURES,**"; in the same line, after "**POLICIES**" insert a comma; in line 7, strike "**THE AVAILABILITY OF SELF–DIRECTED SERVICES**" and substitute "**ALL MODELS OF SERVICE AVAILABLE TO THE RECIPIENT, INCLUDING SELF–DIRECTED SERVICES, TRADITIONAL SERVICES, AND PROVIDER–MANAGED SERVICES, TO ASSIST THE RECIPIENT AND THE RECIPIENT'S FAMILY OR REPRESENTATIVE IN MAKING AN INFORMED CHOICE ON WHICH SERVICES THE RECIPIENT WOULD LIKE TO RECEIVE**"; in line 14, strike "**OFFERED**" and substitute "**PROVIDED INFORMATION ON**"; in the same line, after "**SERVICES**" insert "**, TRADITIONAL SERVICES, AND PROVIDER–MANAGED SERVICES**"; in line 21, strike "**ON**" and substitute "**:**

(I) ON";

in the same line, after "BASIS;" insert "AND"; after line 21, insert:

"(II) WITHIN THE LIMITS OF THE APPROVED ANNUAL BUDGET GENERATED BY THE DEPARTMENT'S LONG TERM SERVICES AND SUPPORTS SOFTWARE SYSTEM OR ITS REPLACEMENT SYSTEM;";

in line 24, after "SYSTEM" insert "OR ITS REPLACEMENT SYSTEM"; and in line 26, after "RECIPIENT" insert "AND WITHIN THE RECIPIENT'S TOTAL APPROVED ANNUAL BUDGET".

On page 9, strike beginning with "FOR" in line 2 down through "TO" in line 4 and substitute "TO THE OWNER OF A SPECIALIZED, MODIFIED, OR ACCESSIBLE VEHICLE DRIVEN BY AN EMPLOYEE OF THE RECIPIENT AND FOR THE PURPOSE OF THE RECIPIENT ENGAGING IN ACTIVITIES SPECIFIED IN"; strike beginning with "SUBSTANTIALLY" in line 7 down through "POSITIONS" in line 9 and substitute "THE ABILITY TO USE FUNDS FROM THE RECIPIENT'S APPROVED ANNUAL BUDGET FOR THE PURPOSE OF FUNDING AT LEAST ONE POSITION TO ASSIST THE RECIPIENT IN MANAGING THE RECIPIENT'S HOME, STAFF, AND OTHER ADMINISTRATIVE DUTIES AND PAY ADMINISTRATIVE EXPENSES NEEDED TO OPERATE THE RECIPIENT'S PLAN OF SERVICE, INCLUDING INTERNET SERVICE AND OFFICE EQUIPMENT"; in line 11, after "SUPPORTS" insert "PROVIDED THROUGH PERSONAL SUPPORT SERVICES CARRIED OUT USING THE RECIPIENT'S EMPLOYER OR BUDGET AUTHORITY"; in the same line, after the first "THE" insert "EMPLOYEE, VENDOR, OR"; strike beginning with ", INCLUDING" in line 12 down through "SUPPORTS" in line 14; in line 25, strike "UNDER" and substitute "BY REGULATIONS ADOPTED OR"; in line 29, after "(C)" insert "(1)"; in the same line, strike "THE" and substitute "**SUBJECT TO PARAGRAPH (2) OF THIS SUBSECTION, THE**"; and in line 30, strike "**(1)**" and substitute "**(I)**".

On page 10, in line 1, strike "**(2)**" and substitute "**(II)**"; in the same line, strike "**OVERNIGHT SUPPORTS**" and substitute "**PERSONAL SUPPORT SERVICES**"; in line 2, after "**SERVICES**" insert "**THAT:**

1. ARE NECESSARY FOR THE HEALTH AND SAFETY OF THE RECIPIENT; AND

2. ARE AUTHORIZED BY REGULATIONS ADOPTED OR GUIDANCE ISSUED BY THE FEDERAL CENTERS FOR MEDICARE AND MEDICAID SERVICES UNDER § 1915(C) OF THE SOCIAL SECURITY ACT.

(2) A RECIPIENT MAY NOT RECEIVE SERVICES OR SUPPORTS IN EXCESS OF THE RECIPIENT'S ANNUAL APPROVED BUDGET";

in line 8, after the second "**SERVICES**" insert "**, AS NEEDED BY THE RECIPIENT AND WITHIN THE RECIPIENT'S TOTAL APPROVED ANNUAL BUDGET**"; and in line 11, strike "**UNDER**" and substitute "**BY REGULATIONS ADOPTED OR**".

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March 8, 2022

Senate Finance Committee

Senate Bill 868 - FAVORABLE – Developmental Disabilities Administration – Self-Directed Services (Self-Direction Act of 2022)

The Self-Direction Act of 2022 distills a set of policy issues that we have been trying to resolve through legislation for the last three years. SB 868 is the products of a summer study (June through December 2021) that was completed by the House HGO committee on DDA's self-directed option for Marylanders with developmental disabilities. The complete report has been submitted to the committee for review. This legislation codifies the essential aspects of the program under jeopardy since 2014, when the Self-Direction Waiver, New Directions, was coupled with the waiver that was previously only for provider-managed services.

This bill does not seek to add new elements to Maryland's groundbreaking SD program -- which was initiated by participants and family advocates in 2005 – the aim is only to restore what has been lost and to protect other aspects that have been at risk for several years.

Marylanders who self-direct are by and large doing remarkably well these days, and the self-direction program continues to grow. Many participants employ family members, so they did not experience the upheavals others endured during the Covid crisis. In fact, self-directed participants had measurably better health outcomes during Covid. Indeed, many people who self-direct were able to adapt their services in a way that allowed them to continue many of their regular activities -- preserving both their physical and mental health. However, allowing family to work at staff has been threatened for the last six years in various ways. This bill codifies that hiring a family member as staff shall be an option if desired by the individual receiving services.

Program participants have finally achieved financial parity with their peers in provider-managed services, thanks to a recent DDA policy change. And seemingly overnight, the overnight programs have been provided as was a main goal of this group for year. In FY22 DDA started the same budgeting formula in the LTSS software system it uses for provider-managed services to also determine self-direction budgets, something the DDA waiver has always called for but has never been realized before. This is a change for participants accustomed to sacrificing goals and services to stay within their very limited budget.

There have also been other admirable changes from DDA administrators. DDA now meets monthly with representatives from SDAN, the Self-Directed Advocacy Network of Maryland—the driving force behind this legislation. As a result of that collaboration, DDA has implemented several program improvements. A recent example is a revised participant agreement which is finally based on the supported decision making model that SDAN has recommended for at least four years. This brand new agreement allows participants to get the help they need to administer their services without relinquishing their autonomy.

Deputy Secretary Simons has also taken steps to respond to SDAN's urgent request to restore the availability of overnight supports, which his department eliminated in the 2018 waiver renewal. Mr. Simons has made it clear that he wants "no one hurt," and has accessed "state only" funding for staff supports for overnight care on a case by case basis. And last Friday—just four days before this hearing--his department issued a memo notifying all participants that those supports are available again under waiver funding. That is wonderful news for people who have gone without the supports they need for the last four years.

With all of the recent progress, my colleagues may ask why legislation that guarantees these and other important aspects of self-direction is even necessary. There are two reasons.

First, there is still much lost ground to recover, including DDA policies which have minimized the role of the support broker—the lynchpin of Maryland's original New Directions program. Reducing access to the only team professional who specializes in self-direction has resulted in long service delays for transitioning youths and has made it difficult for individuals from disadvantaged communities, or those who lack a strong family support network, to self-direct at all.

The second reason for codifying the principles of self-direction into law is that DDA is like most state agencies: It is filled with well-intentioned people who are consumed with tasks that distract them from the needs of the very people they are meant to serve. Despite their dedication, they are sometimes out of touch with their constituents and unaware of the consequences of the policies they make.

Since 2016 DDA has attempted to eliminate the participant's right to hire family members, to eliminate choice in essential fiscal management services, to eliminate independent support brokers, to impose competency testing, to force people to relinquish their budget and employer authority to a single representative, and to eliminate personal supports altogether, forcing participants to seek supports from another state program not intended for the Maryland population with Intellectual/Developmental Disabilities.

Consequently, since 2016 a small group of volunteers, have pushed the State to restore these facets of the program. They have persistently worked to restore Maryland's original vision for self-direction: flexibility, person-centeredness and participant choice and control of services, repeatedly stating that all people can self-direct with the right supports. We all appreciate DDA's new willingness to listen and change, but Marylanders with developmental disabilities should not have to rely on the *persistence* of one small group of volunteers or on *the good will* of a few DDA administrators to retain the supports and services that they need. Codifying self-direction principles into law will prevent future regressions in support and service options. This bill will ensure that future Maryland DDA administrations maintain a flexible, person-centered program as envisioned, allowed and funded by The Federal Centers for Medicare and Medicaid Services (CMS).

This bill complies with all regulations and guidance by CMS and will not jeopardize the Federal Match.

Nothing in this bill is intended to increase the funds already earmarked for individuals' needs by the State. It merely gives them **flexibility in the use of and access** to the total amount of funds already allocated for their supports by the formula used for all budgets. The amendments made to the original bill, attempt to clarify this intention.

For these reasons, I request a favorable report with the amendment provided in your packet on SB 868.

Fiscal Note Concerns:

Personnel Costs

DDA must complete the renewal and have CMS approval for the Community Pathways waiver by July 1, 2023. This bill only moves that deadline up by six months. If DDA does indeed need to contract with additional staff to make the few changes required by this bill, that same staff would also work on other aspects of the waiver renewal. The actual cost of implementing these changes into a new waiver is far less than the MDH OLS estimate. Required Training DDA already conducts regular, required training for both Coordinators of Community Services and Support Brokers. SDAN already meets regularly with DDA and supplies it with detailed recommendations for all aspects of self-direction at no cost. Specific recommendations regarding training for Coordinators of Community Service and Support Brokers could be seamlessly implemented into existing training at little to no additional cost to the State.

Individual and Family Directed Goods and Services

This entry by MDH OLS contains two errors. First, to our knowledge, the current cap on Individual and Family Directed Goods and Services (IFDGS) is $5,000, not $7,500. Second, the term "therapies" does not appear in the current bill. It was eliminated during the amendment process. Therefore, DDA would not be required to fund any therapies for all Community Pathways participants in provider-managed services. Furthermore, removing the cap from the IFDGS category would not require the state to allocate any additional funding for people who self-direct and who want IFDGS to fund "activities." As is now the case, participants can only access the IFDGS category by using their "savings," redirecting funds already allocated for them in the approved Person-Centered Plans and budgets. The $81 million price tag for this change is imaginary.

Support Broker (SB) Services

The MDH DLS estimate of $31.2 million is based on the false assumption that 50% of participants will use the maximum allowance of 40 hours per month. Note that participants must justify their need for every service they request in the Person-Centered Plans. To gain approval for 40 hours of SB services, participants would have to demonstrate a special need for 40 hours of Support Broker services, which DDA reviewers must then approve. Examples of individuals who might require maximum SB support are those who don't have a strong family network or those from disadvantaged communities. A closer estimate of those who would use the maximum allowance is 5% of 2,000 people--an additional cost of

$3.2 million. SDAN recommends that participants who require additional SB supports draw them from their existing funding so that there is NO extra cost to the State.

Vehicle Use Reimbursement

The MDH DLS estimate of $5.8 million is based on a false assumption. The actual additional cost to the State for this aspect of the bill is ZERO. MDH assumes that everyone in self-direction uses a specialized van adapted for wheelchair use. Over 90% of individuals do not require a special van and travel in their employees' personal vehicles. And those employees are already reimbursed for mileage from the participant's currently allotted budget. This stipulation merely allows participants to use existing funding to reimburse family members who are NOT employees for mileage costs associated with the specialized vans they provide for their loved ones-- so that their employees can drive them to and from community activities.

Please view these videos for more info about Self-Direction

TRAILER - Why Work in Self-Direction? - YouTube

"Self-Direction and the Good Life: Many Lives, Many Choices" - YouTube

Self Direction Workgroup Recommendations Final Dra

Uploaded by: Susan Lee

Position: FAV

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

Annapolis, Maryland
March, 2022

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

Maryland General Assembly
Office of Delegate Karen Lewis Young
Annapolis, Maryland

March 7, 2022

Contributing Staff

Writer
Kristopher Fair

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to contact the General Assembly.

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KAREN LEWIS YOUNG
Legislative District 3A
Frederick County

Health and Government
Operations Committee

Subcommittees

Government Operations
and Estates and Trusts

Insurance and Pharmaceuticals

THE MARYLAND HOUSE OF DELEGATES
ANNAPOLIS, MARYLAND 21401

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March 7, 2022

The Honorable Shane Pendergrass, Chair
Health and Government Operations Committee
Room 241
House Office Building
Annapolis, MD 21401

Chair Pendergrass:

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The workgroup spent the interim thoroughly evaluating the complex system of programs and waivers contained within the self-direction program. During our seven public committee meetings and six public subcommittee meetings, we heard testimony from dozens of expert witnesses, advocacy organizations, participants in self-direction, caregivers, and representatives from The Maryland Department of Health (MDH) and Developmental Disabilities Administration (DDA).

In addition to our workgroup, I organized two subcommittees. One subcommittee reviewed the application of Center for Medicare and Medicaid Services (CMS) waiver services to ensure that Maryland was accessing all the funds available for self-direction participants. The second subcommittee provided participant analysis and suggestions to strengthen the self-direction program. Each workgroup meeting studied written materials, presented best national practices, and provided equal opportunity to present and debate various aspects of the self-direction program.

As a result, the workgroup has put forward nine recommendations set forth on pages 3 through 5 of this report. I am proud of this work product and believe that these recommendations are sound, necessary, and consistent with the original intent of self-direction. In response, I have filed HB 1020 – The Self-Direction Act of 2022, which incorporates each of these recommendations.

It has been a privilege and pleasure to serve as chair of the workgroup, and I thank you for giving me this opportunity to guide the work of this important body. I look forward to a productive legislative session incorporating much of this work to strengthen our self-direction program.

Sincerely,

Karen Lewis Young

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2021 Interim
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Senate Members
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Delegate Members
Heather Bagnall
Lisa Belcastro
Harry Bhandari
Nicholaus Kipke
Kirill Reznik
Geraldine Valentino-Smith

Public Members
Ken Capone
Laura Howell
Ande Kolp
Rachel London
Serena Lowe
Megan Rusciano
Patti Saylor
Esther Ward
Alicia Wopat

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

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The Workgroup was charged with:

- Reviewing and understanding the self-direction model for participant-led healthcare.
- Determining if program accessibility and flexibility have decreased.
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- Investigating financial concerns by reviewing existing CMS waivers for participants

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At the November meeting, the committee began framing out a list of recommendations for the Workgroup to consider. Utilizing the feedback from the CMS and Participants subcommittees, the Workgroup built a list of requested changes to current policy and discussed what policies needed to be addressed on an administrative level versus a legislative level.

December 29, 2021 Meeting

SDAN provided guidance on a few additions to the Workgroup's recommendations at the final meeting. The Workgroup reviewed and discussed the definitive list of recommendations and built a final matrix outlining the suggested changes to various programs available to self-direction participants. Chair Lewis Young also reported meeting with MDH representatives regarding the committee recommendations. She said that MDH has agreed to one recommendation and would change that policy internally. Finally, Chair Lewis Young informed the committee that she had forwarded the recommendations to Legislative Services (MLIS) to draft them into a bill for the 2022 session.

Recommendations

The Workgroup issued nine recommendations to provide greater access and flexibility to self-direction participants. These recommendations have been incorporated into House Bill 1020 and are set forth below.

Recommendation 1 – Overnight Supports and Personal Supports

- Reinstate full employer authority for all personal supports to self-directed participants.
    - Include those with an established need for overnight supports.
    - Include those living independently or in their family homes.
- Amend the current Community Pathways Waiver to allow the State to receive Medicaid federal matching funds.
- Remove the 82-hour limit on personal supports under the current CPW waiver.
    - Personal supports would be determined ***based on individual needs.***

Recommendation 2 – Support Brokers

- Increase Support Broker hours from ‘up to four hours per month’ to ‘up to forty hours per month.’
- Restore support brokers’ responsibilities to match the federal CMS position description.
- Enact a policy that requires a third-party support broker to be hired if the individual hires a family member or guardian as paid staff.

Recommendation 3 – Coordinator of Community Services

- Invest in increased training for the Coordinator of Community Services.
    - Training includes proper policies, resources, and roles.
    - How to work with transitioning youth, individuals without strong family supports, and historically disadvantaged communities.
    - Budget allocations whenever self-direction is changed through legislation to ensure proper education training about the changes.

Recommendation 4 – Transportation

- Expand coverage of transportation services to allow for mileage coverage to owners of vehicles who are not paid staff but are supporting participants under self-direction.
- Expand coverage of transportation services to allow for mileage reimbursement to non-employee owners of vehicles used by the participant for plan goals and activities.
    - Update the necessary DDA waivers to reflect this change.

Recommendation 5 – Individual and Family Directed Goods and Services

- Create more flexibility with Individual and Family Directed Goods and Services
- Remove the five-thousand-dollar cap on IFDGS
    - IFDGS would be determined ***based on individual needs.***
- Allow participants to self-identify their IFDGS without constraints
    - Ensure the participant stays within their budget
    - Ensure their budget matches the provider-based model

Recommendation 6 – Competency Testing

- Eliminate competency assessment in any form from all DDA policies and proposals.

Recommendation 7 – Budget Transparency

- Allow participants to access the Long-Term Services and Supports Computer System (LTSS)
    - Ensure plans and budgets are easily accessible.
    - Ensure the funding is consistently updated for tracking.

Recommendation 8 – Provider Managed and Self-Direction Parity

- Codify in regulation the parity in budgets and compensation for individuals participating in the self-direction program, so they align with the budgets and compensation for individuals utilizing a provider-managed program.

Recommendation 9 – Annual Report

- The Developmental Disability Administration (DDA) will provide an annual update to the Maryland General Assembly for three years outlining its implementation and relevant outcomes of the Workgroup's recommendations.

Conclusion

The Workgroup extends its appreciation and gratitude to the Maryland citizens who participated at each Workgroup meeting. Your input and involvement are invaluable to identifying the self-direction program's strengths and the opportunities to increase participants' positive outcomes. The Workgroup would also like to thank the Health and Government Operations staff, Maryland Department of Health, and the following individuals who assisted by providing testimony or serving on the Participant's subcommittee:

- JP Shade
- Carmen Hudlud
- Mat Rice
- Thomas
- Rob Stone
- Jeneva Stone
- Sunny Cefarratti
- Carol Custer
- Susan Goodman
- Barbara Reff
- Alarice Vidale de Palacios
- Irene Souada
- Karina Jones
- Karen Blanchard
- Patricia Eisenberg
- Marla Hollander
- Beth Monroe
- Gail Goodwin
- Kate
- Paulette
- Lisa Lorraine

The Workgroup members look forward to working on the legislation incorporating its recommendations and seeing that legislation through to passage and enactment.

2022-Bill-My-Story-Jonathan Bamberger.pdf

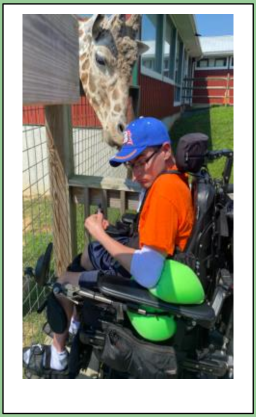
Uploaded by: Terry Bamberger

Position: FAV

SDAN
Self-Directed Advocacy Network of Maryland, Inc.

I Support HB1020/SB868

The Self-Direction Act



Choice and Control Matter Matter to Me!

Self-Direction is important to me because…

I can hire family as staff – this makes me feel safe because they know me better than anyone else. I spend more quality time with them too!

I spend my days out in the community doing jobs that are based on my abilities rather than watching from the sidelines like I did during my day program.

I deliver books to the library, meals to family and friends and run errands for people. This has allowed me to form relationships with people in the community. I'm no longer anxious talking to them.

I can hire a caregiver that fits my personality. She is one of my best friends!

I decide how to budget my funds – road trips help calm me down so I can use my budget for mileage reimbursement

Jonathan Bamberger
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SB868.Carol_Custer_SDAN.FWA.pdf

Uploaded by: Carol Custer

Position: FWA

Carol Custer, 3527 Chick Lane, Knoxville, MD 21758
Secretary, Self-Directed Advocacy Network of MD, Inc.

- Maryland was a trailblazer and national model with its New Directions Waiver in 2005
- 2013/2014 New Directions was combined with the provider-centered Community Pathway Waiver, which resulted in less choice and flexibility than the original waiver
- In 2016, significant changes were proposed by MDH/DDA that would have taken away many participant choices and control of their programs. Many of these changes were enacted and some harmed Maryland stakeholders.
- Grassroots efforts began to return Maryland to its original vision
- From June to December 2021, House HGO Held a Workgroup to evaluate how legislation could help preserve and protect Self-Direction in Maryland

Recommendations from House Workgroup on Self-Direction

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SB868 Favorable with Amendment
Support Disability Rights Maryland amendments.

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Self-Direction Act Goals

- To restore aspects of self-direction that have been lost or diluted since 2014
- 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.
- MDH/DDA should refrain from requiring any participant in any of the state's HCBS authorities from having to demonstrate competency of suitability (either by completing a competency examination or evaluation) to participate in self-direction. Anyone should be deemed capable of self-directing with the right supports.

Please review full report and appendix for more information. SDAN is willing to work with the Committee/Subcommittee to correct the wording issues addressed by Disability Rights Maryland as our principles and intentions align.

Thank you.

Carol Custer, Secretary

Self-Directed Advocacy Network of Maryland, Inc.

SDAN
Self-Directed Advocacy Network of Maryland, Inc.

THE SELF-DIRECTED SERVICES ACT OF 2022 (HB1020/SB868)

Self-direction allows an individual with Intellectual/Developmental Disabilities to have choice and control of their Medicaid waiver services, including choosing the staff that supports them (employer authority) and how their budget is spent (budget authority)so they can tailor their daily activities to meet their own needs and interests.

History: Maryland was a trailblazer with its Self-Direction (SD) Waiver in 2005

- 2013/2014 – it was combined with the provider-centered Waiver which meant less choice, control and flexibility for SD
- 2016 – further DDA changes took away many participant choices and control
- Grassroots efforts since then culminating in this Act

Goals:

- To achieve greater equity by ensuring that people in disadvantaged communities, those with language barriers and those who lack robust family supports can also access SD
- To restore and maintain flexibility and access to SD while retaining cost-savings
- To ensure that anyone be deemed capable of self-directing with the needed supports

The bill stipulates:

1. Case managers (CCSes) will be better trained in self-direction and will fully orient new and current participants about self-direction annually (PCP).
2. Reinstate Support Broker roles and increase hours available where needed.
3. Reinstate Self-Directed Overnight Supports (this waiver service removed in 2018)
4. No Prohibition to Having Family as Staff per CMS rules
5. Transparency in Person Centered Planning (PCP) – ability to track
6. Mileage Reimbursement for Specialized Vehicles
7. Remove Competency Requirements in Favor of Team Support
8. Parity in Budgets/Services – SD doesn't have all needed services
9. Individual Family Directed Goods & Services (IFDGS) to be more flexible per needs
10. Progress Report to Legislature Annually – 3 years

Takeaway:

- **NOTHING in this bill causes the state to lose federal matching dollars.**
- **EVERYTHING in this bill complies with CMS rules/regulations ensuring federal match.**
- **Policy changes can be addressed with current allocations - no increase in cost.**
- **SD services are generally less expensive than traditional provider managed services.**

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At the November meeting, the committee began framing out a list of recommendations for the Workgroup to consider. Utilizing the feedback from the CMS and Participants subcommittees, the Workgroup built a list of requested changes to current policy and discussed what policies needed to be addressed on an administrative level versus a legislative level.

December 29, 2021 Meeting

SDAN provided guidance on a few additions to the Workgroup's recommendations at the final meeting. The Workgroup reviewed and discussed the definitive list of recommendations and built a final matrix outlining the suggested changes to various programs available to self-direction participants. Chair Lewis Young also reported meeting with MDH representatives regarding the committee recommendations. She said that MDH has agreed to one recommendation and would change that policy internally. Finally, Chair Lewis Young informed the committee that she had forwarded the recommendations to Legislative Services (MLIS) to draft them into a bill for the 2022 session.

Recommendations

The Workgroup issued nine recommendations to provide greater access and flexibility to self-direction participants. These recommendations have been incorporated into House Bill 1020 and are set forth below.

Recommendation 1 – Overnight Supports and Personal Supports

- Reinstate full employer authority for all personal supports to self-directed participants.
    - Include those with an established need for overnight supports.
    - Include those living independently or in their family homes.
- Amend the current Community Pathways Waiver to allow the State to receive Medicaid federal matching funds.
- Remove the 82-hour limit on personal supports under the current CPW waiver.
    - Personal supports would be determined ***based on individual needs.***

Recommendation 2 – Support Brokers

- Increase Support Broker hours from ‘up to four hours per month’ to ‘up to forty hours per month.’
- Restore support brokers’ responsibilities to match the federal CMS position description.
- Enact a policy that requires a third-party support broker to be hired if the individual hires a family member or guardian as paid staff.

Recommendation 3 – Coordinator of Community Services

- Invest in increased training for the Coordinator of Community Services.
    - Training includes proper policies, resources, and roles.
    - How to work with transitioning youth, individuals without strong family supports, and historically disadvantaged communities.
    - Budget allocations whenever self-direction is changed through legislation to ensure proper education training about the changes.

Recommendation 4 – Transportation

- Expand coverage of transportation services to allow for mileage coverage to owners of vehicles who are not paid staff but are supporting participants under self-direction.
- Expand coverage of transportation services to allow for mileage reimbursement to non-employee owners of vehicles used by the participant for plan goals and activities.
    - Update the necessary DDA waivers to reflect this change.

Recommendation 5 – Individual and Family Directed Goods and Services

- Create more flexibility with Individual and Family Directed Goods and Services
- Remove the five-thousand-dollar cap on IFDGS
    - IFDGS would be determined ***based on individual needs.***
- Allow participants to self-identify their IFDGS without constraints
    - Ensure the participant stays within their budget
    - Ensure their budget matches the provider-based model

Recommendation 6 – Competency Testing

- Eliminate competency assessment in any form from all DDA policies and proposals.

Recommendation 7 – Budget Transparency

- Allow participants to access the Long-Term Services and Supports Computer System (LTSS)
    - Ensure plans and budgets are easily accessible.
    - Ensure the funding is consistently updated for tracking.

Recommendation 8 – Provider Managed and Self-Direction Parity

- Codify in regulation the parity in budgets and compensation for individuals participating in the self-direction program, so they align with the budgets and compensation for individuals utilizing a provider-managed program.

Recommendation 9 – Annual Report

- The Developmental Disability Administration (DDA) will provide an annual update to the Maryland General Assembly for three years outlining its implementation and relevant outcomes of the Workgroup's recommendations.

Conclusion

The Workgroup extends its appreciation and gratitude to the Maryland citizens who participated at each Workgroup meeting. Your input and involvement are invaluable to identifying the self-direction program's strengths and the opportunities to increase participants' positive outcomes. The Workgroup would also like to thank the Health and Government Operations staff, Maryland Department of Health, and the following individuals who assisted by providing testimony or serving on the Participant's subcommittee:

- JP Shade
- Carmen Hudlud
- Mat Rice
- Thomas
- Rob Stone
- Jeneva Stone
- Sunny Cefarratti
- Carol Custer
- Susan Goodman
- Barbara Reff
- Alarice Vidale de Palacios
- Irene Souada
- Karina Jones
- Karen Blanchard
- Patricia Eisenberg
- Marla Hollander
- Beth Monroe
- Gail Goodwin
- Kate
- Paulette
- Lisa Lorraine

The Workgroup members look forward to working on the legislation incorporating its recommendations and seeing that legislation through to passage and enactment.

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

Annapolis, Maryland
March, 2022

Contents

KAREN LEWIS YOUNG
Legislative District 3A
Frederick County

Health and Government
Operations Committee

Subcommittees

Government Operations
and Estates and Trusts
Insurance and Pharmaceuticals

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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 <u>not</u> 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 non-medical 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
Administration for Community Living
330 C Street, SW
Suite 1233B
Washington, DC 20201
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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

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Ande Kolp, The Arc Maryland

Heather Shek, MDH

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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: 1:10 – 1:25

1. Questions for MDH | Heather
2. Edits to Meeting Minutes | Erin

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

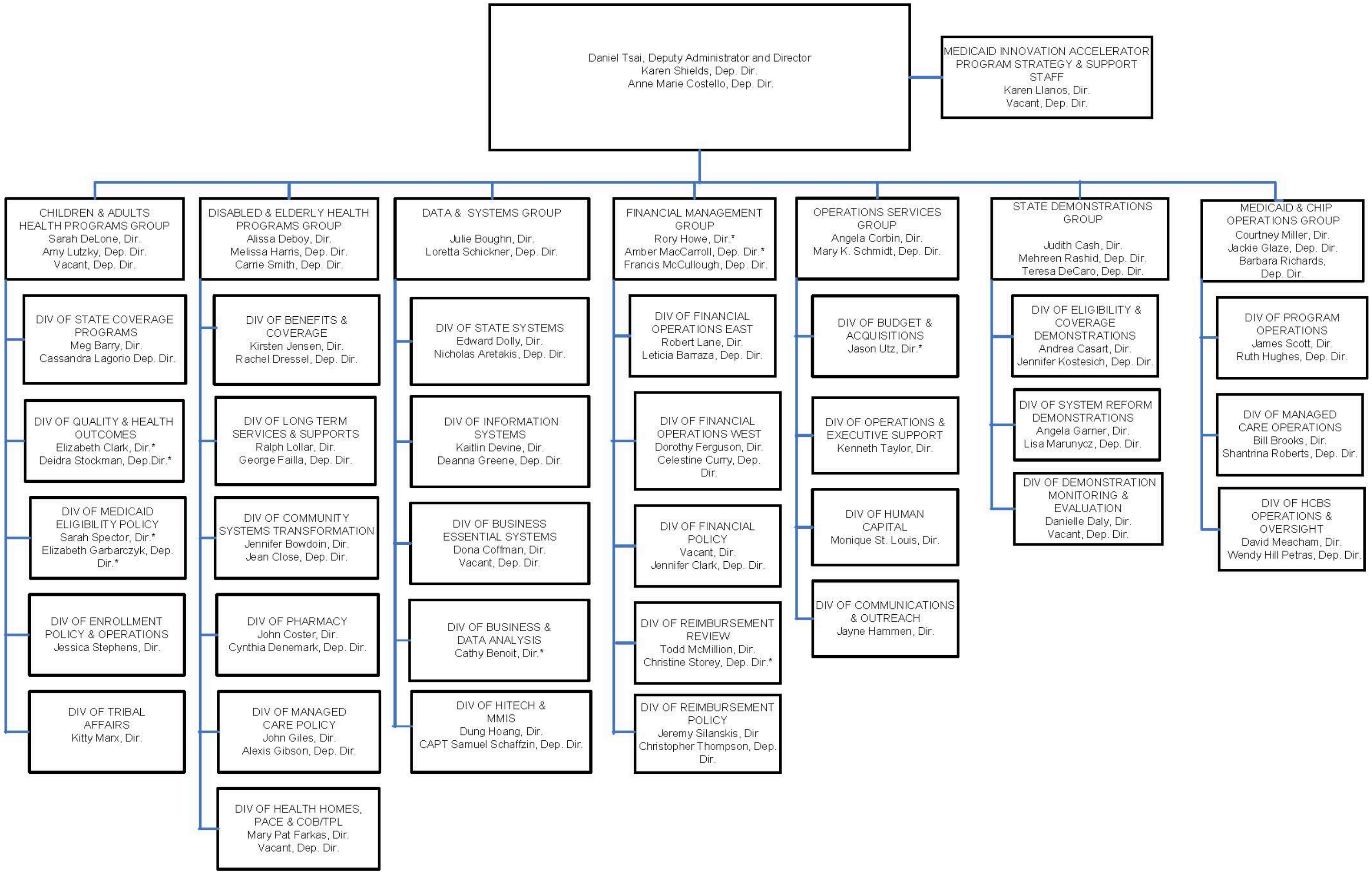
        - iv. Question 12 should also be placed on hold because responses are still unclear and somewhat contradictory.

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**



- Daniel Tsai, Deputy Administrator and Director
Karen Shields, Dep. Dir.
Anne Marie Costello, Dep. Dir.
  - MEDICAID INNOVATION ACCELERATOR PROGRAM STRATEGY & SUPPORT STAFF — Karen Llanos, Dir.; Vacant, Dep. Dir.
  - CHILDREN & ADULTS HEALTH PROGRAMS GROUP — Sarah DeLone, Dir.; Amy Lutzky, Dep. Dir.; Vacant, Dep. Dir.
    - DIV OF STATE COVERAGE PROGRAMS — Meg Barry, Dir.; Cassandra Lagorio Dep. Dir.
    - DIV OF QUALITY & HEALTH OUTCOMES — Elizabeth Clark, Dir.*; Deidra Stockman, Dep.Dir.*
    - DIV OF MEDICAID ELIGIBILITY POLICY — Sarah Spector, Dir.*; Elizabeth Garbarczyk, Dep. Dir.*
    - DIV OF ENROLLMENT POLICY & OPERATIONS — Jessica Stephens, Dir.
    - DIV OF TRIBAL AFFAIRS — Kitty Marx, Dir.
  - DISABLED & ELDERLY HEALTH PROGRAMS GROUP — Alissa Deboy, Dir.; Melissa Harris, Dep. Dir.; Carrie Smith, Dep. Dir.
    - DIV OF BENEFITS & COVERAGE — Kirsten Jensen, Dir.; Rachel Dressel, Dep. Dir.
    - DIV OF LONG TERM SERVICES & SUPPORTS — Ralph Lollar, Dir.; George Failla, Dep. Dir.
    - DIV OF COMMUNITY SYSTEMS TRANSFORMATION — Jennifer Bowdoin, Dir.; Jean Close, Dep. Dir.
    - DIV OF PHARMACY — John Coster, Dir.; Cynthia Denemark, Dep. Dir.
    - DIV OF MANAGED CARE POLICY — John Giles, Dir.; Alexis Gibson, Dep. Dir.
    - DIV OF HEALTH HOMES, PACE & COB/TPL — Mary Pat Farkas, Dir.; Vacant, Dep. Dir.
  - DATA & SYSTEMS GROUP — Julie Boughn, Dir.; Loretta Schickner, Dep. Dir.
    - DIV OF STATE SYSTEMS — Edward Dolly, Dir.; Nicholas Aretakis, Dep. Dir.
    - DIV OF INFORMATION SYSTEMS — Kaitlin Devine, Dir.; Deanna Greene, Dep. Dir.
    - DIV OF BUSINESS ESSENTIAL SYSTEMS — Dona Coffman, Dir.; Vacant, Dep. Dir.
    - DIV OF BUSINESS & DATA ANALYSIS — Cathy Benoit, Dir.*
    - DIV OF HITECH & MMIS — Dung Hoang, Dir.; CAPT Samuel Schaffzin, Dep. Dir.
  - FINANCIAL MANAGEMENT GROUP — Rory Howe, Dir.*; Amber MacCarroll, Dep. Dir.*; Francis McCullough, Dep. Dir.
    - DIV OF FINANCIAL OPERATIONS EAST — Robert Lane, Dir.; Leticia Barraza, Dep. Dir.
    - DIV OF FINANCIAL OPERATIONS WEST — Dorothy Ferguson, Dir.; Celestine Curry, Dep. Dir.
    - DIV OF FINANCIAL POLICY — Vacant, Dir.; Jennifer Clark, Dep. Dir.
    - DIV OF REIMBURSEMENT REVIEW — Todd McMillion, Dir.; Christine Storey, Dep. Dir.*
    - DIV OF REIMBURSEMENT POLICY — Jeremy Silanskis, Dir; Christopher Thompson, Dep. Dir.
  - OPERATIONS SERVICES GROUP — Angela Corbin, Dir.; Mary K. Schmidt, Dep. Dir.
    - DIV OF BUDGET & ACQUISITIONS — Jason Utz, Dir.*
    - DIV OF OPERATIONS & EXECUTIVE SUPPORT — Kenneth Taylor, Dir.
    - DIV OF HUMAN CAPITAL — Monique St. Louis, Dir.
    - DIV OF COMMUNICATIONS & OUTREACH — Jayne Hammen, Dir.
  - STATE DEMONSTRATIONS GROUP — Judith Cash, Dir.; Mehreen Rashid, Dep. Dir.; Teresa DeCaro, Dep. Dir.
    - DIV OF ELIGIBILITY & COVERAGE DEMONSTRATIONS — Andrea Casart, Dir.; Jennifer Kostesich, Dep. Dir.
    - DIV OF SYSTEM REFORM DEMONSTRATIONS — Angela Garner, Dir.; Lisa Marunycz, Dep. Dir.
    - DIV OF DEMONSTRATION MONITORING & EVALUATION — Danielle Daly, Dir.; Vacant, Dep. Dir.
  - MEDICAID & CHIP OPERATIONS GROUP — Courtney Miller, Dir.; Jackie Glaze, Dep. Dir.; Barbara Richards, Dep. Dir.
    - DIV OF PROGRAM OPERATIONS — James Scott, Dir.; Ruth Hughes, Dep. Dir.
    - DIV OF MANAGED CARE OPERATIONS — Bill Brooks, Dir.; Shantrina Roberts, Dep. Dir.
    - DIV OF HCBS OPERATIONS & OVERSIGHT — David Meacham, Dir.; Wendy Hill Petras, Dep. Dir.

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
Health Insurance Specialist
U.S. Department of Health and Human Services
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330 C Street, SW
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Washington, DC 20201
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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 <u>not</u> prohibit <u>nor</u> 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.

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[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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Kris Fair, Committee Secretary

Erin Hopwood, Committee Counsel

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.

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[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.

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[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

sb868_annaburns_fwa.pdf
Uploaded by: Elizabeth LaFrance
Position: FWA

SB868 The Self-Direction Act
Anna Burns
Favorable with amendments

From: finesupport@hotmail.com
Date: February 21, 2022 at 11:38:52 PM EST
To: bernard.simons@maryland.gov
Subject: Urgent health and safety issue - NOTICE OF EXPIRED BUDGET STATUS – FMS STOP PAYMENT – Dept 3388

My son, Michael Fine, requires 24 hour a day care due to significant disabilities and severe self-injury and aggression. He has been approved for Medicaid Waiver self-directed services -which he needs for health and safety reasons- since 2005.

We were notified tonight that the FMS is stopping payment for services due to the DDA's failure to process his current IP and budget in time. The new budget was supposed to go into effect on Jan 1, 2021. We submitted the budget to the DDA months ahead of the deadline. My son's CCS requested a phone meeting to resolve issues via e-mail on Feb 9, 2022.

No one from the DDA will even respond to her. We can not resolve the issue since no one from the DDA will talk to us. We cannot exercise our legal right to file an appeal under Medicaid regulations since no one from the DDA will issue a denial in writing. It is my understanding that Medicaid regulations require that health and safety needs of participants

Sincerely,

Anna Burns

Sent from my iPhone
Begin forwarded message:

sb868_debbiehamann_fwa.pdf

Uploaded by: Elizabeth LaFrance

Position: FWA

SB868 The Self-Direction Act
Debbie Hamann
Favorable with amendments

From: Debbie Hamann <expressionscater@aol.com>

Date: Tue, Mar 1, 2022 at 2:49 PM

Subject: Self direction act bill

To: <Matt.Morgan@house.state.md.us>

Cc: Carol Custer <carol@custerllc.com>

Hi Matt:

We have met a few times and talked regarding self direction. I was the owner of. Expressions of St Marys catering company (located at historic St. Marys City) until I retired in 2015.

I live in Leonardtown and have an adult special needs son who, after being neglected and abused in his St Mary's Group home, was brought home four years ago to live with me under a Community Pathways Waiver called Self Direction. This means, with his current budget, he and his team of supports, decide how to spend it, hire his own support staff, community learning supports, camp, etc.

This was crucial for Ryan's health and welfare and he's back to being happy and secure again. I am allowed under self direction to be one of his caregivers (personal supports) which has enabled me to take him to multiple outings and get him trusting people again.

Over the past few years, DDA has been veering away from the initial backbone of this program. We, as SDAN which is the Self Direction Advocacy Network, have been lobbying to get this program back to its initial purpose which allows family to be staff, allowed to have a support broker to help with HR type duties, have overnight supports (removed from the program!!!) as well as other important issues. The overnights is extremely important to me as I still work nights and weekends as well as need some personal breaks. Without this, I couldn't be the full time person to be with Ryan. He would have to go back to a group home which would be devastating!

I am asking for your help. As a constituent in your district, Can you please support Bill SB868/HB1020

I would love to talk with you if you need more information. Any help you can give to convince anyone else on your committee would be appreciated and I am offering my assistance as well.

All my <image0.jpeg>Best! (This is Ryan enjoying being at home with his dog)

Debbie Hamann

301-717-2211

41710 Mattingly St

Leonardtown, Md. 20650

SB868_elafrance_fav.pdf
Uploaded by: Elizabeth LaFrance
Position: FWA

SB868 Self-Directed Act

Elizabeth LaFrance

In favor

Not one of us would choose to be disabled, much less to be disabled and put 'in a program'.

At its core, the Self-Direction Act is an endorsement of the right to determine the course one's own life.

Self-direction upholds the fundamental values that we all share:

- Limited Government.
- The Rule of Law.
- Fiscal Responsibility.
- Free Markets.
- Human Dignity.

In traditional services, a provider business chooses to accept the participant; people with high needs are left with few, if any, options because providers refuse to service them. Providers determine which staff work with participants, and often the activities that they do. Participants may need to go to the providers location or settle for virtual services. In some cases, providers choose where a participant lives and who lives with them.

In self-directing their services, people with disabilities—often with the support of families, case managers, and support brokers—personally choose their own staff, they choose the activities they do at home and in the community. They choose where and with whom they live. Often at far less cost than traditional services, which is heavy on overhead and management salaries.

It's understandable that traditional providers and the Developmental Disabilities Administration itself are opposed. Preserving the status quo is seemingly in their own self-interest.

Self-direction is contrary medical model of disability, where the experts know best and disabled persons have no agency. They are a problem to be managed.

There are changes that traditional providers and DDA could allow which would keep people in self-direction as their customers… DDA could simply allow people in self-direction to choose from a menu of provider services. Providers would have to create services that people want to choose, rather than enjoy a monopoly on the participants they accept.

Thank you for your time and attention.

Please, stand up for Maryland citizens with different abilities. Stand up for Maryland families.

Support the Self-Direction Act of 2022.

sb868_heathernewcomb_fwa.pdf

Uploaded by: Elizabeth LaFrance

Position: FWA

SB868 The Self-Direction Act
Heather Newcomb
Favorable with amendments

----- Forwarded Message -----
From: Heather Newcomb <changedgoals@yahoo.com>
To: jb.jennings@senate.state.md.us <jb.jennings@senate.state.md.us>
Sent: Friday, February 18, 2022, 08:22:38 PM EST
Subject: SB868/HB1020 The Self-Directed Services Act of 2022

Senator Jennings

I am reaching out to you to encourage you to vote in support of SB868/HB1020 The Self-Directed Services Act of 2022. If passed this act will maintain and restore support services to individuals with intellectual and developmental disabilities that are tailored to meet their needs, like my daughter Hanna. The Self-Directed Services Act allows participants to have choice and control over their Medicaid waiver services and how their budget is spent while fully adhering to all applicable laws and rules/regulations set forth by CMS.

The Self-Directed Services Act personally helps, my daughter Hanna, maintain the flexibility of allowing her to continue to choose family as staff to supply her support services. This flexibility of staff choice is crucial for her due to her profound disabilities and medical fragility. Another reason this act is so important to us is that it restores the reinstatement of the Self-Directed Overnight Support Service. This support service was removed from the waiver in 2018. The Overnight Support Service is essential for the health and safety of the participants who meet the need for this service.

It has taken me years to navigate and advocate for services for my daughter. Having services available that are flexible and can be tailored to meet the needs of the participant result in a more positive outcome. The Self-Directed Service Act of 2022 supports this flexibility, and in most cases, provides a less expensive outcome for the state of Maryland.

You have helped me in the past with some Maryland Medicaid waiver service issues for my daughter. I am hoping that you will also support the self directed community of intellectual and developmentally disabled persons with passing SB868/HB1020 The Self-Directed Services Act of 2022.

Sincerely,
Heather Newcomb for participant Hanna Newcomb

sb868_josephlindemon_fwa.pdf

Uploaded by: Elizabeth LaFrance

Position: FWA

SB868 The Self-Direction Act
Joseph Lindemon
Favorable with amendments

Joseph Lindemon
22 Brian Daniel Ct.
Reisterstown, Md. 21136

Legislative District 10

The Honorable Delores Kelly
3 East Miller Senate Office Building
11 Bladen St.
Annapolis, Md. 21401

Dear Senator Kelly,

I am writing you today in reference to House Bill 1020 – SB 868 **the Self-Directed Service Act.** There is no bill that I can think of that better represents President Biden's desire for us all to "Build Back Better." Here is a rare opportunity to restore services to the control of the adults in DDA's self-direction option, without costing the state any additional funding. I am a 40-year special educator in the state of Maryland, in addition to being a proud parent of the 29-year-old adult son with Autism. In my 40 years I have seen many attempts to support the developmentally disabled community, but self-direction is the only program where the participant has control over decisions affecting their day-to-day life. In the last several years that control has been eroded by decisions beyond the control of the disabled community. This bill, **House Bill 1020 – SB 868,** will restore autonomy to Self-Direction Services and provide the greatest possibility for equitable outcomes for the clients it serves.

My son Dylan Lindemon is a primary example of why self-directed services are a viable life choice for so many adults with neurological challenges. Because of a birth injury, he lives in a constant state of anxiety that sometimes results in rage episodes that causes him to self-injury and be aggressive. Dylan's psychiatrist has diagnosed him with Intermittent Explosive Disorder which causes him to overreact to small inconveniences or annoyances. His psychiatrist equates his behavior to the road rage adult on our highways today. Dylan also suffers from a severe speech and language disorder. While he understands nearly every word he hears, he lacks expressive speech. We believe that the frustration this causes him compounds his Intermittent Explosive Disorder.

I cannot describe how difficult life with Dylan can be, but I can tell you that self-direction has enabled him to grow and given us hope. Were Dylan enrolled with a traditional provider; I believe their emphasis would be on containing his behavior and minimizing risk. He would likely spend his days languishing in a very restrictive setting. Self-Direction has empowered us to work towards real solutions. We have learned that Dylan copes best in an environment that allow for flexibility, choices, clear expectations, and consistent adult support. In self-direction we are able to provide Dylan with an environment that minimizes the outbursts and allows him to safely participate in his community. We have also discovered a remarkable communication program, known as Spelling 2 Communicate (S2C) that enables people with autism to use a spelling board to express themselves. I now know that I have a remarkable intelligent and observant son who has so many feelings and opinions to share. I know this because he is able to spell those thoughts about himself to me.

To support Dylan we have assembled an extensive team, including his psychiatrist, his language consultant, a board certified behavior analyst, his support broker, his coordinator of community services, and his self-directed staff members. We have learned how to implement his S2C communication program and hope to teach his employees to use it as well. For us and for people like Dylan there are no magic bullets. We have plenty of bad days, and progress is slow and intermittent. But self-direction has helped Dylan begin to realize his personal potential.

The Self-Directed Services Act will ensure that Dylan retains the ability to self-direct and can continue to access and customize available DDA resources to promote growth and to meet his specific needs. It is my goal, as I'm sure it is with you, that we do all we can to help our children achieve a successful adult life. Please help me fulfill this dream for my son and the many other sons and daughters receiving self-direction services.

I am asking you to vote in the affirmative for **Bill 1020 – SB 868**.

Thank you for your time and May God bless you.

Sincerely Joseph Lindemon

sb868_kayspain_fwa.pdf

Uploaded by: Elizabeth LaFrance

Position: FWA

SB868 The Self-Direction Act
Kay Spain
Favorable with amendments

Hello, my name is Kay Spain, mother of 35 year old daughter Christy Spain who has an acquired traumatic brain injury from an automobile accident in 1999. Christy is very intelligent, however she has gone blind in her right eye and has left side hemiplegia which causes her to have balance issues. Christy needs assistance with her meals, addressing her daily pills to take, needs reminders as her TBI causes her to have short term memory issues. Christy is unable to drive and uses a scooter or wheelchair to navigate the community. We are currently with the Self Directed Agency in Carroll County Md.

I am for the Bill HB1020/SB868 Self Directed Advocacy.

We went with the Self Directed Program in November of 2019 because the agency we were with was having issues with regards to the consistent care of Christy. It was the best decision we could have made. Christy was traveling over an hour each way, while picking up other clients, sometimes with drivers not showing up on time. Once Christy would get to her agency the staff was always changing and Christy would routinely be placed in a small room to do word puzzles on the computer until a staff member would be assigned to her. Her days had become non-routine and not consistently challenging. It was more of a “lets fill the day with stuff to do” rather than a progressive program which she deserves.

Part of continued progressive care for Christy includes consistency, scheduled events, low stress environments and positive experiences. Christy is a generous, funny, creative and positive young lady. Currently she now has a part time job at Michaels Craft store in Westminster, has horseback riding lessons in good weather, goes to physical therapy twice a week, volunteers in the community (is a member of the AKTION Club, the South Carroll Lioness Lions club), crafts, bakes, goes to social activities including theater, music events and more.

Currently there is no Self-Directed Overnight Supports (This waiver service was removed in 2018). **I personally was unaware of this and am extremely concerned**. Christy’s life, your life, and my life does not shut down at 4 or 5 p.m. and then again restart at 8 or 9 a.m. If something were to happen to me, Christy could be in a potential disastrous situation without assistance from 5 p.m. to 9 a.m. As stated before she needs daily assistance with many daily tasks that you and I take for granted.

We also need to have DDA to be transparent and consistent with what is approved, not to have rights and things that have been approved taken away (as the overnight supports was in 2018). We rely on consistent care, that we can rely on. Our support staff is extremely important to us and they need to rely on their benefits so they stay with us. They become family, trusted individuals that we don’t want to leave.

Once again we are for **the Bill HB1020/SB869 Self Directed Advocacy.**

Thank you for your time.
Kay Spain Kspain50@gmail.com

SB868_pauletteroseboro_fwa.pdf

Uploaded by: Elizabeth LaFrance

Position: FWA

SB868 The Self-Direction Act
Paulette Roseboro
Favorable with amendments

From: paulette roseboro <proseboro@hotmail.com>
Subject: Meeting Regarding Senate Bill SB868 - The Self-Directed Services Act of 2022
Date: March 1, 2022 at 4:11:45 PM EST
To: "joanne.benson@senate.state.md.us" <joanne.benson@senate.state.md.us>
Cc: Alicia Wopat <awopat@comcast.net>, Ranetta Marable <ranettamarable@yahoo.com>

Thank you, Senate Benson, for taking the time to meet with us yesterday evening. Thank you for sharing how, Tody, Ranetta and Mike's family dog (also known as my “Grand-pup”) has impressed you. He does brighten up a day with his enthusiasm at just enjoying his life.
The self-direction service option under the Developmental Disabilities Administration (DDA) can be a very successful way for recipients and their families and/or caregivers to receive support services based on the recipient's personal goals and desires. This service option is provided under the Centers for Medicare and Medicaid (CMS) for states to allow waiver participants the greatest flexibility to obtain support services under the Home and Community Based (HCBS) waiver.
Although this service method is challenging and paperwork intensive, participants and their chosen support team, have the best opportunity to develop a personalized program that builds skills and provide enriching experiences which places the individual on the best trajectory to successfully reach their goals, integrate into their community, and increase opportunities for employment.
As I mentioned in our meeting, upon the start of the COVID pandemic Brianna was able to transition from her in-person activities to virtual relatively easy. Brianna receives her HCBS services under the self-directed service method. This is allows her to have a direct relationship with the individual (her staff) or agency (business) delivering her services. With this direct and flexible relationship, Brianna and her caregiver and program coordinator (me) could creatively make the necessary changes to her then current services to virtual programming and add new virtual programming. This has significantly enhanced Brianna's skill building capabilities. This was accomplished quicky, with very little disruption of services, and with continuity in her service delivery.
What Senate Bill SB868 (The Self-Directed Services Act of 2022) does is to provide increased flexibility to the maximum allowed under CMS guidelines, choice, and transparency. All of this can be accomplished within CMS guidelines and with no increase to Brianna's available funding. Self-direction is a very cost-effective service delivery method. Increasing the participant's flexibility does not increase the participant's funding but it will allow recipients further opportunity to obtain the greatest and most cost-effective use of their funding.
We ask that you favorably review and vote to pass this bill.

Finally, please don’t hesitate to contact me if you have any additional questions regarding the self-directed service method and its success for Brianna and many of her peers living in Prince George's County. Many other families living in Prince George's County who have members with developmental and intellectual disabilities could greatly benefit from this service method.
Please note that I have reviewed Senate Bill 660 and will send you my comments under a separate email.

Thank you again,
Paulette and Brianna Roseboro

1 Staton Drive, 20774

sb868_ruthlitzenberger_fwa.pdf

Uploaded by: Elizabeth LaFrance

Position: FWA

SB868 The Self-Direction Act
Ruth Litzenberger
Favorable with amendments

Re: The Self-Directed Services Act of 2022 (HB1020/SB868)

I have a 28yo granddaughter with severe autism. I am a significant part of her care. She has no physical disabilities, but her thought processes are ‘different’. She has been in the SDS Program several years, and she is doing well in meeting the goals of the program.

We have accomplished this by using some of her 4 siblings as staff. They understand her communication signs and limited vocal language. We have had outside instructors in the past that have been sporadic in helping us thru many of life’s changes.
We feel the need to continue using family as staff at this point, so we’re asking it be continued as part of the program.

During 2020-2021, we were without a Support Broker. It was very difficult to complete C’s Participant Care Plan especially with the changes the Covid pandemic imposed. We never were able to use any of the $2000.00 expense money provided in the waiver.

We now have an experienced Support Broker whose work in invaluable in keeping us using all parts of this complex program correctly. Having a Support Broker is a vital part of the program. Please help us keep this service.

C’s current Service Coordinator is excellent in helping us put together & submit the annual renewal of C’s Participant Care Plan. In fact, it is already approved for the 2022-2023 year. This has not been the case in the past and I strongly support funding for training for new service coordinators as they are newly employed to be our vital link with the DDA.

We use the ‘team approach’ with C. to complete her paperwork. She signs her own staff timesheets. Her competency to participate in the SDS program is verified in many ways. Staff has worked with her to achieve progress with the best outcomes. Please help us keep this ‘team approach’ for C. and others needing assistance in completing the requirements of the program.

I am asking for your support for SB868/HB1020, the Self Direction Act of 2022.

Thank you for listening and for all the work that you do,

Ruth Litzenberger
910 Taxus Drive #102
Odenton, MD 21113-3798
410-695-2303
ruth.litz@comcast.net

sb868_susankrebs_fwa.pdf

Uploaded by: Elizabeth LaFrance
Position: FWA

SB868 The Self-Direction Act
Susan Krebs
Favorable with amendments

From: caseyhuether@aol.com
To: susan.krebs@house.state.md.us <susan.krebs@house.state.md.us>
Sent: Wed, Feb 16, 2022 3:25 pm
Subject: House Bill 1020/Senate Bill 868, The Self Directed Services Act of 2022

Hello,

I am a citizen of Carroll County who votes and pays taxes. I live in Finksburg with my 23 year old daughter Eva who has Down syndrome. She recently began receiving Medicaid waiver services through self-direction, which means she is able to hire her own staff to support her, determine how her Medicaid budget is spent and tailor her daily activities to meet her needs and interests. Under the old traditional method, most young adults with intellectual/developmental disabilities were forced to use agencies who provided one size fits all services. Self-directed services give Eva the choice on how to spend her budget for services she wants to live her best life.

We are asking for your support on passage for HB1020/SB868. This bill has three simple goals. It gives greater equity and access to appropriate services for self-directed participants, restores flexibility that was taken away by DDA and presumes competence of the individuals who the program is designed to serve. We have a team that supports Eva in her decisions on what she needs and how to spend her budget. We've helped her hire staff who take her shopping, out to exercise, visit with friends and volunteer for meals on wheels delivery. Eva has plans to get a job once we know it's safe from Covid. She's working hard to become more independent because I will not be around forever. It comforts me to know her support system will be set when I'm gone.

Please vote to recommend passage of this bill out of committee. Everything in this bill complies with CMS rules/regulations ensuring the federal match. Current DDA policies forfeit matching funds unnecessarily. As the mother of someone with a developmental disability, I ask for your uncompromising support of her right to choose the types and intensity of supports and services she receives, so that she has control over how she wants to live her own life, just like the rest of us.

Please feel free to contact us if you have any questions about how self-directed works, or if you want more info. Thanks for your support,

Casey and Eva Huether
989 Ridge Road
Finksburg MD 21048
(410) 935-0618

sb868_terripumpitis_fwa.pdf

Uploaded by: Elizabeth LaFrance

Position: FWA

SB868 The Self-Direction Act
Terri Pumputis
Favorable with amendments

From: "Terri Pumputis" <tp@slatehillrabbitry.com>
To: "delores.kelley@senate.state.md.us" <delores.kelley@senate.state.md.us>
Sent: Thu, Feb 24, 2022 at 10:51 AM
Subject: The Self Direction Act - (SB868/HB1020)
February 24, 2022

Honorable Senator Delores G. Kelley,

As one of your constituents, in Baltimore County, Reisterstown, I am writing in hopes that you would support The Self-Direction Act - (SB868/HB1020). These are several subjects in the bill that pertain to my son. 1)No prohibition to having family as staff per CMS rules. If it wasn't for family members, a lot of participants would not have any program. This will ensure that family members will always be able to work as staff following CMS rules. 2) Remove competency requirements in favor of Team Support. Since my son has been in this program, it has always been a team approach, which makes for a better program. As there are many points in the bill that pertain to my son and many others in the Self Directed program, these items in the bill do not cost the State of Maryland any more, conforms to CMS guidelines and the State of Maryland will NOT lose any Federal funds.

A little history about my son. Once my son left school, he started in a vocational program with a Provider Agency in Westminster. The situation started out well, but didn't end that way. My son started getting aggressive for OCD issues associated with favorite items, that were out in the open. It was suggested putting some of these things away (out of sight, out of mind). It was decided by the Provider Agency that they weren't going to remove those items, so my son started getting aggressive. We worked with DDA to suggest even having two 1:1's for my son, but the agency decided to discharge him from their program anyway, because they weren't going to work with individuals with behavior issues.

So, in 2014 we were left with deciding what else to do. I (as my son's parent) ended up leaving my employment, and with the CCS, Support Broker, him and our family, we decided that my son would be applying for the Home & Community Self Direction program. The Self Direction program has allowed my son to choose family as staff (which has been the best choice for him), he makes his own schedule, he does things that he wants to do and what is important to him. He likes feeding the ducks at the pond, we've taken his love of doing puzzles and developed that into him working on mosaic art projects. His mosaic tile projects have been shipped to many states. He also has the opportunity of volunteering at The Retreat at Beckleysville (therapeutic horse farm) several days per week. Feeds several horses at another farm multiple times per week. He's learned how to use many household items as dishwasher, washer & dryer, etc. He likes cooking (one of his favorites). He goes into the community almost every day, and with him being in the Self Directed program, it has allowed him to live at home with his family, which is the least costly option then in a residential facility. Right now in the Self Directed program, he is living the life he wants to live!

I'm truly hoping you would consider supporting The Self-Direction Act (SB868/HB1020), as it is very important to many individuals, and helps keep the original scope of The Self Direction program.

If any questions, you can contact me at 410-382-7519, or email: tp@slatehillrabbitry.com. Look forward to hearing from you.

Regards,
Terri Pumputis & Justin Sauter

SB 868 Self-Direction 2022 DRM.pdf

Uploaded by: Megan Rusciano

Position: FWA

Disability Rights Maryland

Empowerment. Integration. Equality.

1500 Union Ave., Suite 2000, Baltimore, MD 21211
Phone: 410-727-6352 | Fax: 410-727-6389
www.DisabilityRightsMD.org

Senate Finance Committee
March 8, 2022
SB 868: Developmental Disabilities Administration – Self-Directed Services
Position: Support with Amendment

Disability Rights Maryland (DRM), formerly *Maryland Disability Law Center,* is Maryland's federally-designated protection and advocacy organization charged with advancing the rights of people with disabilities for over 40 years. In our practice, DRM has seen firsthand both the value and opportunities that people with intellectual and developmental (I/DD) disabilities have when they utilize self-directed services and the difficulties they encounter due to systemic issues and barriers in the program. We understand that sponsor has made significant amendments to this bill that we support. We believe that the few additional changes outlined below help preserve the bill's focus on ensuring the people with I/DD have access to the supports and services they indicate they need. We have spoken with the advocates who have driven this bill and understand that they are amenable to making these changes. **As such, DRM currently supports SB 868 with the amendments outlined below, but we anticipate being fully and strongly supportive of the bill once these changes are made.**

Background:
Today, a growing number of people with developmental disabilities are choosing to direct the supports and services they receive in the community through the Developmental Disabilities Administration (DDA). This means that people with disabilities, with support from their families and others, as needed, take responsibility for managing their services, including choosing, hiring, and supervising the people who provide their direct support. In this way, self-direction allows a person to be the architect of their services—it increases a person's self-determination by empowering them to make fundamental decisions about how and from whom they receive supports.

In 2005, the state of Maryland worked with people with developmental disabilities, families, and other advocates to create a waiver pilot program under which people self-directed the funding they received from the DDA for their needed supports. By allowing people with I/DD to make funding decisions about services and supports, it gave them more choice and control over what services they received. Individuals in the initial pilot reported remarkable improvements in quality of supports and quality of life. What started as the "New Directions" waiver pilot, became the DDA self-directed services option available through the Community Pathways, Community Supports, and the Family Supports Medicaid waivers in Maryland.

Over time; however, self-directed service definitions and the structure of the program changed significantly through waiver amendments. While some of these changes were necessary to improve oversight, many of these changes have altered and complicated the program's successes. Some service options were eliminated; allowable expenses for services and supports were restructured; and, many of the duties that Support Brokers – people designated by the person to assist with the coordination of self-directed services – were eliminated.

In the wake of the 2021 legislative session, a work group was established to review and make recommendation on how the self-directed services system can be improved in Maryland. DRM participated in that work group and supports its recommendations, the vast majority of which are codified in this bill. We appreciate the commitment of the Department of Health in that workgroup to reforming and bettering the self-directed services system. We recognize; however, that statutory changes are necessary to cement these changes into law.

WHY is this legislation important?

The intention of this bill is to restore and preserve the principles of self-direction envisioned in Maryland and it does so by doing the following:

- Ensuring that all people with disabilities, regardless of their physical or intellectual capacity, can self-direct their services and get the support that they need to do so from people they choose, hire, and trust.
- Codifying access to awake overnight supports, which has been a critical advocacy issue in our community for the past several years.
- Restoring some definitions that were changed in waiver amendments to their former forms, including who people with I/DD may hire as staff and many of the roles of the support broker. This will allow people who do not have access to robust family supports to receive the support they may need to self-direct their services.

What amendments do we believe are needed?

We believe the following amendments help preserve the bill intent and ensure that self-directed services are driven by people with I/DD. Again, we reiterate that we understand that the advocates who have driven this bill are amenable to these changes and as such we anticipating being fully supportive of the bill once these changes are made:

- **Amend the definition of person-centered plan in §7-101(R)(2) to "ensures that the individual is the primary contributor and may receive support from others they choose to develop the plan**". The change in this language is critical to ensuring that the person with I/DD and no one else remains the primary contributor to the person-centered plan. While they may receive support from others of their choosing, they must remain at the center of the development of their person-centered plan.
- **Amend sections, §7-101(AA) by deleting "the individual's family or other representative" and §7-408(B) so that it reads "to assist the recipient and others of their choosing"**. The intent of self-direction is that the person with I/DD is in control of their services. Changes are needed to ensure that while people with I/DD may need support from family and others to make informed decisions, that they remain in control of their services. It is implied that a legal representative would have authority to make decisions for a person if that person lacks the capacity to do so, but as drafted this language appears to automatically grant deference and authority to family members and representatives that may not be contemplated or authorized by the person.

While we do not seek an amendment on this issue, we recognize that the bill changes the nature of individual and family directed services to include services and supplies that are not currently available to people in traditional services. **We underscore the need to ensure parity in the Waiver system, so that there is not greater inequity between people who self-direct their services and those in provider-managed services.**

DRM strongly believes that everyone with an intellectual and/or developmental disability should have the option to self-direct their services, and have access to any support necessary to be successful in doing so. We support Senate Bill 868 as it makes critical changes that will greatly improve and expand the self-directed services program. We believe the small amendments above will be incorporated into the bill shortly and will further enable more people to have the opportunity to manage and control their services.

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Uploaded by: Rachel London

Position: FWA

Maryland Developmental
Disabilities Council

CREATING CHANGE • IMPROVING LIVES

Senate Finance Committee
March 8, 2022
SB 868: Developmental Disabilities Administration – Self-Directed Services
Position: **Support IF Amended**

The Maryland Developmental Disabilities Council (DD Council) is a statewide public policy organization that creates change to make it possible for people with developmental disabilities to live the lives they want with the support they need. The DD Council is led by people with developmental disabilities and their families. From that perspective, the DD Council supports SB 868, but only if amended.

We understand the Sponsor has significant amendments, most of which the DD Council supports. In addition to some of those amendments, we can support if the following recommendations are addressed:

1. **Strengthen language about the person by deleting "and family or representative" from the proposed amendment to §7-408(B) and by deleting "the individual's family or other representative" §7-101(AA).** The goal of self-directed services is to provide people a greater degree of choice and control in how services are delivered. **The person with a developmental disability is at the core of the choice and control.** While people with disabilities sometimes need support from family and others to make informed decisions, we believe it is a problem to codify "and family or representative" in any part of a law created to ensure the person has choice and control.

2. **Amend the definition of person-centered plan in §7-101(R)(2) to "ensures that the individual is the primary contributor and may receive support from others they choose to develop the plan."** The change in this language is critical to ensure the person with developmental disabilities and no one else remains the primary contributor to the person-centered plan. While they may receive support from others of their choosing, they must remain at the center of the development of their person-centered plan.

3. **Remove the proposed amendment to §7-409(A)(6) in its entirety.** The proposed amendment would give people the ability to use funds to hire someone to help manage the person's "home, staff, and other administrative duties." **This is already within the allowable functions of a support broker, and is therefore too broad and unnecessary.** In addition, the proposed amendment adds the ability to use funds to "pay administrative expenses needed to operate the recipient's plan of service including internet services and office equipment. **This is not an allowable expense through any Medicaid waiver.**

4. **Remove the proposed amendment to §7-409(C)(I).** People who self-direct their services receive up to $5,500 for individual and family direct services. According to the approved waiver application, this is for "services, equipment, or supplies that enable the participant to maintain or increase independence and promote opportunities for the participant to live in and be included in the community, relate to a participant's need or goal identified in the participant's Person-Centered Plan, and are not available under the Waiver program or Maryland Medicaid Program." **Similar funds are NOT available to people in traditional services, therefore, removing the cap of $5,500 to individual and family directed services creates greater inequity between people who self-direct their services and people supported by a provider.**

Background: Today, a growing number of people with developmental disabilities are choosing to direct the supports and services they receive in the community through the Developmental Disabilities Administration (DDA). This means that people with disabilities, with support from their families and others, as needed, take responsibility for managing their services, including choosing, hiring, and supervising the people who provide their direct support. In this way, self-direction allows a person to be the architect of their services—it increases a person's self-determination by empowering them to make fundamental decisions about how and from whom they receive supports.

In 2005, the state of Maryland worked with people with developmental disabilities, families, and other advocates to create a waiver pilot program under which people self-directed the funding they received from the DDA for their needed supports. By allowing people with IDD to make funding decisions about services and supports, it gave them more choice and control over what services they received. Individuals in the initial pilot reported remarkable improvements in quality of supports and quality of life. What started as the "New Directions" waiver pilot, became the DDA self-directed services option available through the Community Pathways, Community Supports, and the Family Supports Medicaid waivers in Maryland.

Over time; however, self-directed service definitions and the structure of the program changed significantly through waiver amendments. While some of these changes were necessary to improve oversight, many of these changes have altered and complicated the program's successes. Some service options were eliminated; allowable expenses for services and supports were restructured; and, many of the duties that Support Brokers – people designated by the person to assist with the coordination of self-directed services – were eliminated.

WHY is this legislation important?

The intent of this bill is to restore and preserve the principles of self-direction in Maryland and it to some extent it does that by:

- Ensuring that all people with disabilities, regardless of their physical or intellectual capacity, can self-direct their services and get the support that they need to do so.
- Restoring some definitions that were changed in waiver amendments to their former forms, including who people may hire as staff and many of the roles of the support broker. **This will allow people who do not have access to robust family supports to receive the support they may need to self-direct their services.**

After the 2021 legislative session, a work group was established to study and review self-directed services in Maryland. A number of policy recommendations were made by members of the work group. **While this legislation, with the drafted amendments, addresses some of them, the Council wants to ensure people with developmental disabilities remain the focus of self-directed services. We remain concerned about the resulting inequities for people with developmental disabilities who do not self-direct their services.**

Contact: Rachel London, Executive Director: RLondon@md-council.org

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Uploaded by: Heather Shek

Position: INFO

Maryland
DEPARTMENT OF HEALTH

Larry Hogan, Governor · Boyd K. Rutherford, Lt. Governor · Dennis R. Schrader, Secretary

March 8, 2022

The Honorable Delores G. Kelley
Chair, Senate Finance Committee
3 East Miller Senate Office Building
Annapolis, MD 21401-1991

RE: SB 868 - Developmental Disabilities Administration – Self–Directed Services (Self–Direction Act of 2022) - Letter of Information

Dear Chair Kelley and Committee Members:

The Maryland Department of Health (MDH) respectfully submits this letter of information for Senate Bill (SB) 868 **-** Developmental Disabilities Administration – Self–Directed Services (Self–Direction Act of 2022).

It is estimated that SB 868, as written, will cost MDH an annual increase between $280,176,403 and $558,151,603, with a $140,088,202 – $279,075,802 General Funds impact. This approximation is based on utilization of 50% – 100% of these services for one full year.

It should also be noted, MDH worked tirelessly this past year with the Health and Government Operations (HGO) Self Directed Services Workgroup led by Delegate Lewis-Young. The workgroup was comprised of advocates, stakeholders, and elected officials attending monthly meetings from July through December, 2021. Several subgroups also held additional meetings during that time. MDH continues to have the shared goal of promoting and strengthening self-direction as a service modality that firmly represents our values for empowerment, choice, and control.

At the first workgroup meeting and several times thereafter, it was stated the goal was for the advocates, stakeholders, and MDH to come to a compromise in order to avoid legislation. MDH took this charge seriously and worked tirelessly throughout the second half of the year to accomplish this mission. As a result of the meetings, the workgroup developed six (6) recommended areas for policy changes.

MDH reviewed all the recommendations and shared at the final workgroup meeting that MDH is committed to immediately focusing on three of their specified action areas: (1) near term expansion opportunities, (2) potential expansion opportunities, and (3) areas where the requested flexibility already exists. Areas being actioned by MDH in the near term include, but are not limited to, increasing the allowable support broker hours per month, updating the support broker definition for stronger alignment with the Centers for Medicare and Medicaid Services definition, allowing overnight support as a component of personal supports, and coordination of community services orientation to new and current participants. Please note, all of the recommendations put forth by the workgroup are contributing to MDH's roadmap for our self-direction priority areas and expansion opportunities.

MDH looks forward to continuing to advance the work ahead using the established workgroups and committees to engage and update on the areas of opportunities. We will also leverage these groups to address the areas identified as currently available, but where increased resources and education is needed to ensure that the flexibility of self-direction and the vital role of families in these services is well understood and accessed.

If you have any questions, please contact Heather Shek, Director of Governmental Affairs, at heather.shek@maryland.gov or (443) 695-4218.

Sincerely,

Dennis R. Schrader

Dennis R. Schrader
Secretary

letter of information, Senate Bill 868 the arc Mar

Uploaded by: Mathew Rice

Position: INFO

The Arc
Maryland

People
On the
Go
Maryland

Senate Finance Committee
March 8, 2022
SB 868: Developmental Disabilities Administration – Self-Directed Services

Letter of Information

The Arc Maryland and People on the Go of Maryland are two state-wide advocacy organizations dedicated to the rights and quality of life of and for people with intellectual and/or developmental disabilities. There are currently close to 2000 individuals supported in DDA HCBS Waivers who self-direct their services and support. This means that people with disabilities, with support from their families and others if needed, take responsibility for managing their services, including hiring and supervising the people who provide their direct support.

The intention of this bill is to restore and preserve the principles of self-direction envisioned in Maryland by and for people with intellectual and developmental disabilities. This bill has been brought before the general assembly twice previously, but this bill version comes after a summer-long workgroup, where stakeholders, DDA, and members of the House and Senate came together to try to work through some of the issues and develop solutions. While much work was done this session, and recommendations were made, the workgroup did not have time to work through how certain recommendations could be operationalized to effectively protect the federal match of Medicaid funding upon which the state relies, and to fully meet the intentions of the advocates.

We believe that people with disabilities should be empowered and supported to self-direct their services and to **receive assistance to do so from people they choose, hire, and trust, including family members** with protections built into their plans to address any conflicts of interest.

Self-Directed service options should be designed with **cost-neutrality** in mind compared to traditional service costs and should be flexible to meet the needs of the individual to meaningfully live, learn, work, play, and worship as the person chooses.

While The Arc Maryland and People on the Go (POG) agree with several bill components detailed below and the need to codify certain definitions to restore services and supports to the self-directing participant, there are a couple of changes the bill proposes about which we have concerns. We believe that unintended consequences may come from codifying some of the suggested changes to the program. These are described below.

First: some background on Self-Directed Services.
In 2005, the state of Maryland worked with people with IDD, families, and other advocates to create a waiver pilot program under which individuals with intellectual and developmental disabilities self-directed the funding they received from the Developmental Disabilities Administration (DDA) for their needed supports. The program was called “New Directions,” and it allowed people to hire their own staff and make decisions regarding where and how their funding

would be used to access service options they needed. By allowing people with IDD to make funding decisions about services and supports, it gave them more choice and control over what services they received. The belief was that as a result, funds would be spent more effectively and efficiently. **What started as the "New Directions" waiver, became the DDA self-directed services option available through the Community Pathways, Community Supports, and the Family Supports Medicaid waivers in Maryland.**

Over time, the self-directed service model has remained a wonderful service model for many with IDD, however through waiver amendments, the service definitions and the structure of the program changed significantly over time without clear reasons for some of the deep changes.

We agree with the components of this bill to:

1. **Restore family as staff (with safeguards).**
2. **Restore Awake Overnight as a service that can be self-directed.**
3. **Restore more hours and duties to the Support Broker service option.* (<u>with caveat</u>)**
4. **Ensure CCS provide accurate and complete information to individuals on both the traditional service and self-direction service options.**
5. **Ensure people do not have to undergo a competency test to self-direct.**
6. **Expand Individual and Family Directed Goods and Services to allow for people to have more than $5500 available to access services for which they have an assessed need.* (<u>with caveat</u>)**
7. **Provide Transportation as a reimbursable service. Do not consider funding for transportation is adequately "included" in the rate.**

Justifications for these changes:

- Family, who are not legally responsible for a person, used to able to be hired by the self-directing person as staff. Family members who serve as staff for a person under self-direction, often do not work another job. Working for their loved one IS their job and many times it works out well for the individual to be able to hire a person who knows them best. This option to hire certain family members was initially curtailed through a waiver amendment and then finally restored after a couple of years of stakeholder feedback. **It is important that the person still makes this choice, and that certain oversight and safeguards are in place.**

- Awake overnight supports were cut in one of the waiver amendments despite significant stakeholder feedback this change would create a serious disruption in the lives of many. After approximately 3 years of advocacy, the current Secretary of Health, Dennis Schrader announced last week that DDA would be restoring the service with the next waiver amendment. **People with IDD should be able to self-direct awake overnight supports** if they have an assessed need for overnight support to address behavioral or medical need. **Personal Supports should not be capped at 82 hours** as it is in the current waiver: people who need awake overnight support may need up to 56 hours more of Personal Support Services.

- Support Broker hours and allowable duties were capped and curtailed in one of the waiver amendments. Service hours may now be only 4 hours per month, even though DDA previously estimated people needed an average of 11 hours of support broker assistance per month (see 2013 waiver amendment) and stakeholder feedback to the waiver that this would be highly disruptive to a person's life. The service has not been restored and Coordinators of Community Services (CCS) generally do not have the capacity to take on the additional duties and time commitments for people with IDD on their caseloads. ***While**

we agree that the service should not be capped at 4 hours per month, we do not agree with the arbitrary service cap at 40 hours per month in this bill as it is not rooted in data. The number of hours a person needs should be discussed and agreed to by the individual and their team and reviewed for appropriateness by DDA. There should also be requirements to ensure there is not an overlap of service at any given time between a support broker and a CCS to avoid duplications of duties.

We agree with the bill intention that **support broker "allowed" duties should be written more expansively** as they once were under New Directions, again- with a clarification that the duties and hours may not overlap with CCS hours for the same service.

- **Coordinators of Community Services (CCS) should be trained sufficiently on service definitions and <u>what is possible</u> under both traditional and SDS models so individuals are making informed choices.** Individuals and their families should receive reliable and accurate information about how each model operates, the service definitions under each model, and the responsibilities and requirements of participation in each model.

- **Everyone can self-direct. A person should not have to undergo a competency assessment to prove ability to self-direct.** The RFP for a new Financial Management Service (FMS) initially indicated that the service would include competency testing for individuals in the program. The stakeholders protested and the requirement was removed from the RFP, but then the Designated Representative Form, that the advocates had been working on with DDA for several months, was suddenly reworded to require a person to relinquish their rights in certain areas if they were to assign a "designated representative" to help them. Again, the stakeholders protested, and eventually, the form was reworded to clarify that people may assign supporters to assist them with certain aspects of their plans, but do not have to give up any rights to do so.

- **The list of individual and family directed goods and services should be expanded to other services and supports allowed by CMS for federal match**, and DDA should work with stakeholders to examine the cap which currently restricts an individual's ability to access what they need over $5,000.

  ***We do not agree that the funding available in this category be up to the total dollar amount of the individual's un-utilized annual budget plan.** We support equity between both traditional and self-direction service models, and this would increase the funding for a service that already is unavailable to people in the traditional service model. DDA funding is limited, and we want to support as many people with IDD in the state as the DDA annual budget and quality will allow, not open up "catch-all" pots of funding for people to spend un-utilized amounts of their planned budgets. If this was allowed through Self Direction and extended to traditional services, we believe the effect would have consequences for people on the waiting lists for services.

- **Transportation for people who self-direct should not be included in "wages" to a staff person but should be paid as a reimbursement to staff based on IRS standards.** Currently, transportation for people who self-direct is considered "included in the rate" they receive for the service. This is a problem for people who self-direct as well as a concern of traditional providers as it disproportionately impacts people who live in rural areas or transportation deserts, and especially people who need more expensive transportation (lift vans and paratransit). For these individuals, the rate is not sufficient to cover transportation. In addition, the rate paid to the staff in self-direction through wages is taxed which does not make sense for the employee as they are getting reimbursed for mileage, and this reimbursement should not be taxed.

While some of the changes made by DDA and Maryland Medicaid to the waiver were necessary to improve oversight, some of these changes do not appear to be rooted in data or needed for appropriate oversight, or with consideration for the strain it would cause people in the program and their families.

In the past few years, some of the services and requirements have been restored and changed in response to significant feedback, and especially through the leadership of the current Secretary of Health, such as allowing family members to work as staff, not requiring competency testing, and recently- committing to restore awake overnight as a service that can be self-directed.

While we are grateful and appreciate the commitments and changes that have been made, there is no guarantee that the next Secretary will maintain the changes, and no guarantee that there won't be additional changes to key components of the program.

The Arc and POG **do not support** the following changes this bill would establish:

We do not support the proposed **amendment to §7-409(A)(6).** The proposed amendment would allow a self-directing participant to hire someone to help manage the person's "home, staff, and other administrative duties." If the general assembly restores support broker duties and expands the allowable hours for support brokerage through another section of the bill, we believe the administrative support a person needs will be addressed without this additional amendment. We have concerns that the administrative role that the Sponsor is trying to create through amendment would not be eligible for federal matching funds **and** may be a duplication of what a support broker or a CCS would do.

We also do not support:
(C) THE ADMINISTRATION MAY NOT ESTABLISH A LIMIT ON:
(1) THE DOLLAR AMOUNT OF INDIVIDUAL–DIRECTED FAMILY GOODS AND SERVICES PROVIDED TO A RECIPIENT; OR
(2) THE NUMBER OF HOURS OF OVERNIGHT SUPPORTS PROVIDED TO A RECIPIENT WHO RECEIVES SELF–DIRECTED SERVICES.

DDA and the state should maintain the ability to make certain changes to waiver services and establish limits **however we would support that future changes should be based on measurable and transparent data, and truly incorporate stakeholder feedback provided**.

For more information, please contact:

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