SB441_Support_KKI_Self-Directed Services.pdfUploaded by: Arneson, Emily



DATE: February 16, 2021 COMMITTEE: Senate Finance

BILL NO: Senate Bill 441

BILL TITLE: Developmental Disabilities Administration - Self-Directed Services (Self-Direction Act)

POSITION: Support

Kennedy Krieger Institute supports Senate Bill 441 - Developmental Disabilities Administration - Self-Directed Services (Self-Direction Act)

<u>Bill Summary</u>: Senate Bill 441 forms an Advisory Council for Self-Directed Services. The council would provide recommendations to the Maryland Developmental Disabilities Administration. Senate Bill 441 also increases funding for the Self-Directed service program and preserves self-directed services components that are important to many people.

Background: Over the last three years, Kennedy Krieger Institute has expanded our service delivery to include adults with disabilities through the Developmental Disabilities Administration and Department of Rehabilitation services by becoming a licensed adult service provider. We currently serve 31 adults with disabilities through our Meaningful Community Services programs:

Meaningful Community Services at Kennedy Krieger Institute helps individuals with disabilities obtain and maintain meaningful employment and community engagement through a person-centered approach. Meaningful Community Services include, Project SEARCH, CORE Foundations, and CORE Foundations Community Programming. CORE Foundations services adults with disabilities through self-directed services.

Project SEARCH at Kennedy Krieger Institute is a 10-month, transition to work program for individuals 18 through 24 years of age that provides hands-on job training through integrated worksite rotations, career exploration, innovative adaptations and mentoring from experienced staff. Upon program completion, the ultimate goal for interns to utilize their internships skills to gain competitive employment. Project SEARCH at Kennedy Krieger Institute trains 8-12 interns in each cohort, and currently 21 Kennedy Krieger Institute departments participate in Project SEARCH by hosting interns.

CORE Foundations provides individuals of all abilities with the opportunity and education to continue developing core skills that are the foundation for a successful adult life. We develop a customized program in partnership with each individual to support their independence. The person-centered approach requires an individualized plan, daily schedule, and goals for each individual. CORE Foundations is a certified and licensed Developmental Disabilities Administration adult provider for the state of Maryland and a community-based program serving 7 Maryland counties. CORE Foundations provides employment services through the Department of Rehabilitation Services (DORS).

Meaningful Community Services pivoted to **Virtual Support Services** to continue to provide innovative, person-centered, and engaging services to individuals with disabilities throughout the COVID-19 pandemic.

Rationale:

Self-Directed Services are offered through the Community Pathways Waiver at the Maryland Developmental Disabilities Administration (DDA). "This is service delivery for individuals with developmental disabilities and/or designated representatives who wish to exercise more choice, control, and authority over their supports. Self-direction gives waiver participants and families greater control over the services they receive, how they receive them, and who provides them. At the same time, people who self-direct must be willing to take on the responsibility of managing their services."

The DDA has been undergoing changes in service delivery and fee models for several years and continues to make changes. The number of individuals receiving Self-Directed Services has increased over the last several years, however there is an inconsistency of knowledge of self-directed services and the processes in which the Person-Centered Planning team should follow. An Advisory Council would provide the opportunity to discuss aligning the processes, policies, and expectations of self-directed services to better serve those who are eligible for the program.

Kennedy Krieger Institute is in favor of an advisory council that would make recommendations to support consistency in service delivery, and equity among individuals who have selected self-directed services. Prior submission of this bill requested that self-directed services be removed from the Community Pathways Waiver, and return to a waiver of its own. Self-directed services were a standalone waiver program and only had 41 participants; when self-directed services waiver was combined with the Community Pathways waiver in 2013 it has grown to 1500 participants. We are not in support of this, as it could have implications on eligibility for individuals, and access to self-directed services.

Currently the Person-Centered Planning team consists of the individual receiving services, family member, community of coordinator of service, support broker, vendor provider (if applies), staff, and any other person the individual requests to be at these meetings. The knowledge and experience of each member is inconsistent across Person-Centered Planning teams, which leads to inequalities of the services an individual receives and understands they can access. We have experienced this with individuals who we support receiving services through self-direction. Increased knowledge and consistency would benefit those receiving self-directed services, and the advisory council could evaluate these practices to support progress.

Kennedy Krieger Institute requests a favorable report on Senate Bill 441.

2.12. FAQs on the Self-Direction Act SB441.pdf Uploaded by: Carter, Margaret

FAQs Self-Direction Act HB318 & SB441

1. Why do we need the Self-Direction Act?

Self-direction (SD) is based on the principle of self-determination; therefore, it allows participants both employer and budget authority. Since 2014 when DDA merged the New Directions waiver for self-direction with the Community Pathways waiver, it has restricted both the authorities of the participants—and the choices available to them. These changes are profoundly affecting some people who self-direct. They have included the following:

- Elimination of overnight employee support for people with intense needs
- Restrictions on individualized transportation reimbursements
- Restrictions on customized goods and services
- Elimination of choice and competition for essential fiscal management services
- Limitations on who is even eligible to self-direct
- Limitations on the participant's choice to hire family members as staff
- Changes in DDA budgeting procedures which will inflate most participant budgets and defund others
- Restrictions on the role of the support broker— the only professional on the team with a specific obligation to work for the participant

2. What will the Self-Direction Act do?

The Act will restore choice and control to people who self-direct by mandating those choices as Maryland statutes. As a result, Maryland's waiver applications to the Centers for Medicare and Medicaid Services (CMS) will reflect those statutes. The Act does not seek to add new features to Maryland's program; only to restore what's been lost.

- 3. Why does the Act specifically stipulate the family members can work as staff? In 2016 DDA attempted to completely eliminate the ability of participants to hire family members as support staff. Only an SDAN petition drive to Governor Hogan stopped that proposal. Since then DDA has continued to place limits on this ability. CMS permits family members and legally responsible adults to work as staff. SDAN asserts that the decision to hire family members should be made by the participant with support from their team.
- 4. Why does the Act mandate that anyone eligible for DDA funding can self-direct? In its 2018 and 2019 Request for Proposals (RFP) for a fiscal management service (FMS) Maryland Department of Health (MDH) included an unusual duty for the FMS provider: the obligation to determine whether an applicant for self-direction was "competent" to self-direct. DDA administrators have also publicly suggested that not everyone is capable of self-directing. SDAN "presumes competence" and believes that with the right supports, anyone can self-direct.
 - 5. Why does the Act stipulate that fiscal management services be provided under the waiver?

Marylanders who self-direct have always had a choice of providers for essential fiscal management services. However, MDH's last two RFPs would have brought an out-of-state FMS monopoly to Maryland. SDAN opposed the RFPs on the grounds that monopolies foster complacency—while competition breeds excellence. And even though the state now classifies FMS duties as an *administrative service*, DDA *continues* to require participants to pay for FMS services from the SD

budgets. Since CMS stipulates that participants must have a choice of providers if fiscal management is provided under the waiver, restoring FMS services to the waiver will guarantee that Marylanders retain this important choice.

6. Why is the support broker specifically mentioned in the Act?

Since the beginning of self-direction support brokers (SB) have played a vital role for many participants, assisting them with whatever they needed to create, implement and maintain their vision for their lives. This role included advocating for services when necessary. However, DDA has allotted many previous SB duties to overburdened and undertrained Coordinators of Community Services (CCS), who work for the state, not the participant. DDA now strictly limits the role of the SB to Human Resources. As a result, many new SD participants lack access to a support broker when they most need one—during the initial transition to self-direction. As a result some people have waited months or years to begin services. The Act restores the original SB role as an advocate with a special obligation to the person but does not empower the SB to make decisions for the participant: "A support broker means a person who has a fiduciary duty to advocate on behalf of and as directed by an individual who uses self-directed services...."

- 7. Why does the term Designated Representative appear in the Act?
- SDAN has opposed the concept of the Designated Representative (DR) since DDA introduced it three years ago. SDAN affirms that the DR detracts from the autonomy of the participant and the ability of the participant team to assist the person realize their goals and desires. When people do need assistance, SDAN believes that the team approach, using supported decision making, is best. However HB318/SB441 does allow participants to choose the SB as a designated representative (DR) in order to spare family members from being disqualified as staff members in case the Department forced the choice of a DR. Nevertheless, the DR role presents issues for both participants and for anyone who assumes it. It is possible that this aspect of the bill will be amended to eliminate any reference to the DR. The DR issue would then be left the Advisory Council.
- 8. Why does the Act specifically refer to the Cost of Living Adjustment (COLA)? More than halfway through FY21, the majority of SDAN members report that they have had difficulty accessing the COLA—despite DDA assurances that it has been allotted. The Act will ensure that participants receive the COLA in the future.
 - 9. What is the role of the Advisory Council created by the Act?

The Advisory Council's first duty is to work with DDA staff to either revise the Community Pathways waiver to restore participant choice and control of services—or to design a separate waiver based on the original New Directions program. The Waiver must be effective by June 2022 or a report made to the legislature about why it will not be ready. In future the Council will seek to improve and expand self-direction and to protect participant autonomy.

10. What will the make-up of the Advisory Council be?

The advisory council will be composed of a diverse group of stakeholders, including self-directed participants and advocates, state officials, and advocacy organizations. The Council will be composed of representatives from the following groups:

- 1. Department of Human Services
- 2. DDA
- 3. Department of Disabilities
- 4. Nursing and Waiver services from Md. Medicaid's office of Long Term Support Services
- 5. Interagency Transition Council for Youth with Disabilities
- 6. Division of Rehabilitative Services
- 7. SDAN members

- 8. Individuals who self-direct their services.
- 9. Family advocates of people who self-direct
- 10. A support broker
- 11. A coordinator of community services (CCS)
- 12. A delegating nurse
- 13. Maryland Developmental Disabilities Council
- 14. Disability Rights Maryland
- 15. People on the Go
- 16. The Arc Maryland
- 17. Maryland Works
- 18. A fiscal management provider
- 19. A direct support staff member

11. Who supports the Self-Direction Act?

The Act is supported by the following organizations:

- *The Arc Maryland
- *People on the Go Maryland
- *The Developmental Disabilities Council
- *Disability Rights Maryland
- *Pathfinders for Autism
- *The Special Needs Advocacy Coalition of Maryland
- *The Baltimore County Commission for Women
- *The Maryland Commission on Caregiving
- *The Self-Directed Advocacy Network of Maryland, Inc.
- *Maryland Legislative Latino Caucaus
- *Kennedy Krieger Institute
- *Maryland Legislative Coalition

2.12.21 REVISIONS to resonse to MDH letter of ob

Uploaded by: Carter, Margaret

Regarding, the Self-Direction Act (SB441/Hb318) Responses to a letter of objection from Webster Ye of Maryland Department of Health (MDH)

and to the

Fiscal and Policy Note provided by the Office of Legislative Services.

Note: These responses were originally composed for the House Health and Government Operations Committee, but since SB441 is identical to HB318 we are also submitting this response to the Senate Finance Committee

The Department states that HB318 "creates unreasonable operational challenges that are contrary to recommendations from the Office of Legislative Audits."

Response:

OLA finds that HB318 is not contrary to its recommendations:

 See letter from Gregory Hook to Delegate Lewis-Young stating that the Department may have misunderstood its 2019 findings. Hook states that there is nothing in HB318 that is contrary to OLA's recommendations.

SB441/HB318 does not present unreasonable operational challenges:

- It does not <u>require</u> the Council to create a new waiver; it merely allows that option.
- The Department has voluntarily created two brand new waivers in the last three years. It has also revised the Community Pathways Waiver three times in the last four years. None of these efforts was ever described as unreasonable.
- Including stakeholder input throughout the waiver revision process would eliminate the need for constant revisions and for time-consuming meetings with disappointed stakeholders. The Advisory Council will likely streamline administrative tasks by creating a genuine collaboration between state administrators and stakeholders.

The Fiscal Summary forecasts a \$3.3 million (86% federal funds, 14% general funds) in FY2022 for staff to establish and administer a new Self-Directed Services waiver and staff the advisory council as well as one-time only programming costs.

Response:

The Fiscal Note is both flawed and grossly inflated:

- The Council would first consider revising the current Community Pathways
 waiver before considering a return to the original New Directions waiver
 and would weigh the costs involved with each choice. However, since a
 recent version of the New Directions waiver already exists, neither the
 Department nor the Council would be starting from scratch if that is the
 Council's decision. All revisions could be completed by Council members
 and current Department staff.
- The fiscal note from HB 1171 in 2020, the first iteration of SB441/HB318, states that the advisory council could be staffed with existing resources. That aspect of this bill has not changed.
- SB441/HB318 requires no additional oversight for support brokers. Support brokers are already subject to a complex system of checks and balances which the Act does not alter.
- Reimbursement for the use of vehicles requires no additional funding. It simply allows individuals to dedicate a portion of their <u>existing</u> budget to mileage reimbursement for the use of a specially adapted vehicle.

The Department states that the Centers for Medicare & Medicaid Services (CMS) prohibits states from providing fiscal management services (FMS) under the waiver, as required in the Act and that they <u>must</u> be classified as an administrative service

Response:

The Department is incorrect.

CMS <u>does</u> permit FMS services to be provided under the Waiver. However, it requires that participants have a choice of providers for this essential service if states choose it as a waiver option. Under New Directions FMS services <u>were</u> provided under the waiver—which is why Maryland has always had two FMS providers. The Act seeks to restore FMS services to the waiver to ensure choice of this vital service.

The Department states that the Act allows unlicensed individuals to provide services.

Response:

The Department is incorrect.

 As the analyst who summarized the bill correctly notes, SB441/HB318 just eliminates the need for professionals who are already licensed by the state to seek further credentials from the Department.

The Department states that the bill violates CMS guidelines and jeopardizes the federal match because it "enables support brokers to have a fiduciary duty to the individual to whom they provide services."

Response:

The Act does <u>not</u> jeopardize the federal match.

- SB441/HB318 honors CMS Guidelines on participant choice and control of services. It does not intend to add new features to Maryland's SD program—only to restore approved CMS options that have been retracted by the Department.
- The term *fiduciary duty* is not meant to imply decision-making authority. Instead it is meant to describe the support broker's special obligation to work FOR and in the best interest of the participant, much as attorneys—who do not make decisions for their clients—have a fiduciary duty to them.
- The Act clearly states that it is the support broker's fiduciary duty to take direction from the person: "A support broker means a person who has a fiduciary duty to advocate on behalf of and as directed by an individual who uses self-directed services...." This definition is in complete alignment with CMS guidelines.
- CMS will not review Maryland statutes; it will only review the waiver which results from those statutes. It will be the duty of the Advisory Council to translate the statutes into waiver definitions.
- While the Department has strictly limited the role of the Support Broker (SB) to HR functions, CMS describes the SB <u>as a consultant/counselor/agent</u> who takes direction from the individual and provides the services and

supports to sustain them as they direct their own services. SB441/HB318 is intended to reflect CMS's description. So long as Maryland's waiver reflects the participants' decision-making authority, the federal match is <u>not</u> in jeopardy.

- CMS regulations do allow support brokers to sign timesheets for other employees if that is the participant's preference. However, support brokers have never signed their own payment requests and have always been subject to oversight.
- HB318 allows participants to_choose the SB as a designated representative (DR) to spare family members from being disqualified as staff members in case the Department forced the choice of a DR. However, The DR role presents issues for anyone who assumes it. It might be wise to eliminate any reference to the Designated Representative from HB318 and to let the Advisory Council decide how to deal with the DR role that the Department has developed.

2.10.21 Sunny written testimony SB441.pdf Uploaded by: Cefaratti , Sunny

Sunny Cefaratti—Testimony in Support of the Self-Direction Act-- SB441

My name is Sunny Cefaratti. I am totally blind and autistic. I am also the cofounder of The Musical

Autist, a non-profit organization dedicated to helping autistic people share the joy of music. As a

Troupe leader at the Musical Autist, I mentor others on the Spectrum, and we work together to create
sensory friendly concerts for people of all abilities. In addition to mentoring, I also speak out for people
with disabilities by serving on the Boards of the Self-Directed Advocacy Network and on the

Developmental Disabilities Council. I am also studying entrepreneurship at Anne Arundel Community

College so that I can start my own public speaking and music performance business.

But my life was not always as rich as it is today. After graduating from Maryland School for the Blind in 2007, I was placed in a sheltered workshop-- where my most challenging activity was assembling mass mailings. On some days there was nothing at all for me to do. I remained at the workshop for eight long years before Self Direction changed my life.

I give credit to My Support Broker CJ Shiloh who helped me transition to self-direction in 2015.

Without CJ's help and guidance, I might never have found self-direction at all. I believe that support brokers are essential for many people in <u>all phases</u> of the program—not just as a human resource

consultant. And that's one reason why I support the SB441. Through self-direction I have developed my gifts-- and I am now sharing those gifts with others on the spectrum. What a wonderful thing!

The Self-Direction Act will make it possible for other people like me to develop <u>their</u> talents by restoring choices that have been withdrawn and by building an accountable DDA.

Testimony In Support of SB 441 Jan 2021 DDA.pdf Uploaded by: Ceruolo, Rich

Maryland Senate 11 Bladen St. Annapolis, MD. 21401

In Support - SB 441: Developmental Disabilities Administration - Self - Directed Services

Good afternoon members of the Senate Finance Committee.

I am the parent of a child with multiple challenges and disabilities. I am a member of Parent Advocacy Consortium, and we advocate for children like my son, and other individuals with disabilities that require time, resources and support to help them build their areas of major life skills in the ways that works best for them, as individuals.

Just like the development of major life skills, it is extremely important to preserve the self-directed services that are so very important to so many people within our state. Without this training many of them would be unable to work toward living an independent life. As well as making the best choices for how and where to spend their time during the week.

We also support the establishment an advisory committee on Self-Directed Services for individuals with disabilities, and to help with assessing the level of funding and quality of the services that are being offered at this time. Hoping that we can work to grow the catalog of service offerings across our state.

We are also in support of the delegation collecting information from the workgroup and advisory council in order to make informed decisions that will aid with the funding level decisions that help support so many in our disabled community. These self-directed services are vital to their continuing development and we hope that you will work to maintain the level of support, and working together maybe even increase the service offerings and funding within the state of Maryland.

Please return a favorable report and support SB 441, updating DDA's self-directed services and preserve the choices and services that are vital to the lives of so many within our communities of disabled persons.

Thank you for considering my testimony today.

Kind regards,

Mr. Richard Ceruolo Parent, and Advocate for people with disabilities.

SB 441 Support Doc.pdfUploaded by: Davis, Jackie Position: FAV

I support HB 318 and SB 441

Developmental Disabilities Administration -- Self-Directed Services (Self-Direction Act)

Samantha's Good Life



Because of Self-Direction I...

- Started my own baking business "The Cupcake Queen", now a licensed "cottage farm" business in the State of Maryland.
- started training to participate in 5k races this year.
- Participate fully in my community as a volunteer at the Library and reader at my church.
- Graduated from Wor Wic Community College with an AA Degree in Applied Sciences.
- Serve on the Advisory Council and became a trainer with Shared Support of Maryland under a grant that provides training on the Person Centered Planning process.

My family & I support the **Self-Direction**Act because Choice and Control have
changed my life!





Samantha Davis 5122 Paw Paw Rd Cambridge MD 21613 410-463-3929 Election District 37B I support the Self-Direction bill because it will ...

- Let me continue to make decisions about my life.
- Let <u>me</u> have the people in my life who know me best (my family) and support and help me reach my goals.
- Give me control over my life and let me live the life I want to live.
- Let <u>me</u> keep the support broker who understands my needs and knows how best to support me.

#CARE Md

SB441 Support Ltr.pdfUploaded by: Davis, Jackie Position: FAV

In Support of SB441

To the Maryland Senate Finance Committee:

I am writing today to encourage your support of SB441 – The Self Direction Act.

Self-Direction has been a game changer in my daughter's life. For several years after she was first approved for DDA services she languished in programs that could not meet her needs. My daughter is autistic and has very specific interests and talents. As the saying goes — if you have met one person with autism, you have met one person with autism as each one has their own unique talents and gifts. This goes for everyone in life not just people with disabilities. So instead of placing people with disabilities into "programs" thinking that is the best way to meet their needs, the better idea is to allow each individual to choose their own path in life.

In my daughter's case, when she was first approved for DDA services we chose a service provider because we were unaware of Self-Direction. As I stated above, over three years this service provider would contact my daughter by letter and introduce the direct support person who would work with her. Over that three-year period, she only met one of them because their turnover rate was so high. She never participated in any programs because they had no programs to meet her needs. They kept promising year after year but never delivered. Contrast that to Self-Direction over the past 4 years with me, her mother, as her direct support person, my daughter has – Graduated Community College with an AA in Applied Science, started her own "cottage farm" baking business, volunteers at our local library and is training to participate in 5k's this year.

My daughter is now in charge of her life and is no longer dependent on some program that may or may not take place. She is the driving force of her Self-Direction plan and is loving every minute of it. I serve as her support person and am with her every step of the way. As a mother, it is imperative to me, that she is successful. This is what all parents want for their children and Self-Direction provides that for the families with I/DD individuals in their lives.

On a separate but equally important note, Support Brokers play a crucial role in Self-Direction plans. While families and caregivers are providing the direct support, Support Brokers are in the background making sure the administrative piece of the plan is working, rules are being followed, and timecards are submitted promptly. In fact, our Support Broker has worked on my behalf several times when my pay was incorrect from the FMS.

I hope my letter today helps you understand the importance of Self-Direction for Families and that you will support SB441.

Thank You,

lackie Davis

Douglas Gabler requests your support for SB 441 Uploaded by: Gabler, Martha

I support HB 0318 and SB 441

My Self-Directed Life



My name is Douglas Gabler. I am 24 years old.
I have severe autism and am nonverbal.
I am in the DDA Community Pathways Waiver
Self-Directed services program.

Under Self-Direction I have a wonderful daily program that really meets my needs. I am physically strong and love to be outside. I need to be physically active to use up all my energy. I've also been involved in therapeutic horseback riding since I was 14 years old. Putting all of this together, my family helped me set up a program where I work at the Wheaton Park Stables.

I love it! Every day I go there with a helper, and I'm busy all day long. I unload the hay wagon, deliver hay to the barn, feed the horses, and muck the fields. I'm proud to be taking care of the horses and their pastures. Despite my disability, I am making a contribution to the community.

Choice and Control Matter Matter to Me!





Unloading the hay wagon

Douglas Gabler

10125 Markham St. Silver Spring, MD 20901 emgabler@verizon.net Maryland District 20 My Self-Directed program is good for me, but it's a bureaucratic nightmare for my family. This bill is important to me because I need the supports and flexibility that used to be available under Self-Direction but have been taken away.

- I need a voice via an Advisory Council.
- I REALLY need a strong Support Broker who can do more for me than the minor role the current system allows; i.e, I need that role restored so my Broker can be an advocate for me and help with my program.
- I need to be able to hire relatives as staff -- Who knows me better? It is really hard to find qualified people to work with me and in this time of COVID, it is even more difficult.

My family and I support the Self-Direction Act because it will help me build a life based on my strengths and my choice. Thank you for time and attention.

Sincerely,

Douglas Gabler

2021 Bill Participant About Me Info Sheet.pdf Uploaded by: GRELLI, MARY



My Self-Directed Life



Francis with DN

Because of Self-Direction I can choose my Personal Supports staff. I can spend time with people I like. I can go to music therapy and Bingo every week. I can go shopping, take drives and go to medical appointments with my staff.

I have chosen to self-direct so that I can control what I do and when I do it. I especially like music therapy, walking in my neighborhood and Bingo.

Choice and Control Matter Matter to Me!





Francis Garove 18 Flintlock Ct. Perry Hall, MD 21128 Election District What will the Self-Direction HB-0318 and SB-0441 do?

- Keep DDA accountable.
- Continue to allow family as advocates without restricting family as direct support staff
- Allow participants to choose and have funded activities of their choice as it is designated in their plan
- Mandate that anyone eligible for DDA services can self-direct

#CARE Md

Support testimony in Support of SB-0441 and HB-031 Uploaded by: GRELLI, MARY



Support: testimony in Support of SB-0441 and HB-0318

House Health and Government Operations Committee

Mary Grelli, Kenneth Garove for Francis

January 20, 2021

Hello, I am Mary Grelli and my husband is Kenneth Garove. I am writing to express my concern that DDA, in most recent waiver language, intends to force participants in the self-directed Community Pathways Waiver, to appoint a designated representative. My son, Francis Garove has been in the Community Pathways waiver for the past 5 years. Francis has multiple severe disabilities including Cerebral Palsy and Intellectual Disabilities.

My husband and I have been advocating and caring for our disabled son in our home since he was born 29 years ago. Recently I had the unfortunate experience with a DDA regional office representative challenging my legal standing to ask for current information regarding my son. He asked me who I was. When I reiterated that I was his mother, he explained that he meant who I was regarding guardianship, designated representative or other title. He explained that he did not want to speak with me regarding the issues at hand because of HIPPA restrictions. He also said that he preferred to speak to my son's CCS. This line of questioning was a surprise and left me incredulous. I then explained that I had never heard of this restriction and I subsequently scoured the DDA website for guidance on designated Representative.

After much research and consultation with SDAN I found other elements of the current proposal regarding designated representative (DR) that increased my concern-mainly that no family members of the DR could be employed as staff for Francis. Eliminating all immediate family members of the Parental DR as potential employees is profoundly disruptive for this reason: the unfortunate reality of staffing is that there are few people outside of family willing to do this work. As a rule, family is more reliable, committed and achieve the best possible outcome for the individual.

If the appointment of a DR will remove the ability for a parent to communicate with the DDA regional office or any other agency that the individual receives services from, then that person will potentially lose what is most likely their best caregivers and strongest advocates. The goal or mission statement of DDA for a happy and healthy team based on "...providing support for individuals **and their families** to determine what is important to and for them to achieve that goal" is nullified with this restriction. Let us continue to support the "DDA vision of the good life partnering with people with disabilities and their families to provide support and resources to live fulfilling lives" by specifically suspending consideration of the current DR proposal and supporting house Bill 0318.

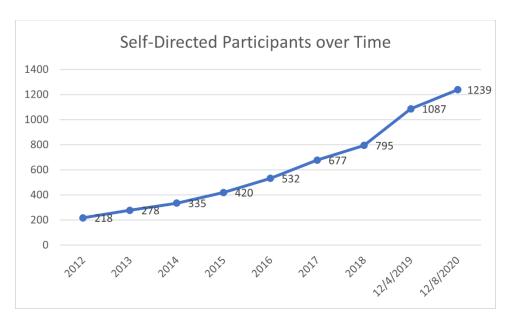
Sincerely,

Mary Grelli, Kenneth Garove

Kenneth Harove May Milli

Parents of Francis

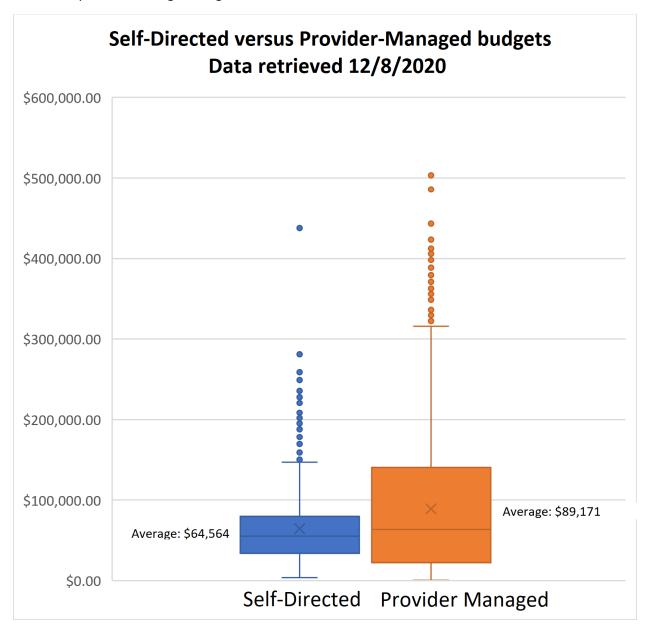
2021 GHL 1 SDS over time.pdfUploaded by: Houston-Ludlam, Genevieve Position: FAV



Self-Direction is currently a small slice of the DDA's waiver service pie, currently representing 1,239 out of 16,768, or 7.4%, of people receiving Medicaid waiver services in Maryland. But as you can see, we are a steadily growing slice of that pie.

2021 GHL 2 Box and Whiskers with narrative.pdf Uploaded by: Houston-Ludlam, Genevieve

Self-Directed Services provide the best of both worlds- flexibility for the participant to live their best life, and cost savings for the State of Maryland! On average, Self-directed budgets are 27% lower than traditional provider-managed budgets.



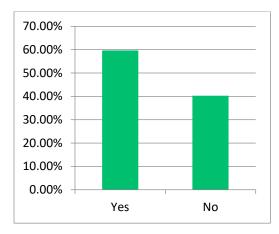
Data provided by DDA from PCIS2 database on 12/8/2020. This data represents 1,162 Self-directed participants and 14,872 participants receiving traditional provider-managed services.

2021 GHL 3 SDAN Survey Q1n2 Results Narrative.pdf Uploaded by: Houston-Ludlam, Genevieve

SDAN Survey Results

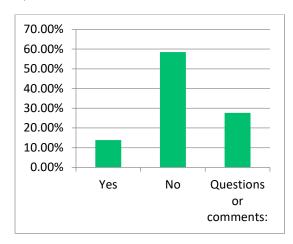
During the month of December 2020, SDAN polled their members to identify issues that Self-directed participants were having with their budgets. Here is a summary of the results of that survey.

Question 1: Issues with plan approval or plan updates?



Results: 59.7% of our survey respondents said that they were having issues with plan approval or updates. As of 1/22/2021, approximately 25-30% of Self-directed plans have not yet been approved. In the comments, most of the respondents cited delays and lack of responsiveness from DDA as their main issues.

Question 2: Have been able to access FY2021 COLA?



Results: 14% of our respondents said they had received the COLA for FY 2021. 58.5% were sure they had not received it, and 28% had no idea. In the comments, they cited confusion about what the COLA is, and whether or not they had received it. In some cases, the CCSs had no idea either. Several respondents who had received the COLA expressed that they had to really fight to get it, citing repeated requests and conversations with their CCSs and DDA directly.

2021 GHL Senate Finance Testimony.pdf Uploaded by: Houston-Ludlam, Genevieve

Genevieve Houston-Ludlam, Ph.D. testimony in favor of SB-441

Hi, my name is Dr. Genevieve Houston-Ludlam. I am a volunteer board member of the Self-Direction Advocacy Network. I am also the mother of Carmen, my charming adult daughter with Down syndrome, who self-directs her DDA Medicaid waiver services. I am here to present you with the data supporting SDAN's concerns.

Self-Direction is a steadily growing slice of the DDA waiver-services pie, having grown from 218 participants in 2012 to over 13 hundred, or 8% of about 16 thousand people receiving DDA Medicaid waiver services in Maryland in 2020. That is about a 500% increase in 8 years. As a growing percent of Medicaid waiver services in Maryland, we think it is critical to intervene in the reduction of the choice and control of self-directed services due to the choices that DDA is making. The more people discover the flexibility of self-direction, the more your constituents will choose this option. Please help us fix this now.

Self-directed services, along with being a more person-centered way of delivering services, is also more cost effective. We received anonymized budget data from the DDA through freedom of information in December 2020, making this a very current snapshot of currently active Medicaid waiver service budgets.

The average budget for people self-directing their Medicaid waiver services is about \$65K, compared to an average budget of about \$89K for people receiving traditional provider-managed services. On average, the self-directed model delivers a 27% cost savings to the State of Maryland, while providing tailored services to the individuals out there living their best lives the way THEY want to live it. WIN-WIN. Self-direction also shows excellent health outcomes, especially during this COVID health crisis.

Finally, you have heard about problems we are having with the DDA, including timeliness of budgets, lack of communication and non-responsiveness. SDAN conducted a survey of their membership on these issues in December of 2020.

60% of our survey respondents said that they were having issues with plan approval or updates. As of mid-January, 26% of Self-directed plans have not yet been approved by the DDA. In the comments, most of the respondents cited delays and lack of responsiveness from DDA as their main issues.

Let me conclude with briefly sharing my own personal experience with these issues. My daughter Carmen transitioned from school-based services in July of 2019. For 6 months, she was left without her waiver services because DDA did not get her budget approved, and I had to stop working as a result. In fact, the only reason it did get approved is that I contacted the Governor's office and the Maryland Department of Health. The next July, her new budget was supposed to begin. It was not approved until September, and only after I threatened to go to the governor's office again.

We are not asking for more money- we are asking to streamline to make our lives easier, and it also saves the state money. WIN WIN.

Thank you.

SB-441 Our Stories.pdfUploaded by: Houston-Ludlam, Genevieve

I AM Ryan Gerhold - Age 34

My History: Normal at birth – meningitis at 9 mos left me brain damaged resulting in OCD, Anxiety, Seizures, ADD and moderate intellectual disability

MY LIKES:

My girlfriend and going out with her
Movies, Restaurants, Concerts, Live shows, the beach
Sleeping with my dog, Jax
Hanging with family, especially mom
Helping around the house
Being able to decide who works for me as staff
Staying busy



WAS RESIDENTIAL in a group home for many years – discovered neglect and abuse. I cried a lot, felt unsafe. Never knew who was going to be taking care of me. Did not get to see my girlfriend or go where I wanted. Many nights I had no lights in my room or toilet paper in my bathroom or milk for my morning cereal. My roommate and some staff were often mean to me. No one was listening!

Self Direction is important to me because I am

- Allowed to manage my DDA budget and decide where/how the money will be spent
 I go to CAMP three times a year and have mileage for staff to take me places
- 2. Select own staff eliminating anxiety about who is going to take care of him
- 3. Able to hire family as paid staff which makes me feel SAFE If I couldn't do this, my mom would be working more outside the home instead of being with me
- 4. Plan my own day. Have a more meaningful day.

5. Staff is more Personal Support staff instead of the "one to one" They can take me to visit my girlfriend, friends, sports events and go anywhere I want. They keep me safe and clean







Enjoying time with my personal support Staff!

XX00 Ryan Gerhold

I support HB 318 and SB 441

Developmental Disabilities Administration -- Self-Directed Services (Self-Direction Act)

Rob's Good Life





Because of Self-Direction I can:

- Be an advocate for health care & disability rights
- Volunteer for Imagination Stage as an usher
- Take classes at Montgomery College
- Be a member of the Spirit Club gym
- Write poems & read them at literary events
- Play Challenger Baseball & go to Nationals & Orioles games

What choices have I made?

- To live in my own home with my family
- To have pets
- To go where I want & do what I want, when I want

My family & I support the **Self-Direction**Act because I have control over my life.
I am in control.







Rob Stone

4415 Highland Ave Bethesda MD 20814 jenevastone@gmail.com 240-401-9693 D-16

Why do my family and I support the Self-Direction Act?) (Put your own comments in place of words below)

- Create a strong Advisory Council to re-establish the principles of self-direction and DDA accountability
- Allow my mom to continue to help me with my advocacy career
- Restore my right to choose a support broker to be my primary advocate because my mom handles a lot of my other administrative needs
- Ensure MY choice and control of all MY services
- Mandate that *anyone* eligible for DDA services can self-direct

#CARE Md

I support HB 318 and SB 0441

Developmental Disabilities Administration -- Self-Directed Services (Self-Direction Act)

Patrick's Good Life



Because of Self-Direction I can ...

- Have an active and happy life while embracing my Autism
- Choose employees who are dedicated to helping me achieve my goals
- Make my own choices about my life, including volunteering and recreation
- Live safely and happily at home with my mom
- Be a part of my community

What choices I have made?

- To go to horseback therapy to manage my anxiety
- To maintain a daily routine and contribute to my family's home by helping with laundry, cleaning, and shopping
- To volunteer at my public libraries, food banks, public schools, and state and local parks and trails

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





Patrick Good 1315 Vanderbilt Rd Bel Air, MD 410-879-4643 District 35B

I support the Self-Direction bill because...

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

#CARE Md. For more information visit MarylandSDS.org

I support HB - 0318/SB - 0441

My name is Melanie Cooper. I am 35 years old. For 14 years I have enjoyed Self Direction through the Medicaid Waiver. I have lived in my very own apartment for the last 7 years. I have a rare seizure disorder (LGS), autism and ID. I need 24/7 assistance that staff and my family provide. I love to swim at the Y and walk the Ma & Pa Trail. I like to deliver lunch to my elderly neighbors and help keep my apartment clean. I enjoy going out to eat and singing. I love being *Aunt Melanie*.

Self Direction is Important to me because...

- (Safety) I hire and train my own staff who always walk beside me to keep me safe as I experience daily drop seizures.
- (Choice) I choose how I wish to spend my days
- (Independence) I can come and go as my energy level and changing moods allow.
- (Support) I have a team that works together for my best life.
- (Health) I have not been hospitalized in 10 years.



Self Direction Gives me Self Worth through Independence









Melanie Cooper
Bel Air MD.
Harford County
kathykcooper@gmail.com
District 34B





Hi! I'm Mary Beth and I love my life now that I am in Self Directed Services. For 10 years I was in traditional services: that is a group home and a day workshop. I wasn't happy and started showing it through my behavior. My family heard there was another way to support me and to help me live the life I wanted. Since 2009 I have been self directing my services and my life is sooooo much better. I get to live in my own condo with a typical roommate and I hire the people I want to support me. I have a great team of part time ladies that help get me to my part-time volunteer activities at nursing homes and soup kitchens (pre Covid of course!) as well as to my community activities such as zumba, fitness classes, bowling, movies, and my favorite - eating out at restaurants. I



need you to pass HB 318/SB 441.

Since my family knows me best, they help with the hiring and training of staff. My Dad is my support broker and I need him to advocate for me. I am non verbal and communicate with signs and gestures and so people outside my family don't always understand what I need and want. **HB 318/SB 441** ensures that my family can always be there to support me and assist me in hiring people who will help me be the best person I can be. **HB 318/SB 441** creates an advisory board to help DDA know what is best for people in self directed services. Having **choices** about what I do each day and who works with me is very important. I need to have **control** over my life to be happy. Thank you for all you do to help me live this good life!



Here I am last year with my staff before Covid 19 and masks!!!

Mary Beth Coffin % Bill and Pat Coffin 720 Springloch Rd Silver Spring, MD 20904 301-625-7737 (h) 301-520-0574 (c) billandpatcoffin@verizon.net

I support HB 318/SB 441

Developmental Disabilities Administration -- Self-Directed Services (Self-Direction Act)

My way my life!



Self-Direction allows me to:

- *Achieve goals that I select and that are meaningful to me
- *Enables me to integrate in the community with support from those I trust and feel comfortable with
- *Allows me to choose whom I employ
- *Provides opportunities to have new and exciting experiences

I support the Self-Direction Act because I deserve to have options. I am special, and I know what works best for me!





Maria Grace Ellis 4324A Necker Avenue Baltimore Md 21236 Self-Direction provides *remarkable outcomes* for people like me who have disabilities! I need this Bill to pass so I will continue to have the opportunities that I choose and will enable me to continue to have a purposeful life!

- **M**ake a strong Advisory Council to *re-establish* the principles of self-direction & DDA accountability
- Allow participants to continue to include family members as support staff
- Restore the participants' right to choose a support broker as their primary advocate
- Imagine life with freedom of choice
- Anyone eligible for DDA services can self-direct

#Maria Needs Self Direction!

I support HB 318 and SB441

Developmental Disabilities Administration -- Self-Directed Services (Self-Direction Act)

Lucy's Good Life



Because of Self-Direction I can...

- Have an active and happy life despite my severe epilepsy
- Choose employees who are dedicated to helping me achieve my goals
- Make my own choices about my life, including volunteering and recreation
- Be a part of my community and live safely and happily in the home I have chosen.

What choices have I made?

- To maintain my fragile health by working out every day
- To ride and volunteer at the Retreat at Beckleysville
- To contribute to my family home by helping with shopping, laundry, and meal prep.
- To cultivate my many community friendships

My family & I support the **Self**-**Direction Act** because Choice and

Control make the Good Life

possible.





Lucy Carter 18224 Gunpowder Rd. Hampstead, Md.21074 410 790 4375 District 42B Historically self-direction has saved the state money while providing remarkable outcomes for people with developmental disabilities. HB318 will preserve that.

What else will the Self Direction Act do?

- Create a strong Advisory Council to *re-establish* the principles of self-direction & DDA accountability
- Allow participants to continue to include family members as support staff
- Restore the participants' right to choose a support broker as their primary advocate
- Ensure participants' choice and control of services
- **M**andate that *anyone* eligible for DDA services can self-direct

#CARE Md. For more information visit MarylandSDS.org

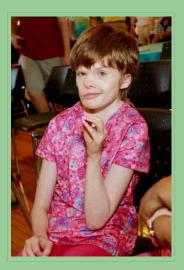
My Successes in SDS



Self-Direction is important to me because...I have become healthier and happier. I exercise more, eat better foods, and am taking fewer meds. That's because my staff are trained by and work for me, not a manager in a building far away. I have learned to swim, ride horses and now work out at a gym. I have had meaningful volunteer experiences at a horse stable, and at a local humane society. I have made new friends in my community. This is my good life!

Choice and Control Matter Matter to Me!



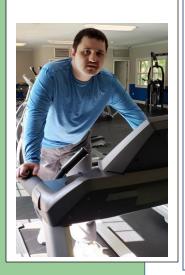


Kate Kolm Indian Head, MD c/o Peg Kolm mlkolm@mindspring.com My primary concern is the DDA policy now requiring that only "providers"--not my staff--can offer third shift/overnight care. I need this support as I am Deaf Blind & nonverbal. And a provider will charge much more per hour than my staff make now. This rule will force me back into provider-directed care, b/c it's all or nothing, says DDA. If I have one shift per day with a provider, ALL shifts must be with a provider. And I already have been in two agencies and left because of health and safety concerns. This will be the end of my good life in self-direction. Help!

I support HB 318/SB 441

Developmental Disabilities Administration -- Self-Directed Services (Self-Direction Act)

My Self Directed Life...



Self-direction is important to me because...

I make my own schedule each day

I choose my own staff, including family members

I go to places I like and choose activities I want to do

I have a support system of my choosing, including family members!

Choices I have made

With Staff, I participate in community outings, working on mosaics, participate in things that keep the home running well, volunteer at local horse farm, and perfect skills I have along with gaining new skills. Because I have many behavior issues and can be aggressive, I'm able to choose staff that will help me diffuse.

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



I support the Self-Direction bill because is will...

- Create a strong Advisory Council to re-establish the principles of self-direction and DDA accountability
- Allow participants to continue to include family members as support staff
- **R**estore the participants' right to choose a support broker as their fiduciary
- Ensure participant choice and control of all services
- **M**andate that *anyone* eligible for DDA services can self-direct

#CARE Md

Justin Sauter 100 Brookebury Dr. Apt B1 Reisterstown, MD 21136 District 10



All About Me



I am a 28 year old Marylander, living with a loving caregiver family, and am loved by my birth family. Unfortunately, I was diagnosed with mental retardation and autism at an early age, affecting my abilities. I relish working and intermingling in the community. Competing at a normal (minimum wage) level in society is not possible, so I volunteer. Behavioral and strategies from past training, used by my caregiver and provider, greatly help me maintain and increase my abilities, in quest toward a higher level of normalcy.

Choice and Control Matter Matter to Me!





John Phillip Woodhead 443-280-1096

crwoodhead@hotmail.com

Self-Direction is important to me because it allows choice, a favored concept amongst free citizens. Self-Direction enables me to be an active part of the community, vs. "vegetating" at an inefficient Day-Habilitation center, where my skills and behaviors decrease. Taxpayer money now goes toward Self-Direction funds, allowing me to employ an assistant to take me to worksites and other meaningful activities. Self-Direction provides a worthwhile and rewarding job for my motivated provider, who does a terrific job using learned behavioral conditioning methods to assist me with tasks and interacting in the community. Family and I worry about DDA changes to Self-Direction being made by self-serving, dispassionate, and disorganized DDA bureaucrats, chronically wasting time, money, and resources; negatively affecting me, my peers, those who care for our wellbeing, and the taxpayer.

I SUpport HB 318 and SB 3/8 Developmental Disabilities Administration – Self-Directed Services (Self-Direction Act)

(1) My Good Life



(2) Because of Self-Direction I can... (Self-direction is important to me because...)

Go to CCBC Single Step Programm

I can volunteer at TRRC & La Cheval Farm

I can sleep in if I am awake all night

Choices I have made (or What choices have I made?

Or some other heading of your choice or no additional heading)

To maintain a healthy weight by

working out every day. To volunteer

at TRRC & La Chevel Farm

(3) My family & I support the Self-Direction Act because Choose and Control make the Good Life possible.

Insert Picture



John Kusik 3007 Terra María Way Ellicottcity MD 21042 U10-480-3919 1B

- (4) What will the Self-Direction Do? (or I support the Self-Direction bill because... or Why do my family and I support the Self-Direction Act?) (Put your own comments in place of words below)
 - Create a strong Advisory Council to re-establish the principles of self-direction and DDA accountability
 - Allow participants to continue to include family members as support staff
 - Restore the participants' right to choose a support broker as their primary advocate
 - Ensure participant choice and control of all services
 - Mandate that anyone eligible for DDA services can self-direct

#CARE Md

Self Direction is important to me because.

I can choose my own staff. My family Knows me best so they are my staff as well.

Have an active and happy life despite my severe autismm

Choose employees who are dedicated to helping me achieve my goals

Be part of my commonsty

Participate in Camp Indusion social events

and participate in The Atism Society events

John Kusik 3007 Terra Maria Way Ellicott City MD 21042 410-480-3919 District 18

Choices I have made

To contribute to my family home by helping with chores, laundry, meal prep, shopping To coltivate my many com munity Friendships To adjust my schedule to suite myneeds I have chose to have my family work for me because they know my health core needs and my rigid schedule. They I cnow my likes and dislikes and understands my health care

> John E Kusik 300 Terra Maria Way Ellicoff Coff MD 21042 410-480-3919

needs the best.

John Kusika His Mom Frances Angarita



Jessica's Self-Directed Life



Self-direction is important to me because it makes feel in charge of my life. It gives me the freedom to hire my own employees who help me engage in my community. My employees help me with meal preparation, shopping, laundry, and housekeeping. By being an employer I have learned about the importance of managing my budget and making choices that match my needs.

I recently completed a course at CCBC in job development. And I also participate in the Arc's Partners in Policymaking program. I am working towards a job as a peer support specialist for people with disabilities.

Self-Direction has empowered me to work towards independence





Jessica Salmon 7507/ Stonecuter Cr. Rosedale, Md. 21237 Election District 8 443 835 8517 I support the Self-Direction bill because... (Why do my family and I support the Self-Direction Act?)

- Create strong Advisory Council to re-establish core principles of self-direction
- Allow participants to continue to include family members as support staff
- Restore the participants' right to choose a support broker as their fiduciary.
- Ensure participant's choice and control of all services
- **M**andate that *anyone* eligible for DDA services can self-direct

#CARE Md

January 19, 2021,

To Whom It May Concern,

This letter is in support of House Bill 318 and Senate Bill 441, Developmental Disabilities Administration-Self- Directed Services (Self-Direction Act). The contents of HB 318 are very important to recipients of services received through the Self Directed Services Delivery Model. Self Direction allows families to tailor services in the most effective and efficient way to best meet the needs of disabled individuals. As everyones disability is

allocate services on an individual need basis.

For my disabled adult, Self Direction allows us to hire and employ family members to carry out services. For us, having family members provides a safe, quality and trusting level of service. In addition, being able to hire family members lowers employee turnover, eliminates staff call outs and especially during times of pandemics provides a medically safer service environment.

unique so are the needs. Self Direction provides the autonomy required to

The bill will help preserve and improve Self Direction. One specific improvement, in the bill, would be the ability to offer employment to all family members. Currently under Self Direction, we cannot hire family members or legal guardians who have a fiduciary duty to or serves as a designated representative for the recipient of services. In many cases, the current exclusion affects parents of disabled adults from being employed as staff.

Self Direction is important to so many in the state of Maryland. We need to continue to offer and improve the Self Directed Delivery Model. As legislatures, you need to hear our voices and help pass House Bill 318/Senate Bill 441.

Sincerely,
Heather Newcomb
Parent of Hanna Newcomb





My Self-Directed Life



Francis with DN

Because of Self-Direction I can choose my Personal Supports staff. I can spend time with people I like. I can go to music therapy and Bingo every week. I can go shopping, take drives and go to medical appointments with my staff.

I have chosen to self-direct so that I can control what I do and when I do it. I especially like music therapy, walking in my neighborhood and Bingo.

Choice and Control Matter Matter to Me!





Francis Garove 18 Flintlock Ct. Perry Hall, MD 21128 Election District What will the Self-Direction HB-0318 and SB-0441 do?

- Keep DDA accountable.
- Continue to allow family as advocates without restricting family as direct support staff
- Allow participants to choose and have funded activities of their choice as it is designated in their plan
- Mandate that anyone eligible for DDA services can self-direct

#CARE Md

I support HB 318 and SB441

Developmental Disabilities Administration -- Self-Directed Services (Self-Direction Act)

My Good Life



Self-injury

Because of Self-Direction I can develop a daily schedule with enough flexibility in it to help me stay calm.

I have intermittent Explosive disorder. I'm like the guy who has road rage. I become very self-injurious and have many scars on my hands and arms. One size fits all programs cause my anxiety to build because I do not always understand what they want me to do.

But in self-direction services my support people are able to reshuffle my activities and provide me with time and space to calm myself. I'm controlling myself in self-direction especially since I've had a behavioral plan designed for me.

My family & I support the **Self-Direction**Act because Choice and selfdetermination make for a Good Life





Special Olympics

Name Address Contact Information Election District I Support the Self-Direction Act because... it will restore self-direction to the flexible program it once was and allow me to maintain control over my plan and my supports and my life

This is important to me because... In May 2019 my medications stop supporting me and I almost ended up in a residential placement. My parents got little support from DDA during my 15 month crises. Because I am self-directing, my parents found resources that slowly turned my trajectory around. I'm now participating with staff confidently and calmly, I have a spelling system I use to express my anxieties, thoughts and choices. I am going into the community and, although I still self-injury, I have fewer episodes that are lasting for shorter periods of time. Self-directed service has given me back quality of life. Please give me more control over my plan so I can continue to flourish. Support HB318 because it will:

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

#CARE Maryland

My Self-Directed Life



My name is Douglas Gabler. I am 24 years old.
I have severe autism and am nonverbal.
I am in the DDA Self-Directed services program.

Under Self-Direction I have a wonderful daily program that really meets my needs. I am physically strong and love to be outside. I need to be physically active to use up all my energy. I've also been involved in therapeutic horseback riding since I was 14 years old. Putting all of this together, my family helped me set up a program where I work at the Wheaton Park Stables.

I love it! Every day I go there with a helper, and I'm busy all day long. I unload the hay wagon, deliver hay to the barn, feed the horses, and muck the fields. I'm proud to be taking care of the horses and their pastures. Despite my disability, I am making a contribution to the community.

Choice and Control Matter Matter to Me!





Unloading the hay wagon

Douglas Gabler 10125 Markham St. Silver Spring, MD 20901 emgabler@verizon.net Maryland District 20 My Self-Directed program is good for me, but it's a bureaucratic nightmare for my family. This bill is important to me because I need the supports and flexibility that used to be available under Self-Direction but have been taken away.

- I need a voice via an Advisory Council.
- I REALLY need a strong Support Broker who can do more for me than the minor role the current system allows; i.e, I need that role restored so my Broker can be an advocate for me and help with my program.
- I need to be able to hire relatives as staff -- Who knows me better? It is really hard to find qualified people to work with me and in this time of COVID, it is even more difficult.

My family and I support the Self-Direction Act because it will help me build a life based on my strengths and my choice. Thank you for time and attention.

Sincerely,

Douglas Gabler



Meet Desi – aka Desmond Langston

Desi has been living with multiple disabilities since being born prematurely. He has intense medical and physical needs. He has a staff of four non-family staff that have worked with him and provided excellent care for at least three years and some as long as 15 years. He loves his staff and wants to keep them with him when he moves into his own home that his parents, now in their 70's, have had built for him in 2020. Desi needs the consistency of having these staff to be successful in his own home and transition to a time when his parents are no longer able to support him in any capacity. A time that all parents with adult children with disabilities fear.

But, despite only needing an additional 21 hours of support to make the move, Desi can't move into his own home

Why? Because DDA policies do not allow him to have all the personal support hours he needs. DDA has been trying to force Desi into a provider-managed service to get his overnight support needs: Supported Living.

So, Desi loses all control of this service. He can pick the agency, but can't count on having the staff he loves and trusts. He will be with strangers in his most vulnerable times.

You would think that DDA is doing this because this will save the state tons of money, but that would be incorrect! This option will actually cost the state a minimum of \$44,000 a year, but more likely over \$70,000/year. (See attached detail)

Desi and his team have been working over a year to get this resolved. During that time, Desi's aging mother's health has deteriorated because of the stress of dealing with Covid19 and the unresolved situation. No one from DDA offers solutions or help. They continue to state that Supported Living is a cost-effective service and he needs to pick an agency.

However, Desi's team has reached out to over 14 agencies, most of which never responded to the call or email. Those who have cannot come close to Desi's staff current salary and benefits. Many are not interested in working with self-direction. Desi faces the very REAL possibility of losing his

treasured staff if their hourly rates are reduced. This situation is LOSE -- LOSE.

HB318 offers a way to give Desi and the State a WIN – WIN! Please help Desi and the many other people caught in this situation there are a lot of them and there will be more.

Dear Sir or Madam,

We urge you to protect The Maryland Disabilities Self-Direction program by supporting and passing bill HB 318/SB 441.

We have a 29-year-old son with severe disabilities who has been using self-direction. Since he started with self-direction, he has been doing much better, has a better sense of purpose and self-worth, and is able to remain living with us rather than move to a group home (which he does not want to do).

Since he has been in self-direction, he has been able to get a part time paying job cleaning eggs at a farm. He would not be able to do any job alone or even with periodic checks. He needs help all the time and must always have a responsible person with him for his safety. We never thought he would be able to get a job, but with self-direction he has been able to.

However, it is always challenging to find good people to work with him. It is also very challenging to keep them since they generally have this job as a temporary career situation. Either they go back to school or get a job with better pay and a better future for them. In two years we have gone through four different care givers.

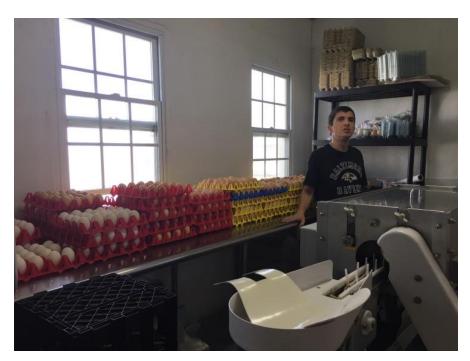
This has not been easy for us, but the ability to have me, his mother, step in as support staff and fill the vacancies has been critical. I have been able to take the role as his caregiver including going to and helping him with his volunteer and job positions. It would be very difficult if this program were not available for us.

Also, since the onset of COVID we have not been able to hire and use additional helpers because he has a compromised immune system. He currently has one helper who goes with him to his job at the farm three days a week for several hours. She also has a compromised system and is also very careful. The job cleaning eggs does not have them interact with any other people, so we feel they are pretty safe there. However, she does not feel safe coming into our house, and we understand and agree, so all other weekly services are currently performed by me.

In addition to being able to be part of his care network it is also important that we are able to continue to use a support broker to help navigate the self-direction program, which can be hard.

Passing Bill HB 318/SB 441 will help Daniel live his life in the best way he can!

Thank You, Colleen, Brian and Daniel O'Mara





I support HB318 and SB441

Developmental Disabilities Administration -- Self-Directed Services (Self-Direction Act)

My Self Directed Life



Self-direction is important to me because I can count on continuity with my staff.

They work with me to make good choices in activities and in daily living.

I can make changes in my staff and use as many hours as my budget allows.

I can use family as staff. They help me meet the purpose of the Program. This also avoids having to frequently orient new staff. I also get more help than the hours budgeted.

Choice and Control Matter to Me!

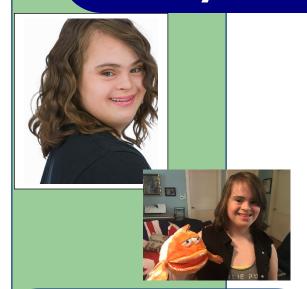




Courtney Litzenberger 8033 Fair Breeze Drive Severn, MD 21144 Ruth.litz@comcast.net District 33 I support the Self-Direction bill because:

- It provides for self-direction and DDA accountability
- It allows me to continue to include family members as support staff.
- I have made progress in language and ADLs since working with my staff in the program.
- It would help me get my Support Broker back so I can meet and have use of all aspects of the Program correctly.
- It insures participant choice of all services as well as being budget friendly to the State.

My Self Directed Life



Choice and Control Matter to Me!

Self-Direction is important to me because...

- I like to decide what I am going to do with my time instead of having to do what someone else tells me.
- I have a lot of interests, like
 - Ventriloquism- I hope to be on America's Got Talent someday
 - Snowboarding- I love to snowboard, and this year I will be able to volunteer as an instructor trainee to help other people with I/DD learn to snowboard.
 - England and Fashion- I love everything about England, and I am saving up my money from my job at MOD Pizza to go to London. I really admire a British fashion model and TV presenter named Holly Willoughby and I like to take pictures of myself wearing similar outfits and posting those pictures on Instagram.
 - Dancing- I love to dance, and I am really proud of my gold medal at the Special Olympics Summer Games in Abu Dhabi in 2019. I was Wonder Woman- one of my favorite superheroes!
- I like having someone that I choose help me do the things I love. My aide Angel is close to my age, and I love to share my interests with her and hang out with her.
- I am proud that I can make my own decisions.



Carmen Houston-Ludlam
PO Box 429
Lothian, MD 20711
Mom's Cell: 443-994-0902
ginger.hl@runningspringsfarm.com

Legislative District: 30B





I support the Self-Direction bill because it will protect my ability to self-direct my services. I love my life!

#CARE Md

I support HB-0318 and SB0441

My Self-Directed Life



Self-direction is important to me because...

Controlling how I spend my day makes me happy. Everyday can be unique.

I can experience new places in the community when the timing is right for me.

I hire employees that truly care about me and help me achieve my goals.

I have been able to safely maintain some of my time in the community even during Covid 19.

I am learning to be more independent at home and that feels great.

I can change my program as I gain more independence because I have a team that support me.

Choice and Control Of My Day Matter to Me!





Al Wopat 905 Monkton Rd Monkton, Md 21111 awopat@comcast.net 410-591-2036

- Historically self-direction has saved the state money while providing remarkable outcomes for people with developmental disabilities. HB 0318 will preserve that by:
- Creating a strong Advisory Council to re-establish the principles of self-direction and DDA accountability
- Allowing participants to continue to include family members as support staff
- **R**estoring the participants' right to choose a support broker as their primary fiduciary
- Ensuring participant choice and control of all services
- **M**andating that *anyone* eligible for DDA services can self-direct

#CAREMd

2021 SB 441- Self Directed Care - NAMI-FAV (1).pd

Uploaded by: Howe, Josh

Position: FAV



February 16, 2021

Senate Bill 441- Developmental Disabilities Administration - Self-Directed Services - SUPPORT

Chair Kelley, Vice Chair Feldman, and members of the Finance Committee,

The National Alliance on Mental Illness, Maryland and our 11 local affiliates across the state represent a statewide network of more than 45,000 families, individuals, community-based organizations and service providers. NAMI Maryland is dedicated to providing education, support and advocacy for persons with mental illnesses, their families and the wider community.

NAMI Maryland supports **SB 441** and the establishment of the State Advisory Council on Self-Directed Services within the Maryland Department of Health (MDH). The work of the State Advisory Council on Self Directed Services outlined in the bill include:

- making recommendations to DDA on how to improve the self-directed services process and experience of using self-directed services;
- providing a forum for input from Maryland residents related to self-directed services;
- inventorying and track services and supports available through home- and community-based services programs;
- reviewing and make recommendations regarding disparities between the services and supports received by individuals who use self-directed services and individuals who use services provided by the State;
- reviewing and make recommendations regarding certain policies to the General Assembly.

The goal of NAMI Maryland is to respect and promote self-determination, recovery and full community inclusion for people who have been diagnosed with a mental illness and who depend on government subsidized mental wellness services. Self-Directed Care is a service delivery model in which program participants make their own healthcare choices and actively participate in their recovery from serious mental illnesses.

Contact: Moira Cyphers

Compass Government Relations

MCyphers@compassadvocacy.com

For these reasons, NAMI Maryland asks for a favorable report on SB 441.

SB 441 Favorable Written Testimony Kate Kolm My Go Uploaded by: Kolm, Margaret

Position: FAV

I support	HB	and
SB	441	

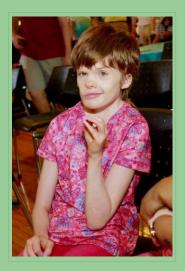
My Successes in SDS



Self-Direction is important to me because...I have become healthier and happier. I exercise more, eat better foods, and am taking fewer meds. That's because my staff are trained by and work for me, not a manager in a building far away. I have learned to swim, ride horses and now work out at a gym. I have had meaningful volunteer experiences at a horse stable, and at a local humane society. I have made new friends in my community. This is my good life!

Choice and Control Matter Matter to Me!





Kate Kolm Indian Head, MD c/o Peg Kolm mlkolm@mindspring.com My primary concern is the DDA policy now requiring that only "providers"--not my staff--can offer third shift/overnight care. I need this support as I am Deaf Blind & nonverbal. And a provider will charge much more per hour than my staff make now. This rule will force me back into provider-directed care, b/c it's all or nothing, says DDA. If I have one shift per day with a provider, ALL shifts must be with a provider. And I already have been in two agencies and left because of health and safety concerns. This will be the end of my good life in self-direction. Help!

NDW SDAN bill 02.2021 pdf.pdf Uploaded by: Kuchar, Carol Position: FAV

Hello

I am writing this letter to give our family's personal experience with Self Directions, from our point of view, and the upcoming Self-Direction Act HB#318/SB#0441. We have a 30-year-old non-verbal, autistic, insulin dependent, diabetic son.

Prior to graduation, I (John's mother) went to many day programs to figure out what would be best for John. IF John were to attend a "day program", a Medical Day Program would be the only option due to John's medical condition and the medication needed. John went into New Directions – which has now been renamed and is currently referred to as Self Directions. In New Directions/Self Directions, John started his own errand business called John the Go2Guy. It is John's goal to be productive out in his authentic community helping others.

By John being in Self Directions, he is able to do things he enjoys. He is happy and productive. Prior to COVID-19, John was in his authentic community every day. Currently he enjoys doing therapeutic horseback riding twice a week, walking at various parks in our area, swimming most days of the week, listening to music, reading books and playing games. He has exceptional staff working with him who have been with him for years.

Self Directions allows John to "live the good life" ~ disabilities or not. He is able to customize his needed supports which meet his unique needs and goals. As I stated previously, without Self Directions John would be "sentenced" to his days spent in a day program due to his intense medical needs. These day programs are quite expensive for the state to have individuals attend, while for some individual's day programs may be their best option. It would not be the best option for John. John enjoys being out and productive in his authentic community. He is a real, productive member of his community. He spends his days happy, productive, safe and all of this at a savings to what Maryland State could be paying for he attending a day program.

John is able to make choices and decisions about how he spends his day, what work he will do and who he will hire to assist him in being productive. This does not come easily but with his incredibly dedicated staff and family (John's team), we manage~always with John's best interest in mind.

Self Directions allows all the individuals in Self Direction to customize their life, receive the supports they need, live their dreams and "live the good life". That is the goal, and it is achieved by many individuals in Self Directions.

Sincerely,

Carol Kuchar 14001 Fox Run Court Phoenix, MD 21131

410-458-4605 cell

Lee_FAV_SB441_2021.pdfUploaded by: Lee, Susan

Position: FAV

Susan C. Lee Legislative District 16 Montgomery County

Majority Whip

Judicial Proceedings Committee

Joint Committee on Cybersecurity, Information Technology, and Biotechnology

Chair Emeritus Maryland Legislative Asian American and Pacific Islander Caucus

President Emeritus

Women Legislators of the

Maryland General Assembly, Inc.



THE SENATE OF MARYLAND Annapolis, Maryland 21401

James Senate Office Building 11 Bladen Street, Room 223 Annapolis, Maryland 21401 410-841-3124 · 301-858-3124 800-492-7122 Ext. 3124 Susan.Lee@senate.state.md.us

February 12, 2021

Senate Finance Committee

Senate Bill 441 - Developmental Disabilities Administration — Self-Directed Services

This is vital legislation to pass in the face of COVID-19, but it is also essential and a common sense practice during so-called normal circumstances for some of Maryland's most amazing yet vulnerable individuals and their families. Senate Bill 441 makes certain that Marylanders with disabilities can self-direct their care with the assistance of family and in the comfort of more affordable accommodation of their home, instead of being institutionalized, isolated and vulnerable to COVID-19. The bill provides definitions for self-directed care and support brokers, further clarifying the responsibilities and abilities of this vital role. SB441 also creates an advisory council to resolve issues in self-directed care.

At its heart, self-direction allows an individual to be involved in all areas affecting their lives. In 2005 Maryland created the New Directions waiver, an independent plus program, to ensure that residents with developmental disabilities may self-direct their lives. The concept was to include self-direction day-to-day care, hiring of employees, and allocation of funds. However, since 2013, these changes have been consistently and considerably reduced. Over the years, self-directed individuals lost the availability for overnight support, had individual transportation options reduced, which affected the ability to attend life-enriching events, and funding has been restricted for therapies like art and riding programs.

The Centers for Medicare and Medicaid allow much flexibility for individuals to direct all areas of service delivery. The Maryland Department of Health's DDA, with the before mentioned changes and reductions, has removed much control of how services are provided and by whom. Recent years have shown the support broker work reduced to that of serving in a human resources role, or financial counseling. Such reduction in the scope of their work contradicts the

CMS description of the support broker as a consultant/counselor/agent who takes direction from the individual and provides the services and supports to sustain them as they direct their services. SB441 mimics this description. The oversight of a Support Broker is essential to be codified, so that the charge and scope of their responsibly is clearly spelled out as well as the consequences for neglecting their duty to the individuals that they serve.

The bill creates the State Advisory Council on Self–Directed Services to examine policies, procedures, and proposals related to self-directed services. The council will make recommendations to improve the process, receive input from individuals receiving services, track services and supports throughout the state, conduct an annual survey of the service process, and review and make recommendations on the services provided to individuals. The composition of the Advisory Council may be staffed with existing resources.

MDH raised some concerns that our legislation creates "unreasonable operational challenges contrary to recommendations from Office of Legislative Audits." Head Auditor Gregory Hook provided Delegate Lewis-Young, sponsor of cross-file HB 318, with a letter that stated absence of conflict between the bill and OLA recommendation. A second concern of the MDH was also the creation of a new waiver, which this bill does not mandate, only allow if deemed desirable. A third issue raised by MDH is the involvement of self-directed individuals' feedback throughout the waiver revision process. The audit demonstrating problems should not be used as an excuse to offshore those problems to others, it should be a call to action to confront them, this bill is that call to action. A legislative policy proposal based not only on the identified faults, but the intended goal and outcome of the program itself.

There is nothing in this bill to jeopardize the federal match, because this has been done under other waivers. At its core, this bill merely restores the original intent of the New Directions waiver and empowers the participants to again self-direct to the full ability intended. Therefore, I respectfully request your favorable vote for SB441.

2021_Self-Direction SB 441 - OTL testimony.pdf Uploaded by: Linville, Owen

I support HB 318 and SB 441

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 trivia, 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.

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





Owen Linville 7290 Ridge Road Marriottsville, MD 21104 Owen.linville2@gmail.com District 9A My family and I support the **Self-Direction Act** because it will:

- Create a strong Advisory Council to re-establish the principles of self-direction and DDA accountability
- Allow participants to continue to include family members as support staff
- $oldsymbol{R}$ estore the participants' right to choose a support broker as their professional advocate
- Ensure participant choice and control of all services
- Mandate that *anyone* eligible for DDA services can self-direct

#CARE Maryland

See the power of self-direction here: https://www.youtube.com/watch?v=277skpmidRY

DD Coalition testimony__SB 441.pdf Uploaded by: London, Rachel





8601 Robert Fulton Dr Suite 140 Columbia, MD 21046



1500 Union Avenue Suite 2000 Baltimore, MD 21211



8835 Columbia 100 Pky Suite P Columbia, MD 21044



Maryland Developmental Disabilities Council

217 E Redwood Street Suite 1300 Baltimore, MD 21202



7000 Tudsbury Road Windsor Mill, MD 21244 Senate Finance Committee
Senate Bill 441: Public Health- Developmental Disabilities Administration- Self-Directed
Services (Self-Direction Act)
February 16, 2021

Position: Support

The Maryland Developmental Disabilities Coalition (DD Coalition) is comprised of five statewide organizations that are committed to improving the opportunities and outcomes for Marylanders with intellectual and developmental disabilities (IDD). As such, the DD Coalition supports SB 441.

Background: Today, a growing number of people with IDD 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 IDD, families, and other advocates to create a waiver pilot program under which people with IDD 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 with IDD to assist with the coordination of self-directed services – were eliminated.

WHY is this legislation important?

The intention of this bill is to restore and preserve the principles of self-direction envisioned in Maryland.

All people with disabilities, regardless of their physical or intellectual capacity, should be empowered to self-direct their services and to receive assistance to do so from people they choose, hire, and trust.

> Self-Directed service options should be flexible to meet the needs of the individual to meaningfully live, learn, work, play, and worship as the person chooses.

WHAT does this legislation do?

- This bill establishes a State Advisory Council on Self-Directed Services to preserve the principles of self-direction in DDA services and supports. Stakeholder members would include people who self-direct their services, their parents, Department personnel, and others integral to the development and maintenance of a responsive system of self-directed supports.
- The purpose of the Advisory Council is to examine, monitor, and make recommendations regarding the provision and delivery of self-directed services, to ensure that they operate efficiency, effectively, and empower people with IDD.
- The bill also restores some definitions that were changed in waiver amendments to their former forms, including who people with IDD may hire as staff and many of the roles of the support broker. It also enables the support broker to take on new responsibilities, including in certain circumstances, acting as a person's designated representative for the person receiving services. In light of these changes, we believe that State Advisory Council should be utilized to develop safeguards to address any conflicts of interest that may arise in these circumstances and to ensure that people with IDD continue to have choice over their use of support brokers.

The DD Coalition 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 441, which will enable more people to take responsibility for managing their services and will create a statewide advisory council to address issues that arise in the provision of these services.

Contact: Megan Rusciano, Interim Co-Managing Attorney, Disability Rights Maryland meganr@disabilityrightsmd.org

SB441 Andys support.pdfUploaded by: Maerzke, Debbie Position: FAV

I support SB 441!

Developmental Disabilities Administration – Self-Directed Services

I am living my Best Life

since I have been able to Self-Direct my services! I am an epileptic and I require lots of sleep. Some days I am up early and ready to go out into the world and adventure. Other days I need to sleep a lot to maintain my health. I am also much healthier, since leaving my over-crowded day program many years ago. I am able to live with my family, and even able to pay them a little for all the time they spend with me, and all the adventures we go on together. I

make choices every day about what I want to eat, where I want to go, and what I want to do. In this photo, I am at a music venue listening to music!

My name is Andy The Self-Direction Act will help me to maintain my ability to make choices and have control over my life. I choose my own staff, and decide which direction to go!!

My family and I support SB441, because it will help to keep options open for me. It will allow me to continue to pay a family member as part of my staff. I have difficulty communicating my needs and wants to anyone who does not know me well. SB441 will restore my right to have a Support Broker, who will be a wonderful, professional advocate for me. It will also help to preserve my freedom to self-direct. Some people want to take away my right to self-direct, because they don't believe I can make my own choices. But I do know what I want, I just need my family to help explain what I want, and help me to be happy and healthy. My family knows that I love to jump on the trampoline on warm summer days, as you can see by my photo! Please help me to stay where I am happy, and living my BEST LIFE for the time that God gives me!

The Maerzke Family (Dan and Debbie and Andy Maerzke) Election District 4 8517 New Cut Road, Severn, MD 21144

Support of SB 441 - Self-Direction Act - PM.pdf Uploaded by: MILLER, PAMELA

Support of SB 441 – The Self-Direction Act Developmental Disabilities Administration – Self-Directed Services Written Testimony 2/16/21

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 be the captain of a trivia team at a local restaurant, 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.

Watch this video to see the life-changing power of self-direction for individuals with developmental disabilities:

https://www.youtube.com/watch?v=277skpmidRY

Historically, self-direction has saved the state money while providing remarkable outcomes for people with developmental disabilities, including my son. **SB441 will preserve that.** Other critical components of the Self-Direction Act will:

- Create a strong Advisory Council to re-establish the principles of self-direction and DDA accountability;
- Ensure participants' choice and control of services;
- Allow participants to continue to include family members as support staff;
- Mandate that anyone eligible for DDA services can self-direct; and
- Restore the participants' right to choose a support broker who acts as their fiduciary.

For more information visit MarylandSDS.org

Thank you for your support,

Pamela R. Miller, Ed.D., mother of a client in self-direction 7290 Ridge Road, Marriottsville, MD 21104

Pamiller8@gmail.com

443-562-9945

District 9A

Self Direction Act Written testimony 2021.pdf Uploaded by: Pumputis, Terri

I am writing in hopes that you would support The Self-Direction Act - (HB#0318/SB#0441). 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 photo is in the video link that I've included in this email below, with one of his finished 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 likes gardening, which he has created a patio garden on our patio. 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 than in a residential facility. Right now in the Self Directed program, he is living the life he wants to live!

I'm including a video presentation from individuals who are in the Self Direction program currently. The video explains what The Self-Direction Act (HB#0318/SB#0441) is truly about, and how it has made a significant difference in my son's opportunities, along with many other individuals. The Self-Direction Act video link: https://youtu.be/277skpmidRY

I'm truly hoping you would consider supporting The Self-Direction Act (HB#0318/SB#0441), 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 Staff/Parent of adult with Autism in the Self Direction Program 100 Brookebury Drive, Apt B1 Reisterstown, MD 21136

PFA Senate Bill 441.pdfUploaded by: Rienzi, Rebecca Position: FAV



SENATE BILL 441

Developmental Disabilities Administration: Self–Directed Services (Self–Direction Act) February 12, 2021 POSITION: SUPPORT

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 19,300 Maryland residents.

PFA supports House Bill 318 to create an advisory council to re-establish the principles of self-direction and create accountability; allow participants to continue to include family members as support staff; restore participants right to choose a support broker as their primary advocate; ensure participant choice and control of all services; and mandate that anyone eligible for DDA service may self-direct if they choose.

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 policy changes to the Self Directed waiver are in direct opposition to what the agency claims to be fundamental rights of all people. These changes will eliminate and restrict Self Directed participants choices and are the antithesis of self-determination.

Specifically, these changes will: Eliminate of overnight support from trusted employees for people with intense needs; eliminate individualized transportation arrangements; eliminate choice and completion for essential fiscal management services; restrict customized goods and services; restrict who is eligible to self-direct; restrict who the participant team's choice to hire family members; and restrict the participants access to support broker- the only professional on the team with a fiduciary duty to the person. The use of provider rates to determine self-directed budgets is fiscally irresponsible as it may overfund many participants while underfunding others. Additionally, research shows that self-directed services cost, on average, 25% less than traditional provider-based services.

I respectfully ask that you vote in favor of SB441. For more information, please contact Rebecca Rienzi, Executive Director, Pathfinders for Autism at 443-330-5370 or rrienzi@pfamd.org.

SB 0441 Patti Saylor written testimony.pdf Uploaded by: Saylor, Patricia

SB 0441

Support

My name is Patti Saylor, I am a nurse working for people who self direct their DDA waiver services. I have worked for over 100 individuals and their families since the inception of Self Directed Service in 2005. I have witnessed the impact of the changes The DDA has made over the last 5-6 yrs. I volunteer with the Self Direction Advocacy Network to represent the needs of my customers, many of whom are consumed with the demands of their lives and rely on advocates to convey their concerns and work on their behalf.

I was going to illustrate to you the negative impact these changes are having through personal examples but I believe the point has been made clear to you through oral testimony.

I will instead tell you...about the human toll - In the course of my job I speak at length with my customers and their families. We laugh and we cry. I tell them it will be ok when they are no longer here... that we will protect the system so it will be here when they are not.

On a daily basis, I see firsthand the pressure they are under... **Families are the best natural resource, our State should value and protect them as such.** They continue shoulder the lion's share of financial and physical support to their loved ones. They love their adult child or sibling **This love and commitment should not be exploited by the government.**

While they are grateful for any and all support they get from the State. Grateful for more flexible services during the State of Emergency, they are exhausted... they are frustrated, they are angry and they are growing more fearful.

- For over eleven months along with the rest of us, they have protected themselves and their vulnerable loved one from COVID.
- Only 30 individuals who self direct their services reported testing positive for COVID. A
 clear benefit of not living in a congregate care setting. No deaths have been reported.
- Family have taken on the role of direct support to limit exposure from staff coming in.
- Endured economic and work pressures and gotten very little sleep and no respite.

In addition to this, they are being **overburdened by the growing bureaucratic system** of red tape, MDH/DDA systems that do not work and policies that **limit choice and control** over their lives. They must simply passively endure if they want services. Or it may be suggested if they are not "happy" perhaps self direction isn't right for them. When for most Self Direction is the option.

They/We need your help to alleviate what pressures you can — This Advisory Council gives them hope that their voices and concerns will be addressed and their lives become more manageable during and after the pandemic

Thomas Supports SB441-converted.pdf Uploaded by: Shade, Doug Position: FAV

My name is Thomas

I use Self-Directed Services through the Community Pathway's Waiver..

I have Autism, Asthma and Crohn's Disease with 4 fistulas. I have lots of doctor appointments because of my Crohn's Disease, fistula's and I cannot sit down for very long because of the setons and I need to use the bathroom a lot.

For my Crohns Disease and fistulas I get a shot of Methotrexate on Mondays and it makes me feel sick and tired. My Humira shot is on every Sunday. My medicines make me immune-supressed. So I can't go where sick people are because it's easy for me to get sick. I cannot go to OBI or a center. I have many doctor appointments in Baltimore, and I can't leave my house on days when I am feeling sick and my fistulas bleed.

I need Self Directed Services because I want to work and be a part of my community.

With Self Directed Services, I have tried and am learning about many things:

- I am learning to grocery shop, cook & clean-up my meals.
- My food allergies and trying to gain weight are very important to my health
- I am learning how to plan and get ready for the day by making schedule.
- My medication chart helps me learn when to take my 11 medicines
- At Arlington Echo, I sorted and typed up a list of all of the books in their library
- I collect food for the Food Pantry and put it into boxes to drop off.
- I help with Harundale Church meals for the homeless. I help wash dishes
- I deliver a newsletter to 200 houses
- I help pick up trash and help with security patrol for my neighborhood.
- At WOODS Church I help keep up a garden all year, I help with Vacation Bible School, and I help with bulletins after church services.
- I help load things into a truck for HOPE For ALL.
- At the Fire Hall, I help clean up the recycle trash after BINGO.
- I advocate for unique needs and independence
- I bake food for the homeless shelter.]
- I make sack lunches for Winter Relief Church Program.
- Daily Exercise is important to my GI system
- I volunteer for Special Olympics for 3 days at the POLAR BEAR PLUNGE where I dress as a SHARK, and hand out bags to Plungers. I also volunteer at Special Olympics fundraising events like "Kegs and Corks", Irish Fest, and other fundraising events.
- My Mom and I walk dogs so we have money to buy things.

Next I want to volunteer at a library. I am good with typing and using the computer. I am good with numbers and letters, and I can find and put away books and DVDs. I would like to work at the library.

I will have a job with a paycheck someday soon because of Self-Directed Services.

Thank you,

Thomas Shade











SB441 SheinbergLetter 20210212.pdf Uploaded by: Sheinberg, Reda

Reda & Marc Sheinberg

(Advocate for) Robert Sheinberg

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Email Reda.Sheinberg@gmail.com

Phone 301-385-5889

In Favor of the SB441, The Self-Direction Act February 12, 2021

To Senator Lee and the Finance Committee:

I write on behalf of our son, Robert, and the individuals who participate in the Self-Directed Services program administered by Maryland's Developmental Disabilities Administration. Please support SB411, The Self-Direction Act. I am in support the positions of the Self-Directed Advocacy Network of Maryland, Inc, SDAN, on this Act. See SDAN FAQs: https://tinyurl.com/yryf7op4

As a parent, I am concerned about DDA's system wide transformation and radical changes to waiver language and policy and restrictive rules being applied by DDA Maryland. I am concerned about the continuation of the Self-Directed Program for individuals like my son.

Maryland self-direction has been available since circa 2004. ALL DDA participants should have self-determination in their plan whether supports are provider managed or completely participant managed. The DDA should provide ease for participants with their circle of supports to move to a more self-determination model no matter which support services are selected.

As the founder and director of an advocacy group in Montgomery County, https://groups.io/g/MCTransitions, we have over 560 members in our e-group and over 225 on our Facebook site, http://www.facebook.com/groups/MCTransitions/. Most participants and their families need a lot of support for services. We are grateful for the combination of DDA State support, family and local support needed to help DDA participants.

Out son, Robert, now 35, with the support of the DDA Community Pathways Waiver, Self-Directed Services, SSDI, other county and private services, is able to live an independent life and integrated into his community as follows:

- Works a part-time retail job at 25 hours a week at Goodwill Rockville, which he has held since October 2020. Worked at Big Lots in Gaithersburg previously
- Lives in his own apartment at 200 Olde Towne Gaithersburg with help of a Housing Opportunity Voucher. He is also in District 17.
- Loves animals and volunteered at the MCPAWS for a number of years.
- Works out regularly in his neighborhood with help of his Self-Directed Staff.
- Meets with 7 other self-advocates to work on daily living skills and social activities thru a vendor contract for part-time staff thru the Integrated Living Opportunities (http://www.ilonow.org) in which we are a participating family.
- With support of his team, selects his own staff and vendors to assist him to live successfully in his own apartment and in the community.

- Values the ability to change team staff and vendors as needs change.
- Values the flexibility of the Self-Direction program that can change with his needs allowing him the independence to mature at his speed.
- Values continuing his life during the COVID Pandemic because of Self-Direction Services, with the help of staff to maintain health standards, allowing him to continue his job and many virtual meetings with his peer group thru Integrated Living Opportunities and other resources.

Picture of Robert at MCPAWS at his volunteer assignment working with one of their dogs. The other picture is of Robert and his loved cat Brocade, who died in 2018. Thru his DDA Self-Directed Waiver, staff works with Robert so he can live, work and volunteer in his community.





Heather SB 441.pdfUploaded by: Slatnick, Helaine Position: FAV

I am in support of the Self-Direction Act SB 441. My daughter, Heather Slatnick, is 29 and has low muscle tone, moderate to severe intellectual disability, swallowing disorder, anxiety disorder and is incontinent. She cannot walk without assistance and uses a wheelchair when out in the community.

We attempted adult day care. There was no consistency with staff and feeding her became an issue. Then I was told because of her behavior, they were not taking her into the community because there wasn't enough staff. I couldn't go with her because I was working and I was told we couldn't hire a one on one for her because that state money, even though was a different service, came out of the same pot and it was not allowed. We had no choice, but to pull her out. She had become a shut in and her social anxiety became worse.

Self-direction has been a lifesaver! She is happy, healthy and living her best life. She goes out into the community daily and she/we can hire staff that Heather likes and is consistent. She has friends, goes to the mall, bowling, grocery stores, participates in classes and more.

Every year, DDA is taking more and more control of what we can and can't do with self-direction. The rules are always changing. They are taking away our support team by putting more restrictions on support brokers who are working for the person as opposed to service coordinators who are employed by the state and county and were told by DDA that their job is to lead us to information and forms, but not actually help us with the ins and outs of making the person-centered plans. DDA is also attempting to put restrictions on who can be an employee including family members. In many cases, the person prefers family and sometimes family are the only ones that can do the job. This has been a blessing during this pandemic. DDA has also defined what community is. My daughter goes to classes at Farring Baybrook Rec Center almost every day (pre-pandemic). DDA rules now state that because she is in classes with her peers and not neurotypical people, it is not considered community. Who are they to decide this? This is her community and as far as I'm concerned, if she's out of the house and going places, she's in the community. What if I told you that you could only interact and be friends with people with intellectual disabilities or you couldn't continue to work at a job you love, because it didn't meet DDA's vision of community?

Self-direction has been an excellent waiver to Heather. The purpose of self-direction is to let the person self-direct their budget to give them their best life and to keep them out of group homes and nursing homes. In the long run, I believe this program saves the counties and the State of Maryland money. As long as the person can prove where the money was spent, there should be minimal rules and constraints imposed by DDA, especially when it comes to community, staff and support brokers.

Thank you for your time and please vote in favor of the Self-Direction Act SB 441. The quality of Heather's life and the lives of others currently in this program are in your hands. Help them to continue living their best life.

Sincerely,

Helaine Slatnick

DDA SDS Participant - Phillip Woodhead.pdfUploaded by: WOODHEAD, CHRISTOPHER



All About Me



I am a 28 year old Marylander, living with a loving caregiver family, and am loved by my birth family. Unfortunately, I was diagnosed with mental retardation and autism at an early age, affecting my abilities. I relish working and intermingling in the community. Competing at a normal (minimum wage) level in society is not possible, so I volunteer. Behavioral and strategies from past training, used by my caregiver and provider, greatly help me maintain and increase my abilities, in quest toward a higher level of normalcy.

Choice and Control Matter Matter to Me!





John Phillip Woodhead 443-280-1096

crwoodhead@hotmail.com

Self-Direction is important to me because it allows choice, a favored concept amongst free citizens. Self-Direction enables me to be an active part of the community, vs. "vegetating" at an inefficient Day-Habilitation center, where my skills and behaviors decrease. Taxpayer money now goes toward Self-Direction funds, allowing me to employ an assistant to take me to worksites and other meaningful activities. Self-Direction provides a worthwhile and rewarding job for my motivated provider, who does a terrific job using learned behavioral conditioning methods to assist me with tasks and interacting in the community. Family and I worry about DDA changes to Self-Direction being made by self-serving, dispassionate, and disorganized DDA bureaucrats, chronically wasting time, money, and resources; negatively affecting me, my peers, those who care for our wellbeing, and the taxpayer.

Desi Cost Breakdown.pdfUploaded by: Wopat, Alicia Position: FAV



Desmond Langston -

One Example of Costly and Ill-conceived policy related to 24/7 support

- Living with multiple disabilities since being born prematurely.
- Intense medical and physical needs.
- Wants to move to the home his family secured for him
- Wants to keep his highly qualified, dedicated staff and maintain their pay and benefits.
- DDA's policies are prohibiting that <u>AND costing the state more money At least \$40,000!</u>
 LOSE-LOSE

SB441 offers a way to give Desi and the State a WIN – WIN! Please help Desi and the many other people caught in this situation!

Desmond				
Langston	Desi's Preferred Services:			
Cost	Personal Supports which is the Most Cost	DDA's Option:		
Comparisons	Effective for State as required in waiver service definition	Supported Living published rate as of 1-1-21		
Items the same in each option	\$64,284.47	\$64,284.47		
Personal Supports; Staff Pay Rate \$19.60 to \$23.75; Nine Holidays Paid at Holiday Differential, 1.5X	\$175,241.84			
Supported Living; staff pay rate \$14.71/hour; unknown benefits; paid at \$590.18/day		\$215,415.70		
Total:	\$239,526.31	\$279,700.17		
Minumum Savings:				
WIN-WIN!	\$40,173.86			
Enomy Canal Custom Doci2s Support Proban for 10 years				

From: Carol Custer, Desi's Support Broker for 10 years

sb441testimonyaw.pdfUploaded by: Wopat, Alicia Position: FAV

I am the President of Self Directed Advocacy Network (SDAN)—an all-volunteer advocacy organization, and the proud mother of a son with autism who is in his 5th year of Self-Direction.

If you haven't already, please watch the 7 minute video SDAN sent, and read the stories from our members in the written testimony. In combination with what you hear today, you will truly understand why we need your support for HB441.

It is important for you to know:

The Federal Centers for Medicare and Medicaid Services (CMS) defines Self-Directed Services (SDS) as allowing "participants to have the responsibility for managing all aspects of service delivery in a person-centered planning process. Self-direction promotes personal choice and control over the delivery of waiver and state plan services, including who provides the services and how services are provided.... participants are afforded the decision-making authority to recruit, hire, train and supervise the individuals who furnish their services." (https://www.medicaid.qov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Self-Directed-Services.html)

The CMS allows states wide latitude in how they implement these programs, and Maryland's DDA is moving away from allowing the participants to control how and by whom they receive supports. Self-direction has been severely curtailed here in the last six years. Nothing in this bill jeopardizes federal dollars. Our bill seeks a restoration of previous levels of choice and control where, incidentally, all federal matching funds were available, contrary to MDH's contention.

An option that was once individualized, person-centered, and efficient is morphing into one that is ever more *standardized*, *state centered*, *and costly*. Policy and procedure changes have included the following:

- Restrictions on who is eligible to self-direct
- Restrictions on the participant team's choice to hire family members, even when it is Participant's preference
- Restrictions on the amount and scope of assistance of a support broker the only professional on the team
 with a fiduciary duty strictly to the person. Support Broker roles have been shifted to overburdened and under
 trained Coordinators of Community Service (CCS).
- Elimination of individualized transportation arrangements so people have funding to get to their community activities
- Severe restrictions on funding for activities and therapies (e.g. music, art and riding)
- Future elimination of choice and competition for essential fiscal management services when choice increases quality and decreases cost
- The 4% COLA that you all voted to give to all DDA Participants as of July 2020 has not been given to most of SD Participants—even though 6 months have passed. At a minimum, 59% of our members do not have it. The mere 14% of participants who have received the COLA expressed that they had to really fight to get it, citing repeated requests and conversations with their CCSs and DDA directly.
- Created dysfunctional methodologies and procedures that are hurting participants by causing confusion and delays
- Elimination of overnight support as a self-directed option what is now offered is an option to hire an agency and lose control of who is hired to provide supports in your home.

One young man in the SD program, Desi, wants his required overnight supports in his home, with staff of his choosing. DDA is forcing him to have his supports provided by an agency. Staff who may be strangers to Desi. Desi is losing choice and control over 128 hours of the 168 hours there are in a week.

This inferior service will cost the State of Maryland an additional \$40K every year. Desi is not alone. Figuring that a mere 10% of those in DDA's SD programs need overnight support, the **additional cost per year multiplies to 5.2 million**.

- In conclusion and most importantly, NONE of these restrictions/eliminations are due to The CMS rules. They are Maryland DDA Choices none of the aspects of SB441 put federal money in jeopardy.
- -SDAN has spent thousands of hours of time
- -We've attended every meeting and work group that DDA has invited us to every time
- -Responded in writing with public and private comments, feedback and recommendations
- -Written emails of concern in numbers too high to count

For 4 years

- -SDAN has met with Secretary Beatty and Deputy Secretary Simons quarterly, now monthly and will continue to do so
- SDAN joined 7 other disability advocacy groups in regular meetings with the then Secretary of Maryland Department of Health Robert Neall to try and right the wrongs
- *Although mandated to seek input, DDA has heard much from us, but they rarely listened.

So here we are with a less flexible, less person-centered program that has left its Participants with less choice and control and some in jeopardy of their health and safety

That is why along with us - other advocacy groups are SUPPORTING this bill – ARC, DD Council, DRM, People On The Go, Pathfinders For Autism, to name a few.

And we are asking for your support too.

Next you will hear testimony from Ginger Houston-Ludlam, SDAN Board Member.

12 - HB 441 - FIN - MDH - LOO.pdf
Uploaded by: Bennardi, Maryland Department of Health /Office of Governmen

Position: UNF



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

February 16, 2021

The Honorable Delores Kelley, Chair Senate Finance Committee 3 East Miller Senate Office Building Annapolis, Maryland 21401

RE: SB 441 - Developmental Disabilities Administration - Self-Directed Services (Self-Direction Act) – Letter of Opposition

Dear Chair Kelley and Committee Members:

The Maryland Department of Health (MDH) respectfully submits this letter of opposition for Senate Bill 441 (SB 441) – Developmental Disabilities Administration - Self-Directed Services (Self-Direction Act) and requests an unfavorable report from the Committee.

While MDH supports and encourages self-direction as a service delivery model, the proposed legislation would create unreasonable operational challenges that are contrary to the recommendations from the Office of Legislative Audits. Moreover, the changes proposed by this legislation are contrary to requirements of The Centers for Medicare and Medicaid Services (CMS) waiver programs under Home and Community-Based Services (HCBS) and jeopardize federal matching funds. If passed, this service may be in jeopardy for possibly losing up to \$31 million in federal matching funds (FY 2020), with a corresponding impact on state general funds. Maryland 'advances' state general funds and then submits to the federal government for the federal review, authorization, and match.

SB 441 enables Support Brokers to have a fiduciary duty to the individual to whom they provide services, which is prohibited by CMS. Support Brokers may not make any decision for the participant, sign off on service delivery or timesheets, or hire or fire workers. The proposed legislation creates a conflict of interest by allowing Support Brokers to validate their own provision of service and payment. CMS requires the separation of these duties and therefore requires the administrative function of a Financial Management Service (FMS) to handle the person's funds,

timesheets, payment of services including the withholding and submission of taxes. This builds a financial integrity system that assists DDA in meeting federal assurances.

Pursuant to federal requirements, MDH seeks stakeholder input on the development and enhancement to Medicaid programs. Since 2013, MDH has continually enhanced the self-directed waiver program, implementing new services and practices and met with the Self-Directed Advocacy Network of Maryland (SDAN) quarterly.

The Office of the Inspector General (OIG) believes that removing license requirements for certain services under DDA creates multiple risks. In the past, the OIG has reviewed cases involving abuse and neglect, and absent certain licensures, it is hard to ascertain who can/cannot provide services and track who is delivering them.

SB 441as written, also applies a duplicative rate increase. Currently, provider rates are developed based on rates for Traditional Services which already has the rate increase built in. If this legislation passes as introduced, the rate increase will be applied twice.

I hope this information is useful. If you would like to discuss this further, please do not hesitate to contact me at webster.ye@maryland.gov / (410) 260-3190 or Heather Shek, Deputy Director of Governmental Affairs at heather.shek@maryland.gov and at the same phone number.

Sincerely,

Webster Ye

Welster

Assistant Secretary, Health Policy