# SB0959

**Self-Directed Advocacy Network of Maryland, Inc. (SDAN)**

**SDAN and the members whose testimonies and information are attached:**

**Support with Amendments**

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# Why is this bill needed?

## 1. DDA unresponsive to stakeholder input – Establishes an Advisory Council

DDA schedules meetings and listening systems to gather stakeholder input, but it is in name only. Very rarely does the final product reflect the spirit of the input.

Often the reason for rejection is "CMS rules." Research has proven that not to be the case nearly every, if not every, time.

Often no reason is given for rejecting a suggestion other than "rejected."

Very rarely is an adequate explanation given for rejecting suggestions.

One of the purposes of this bill is to have some oversight of the interaction and engagement of DDA with their stakeholders by forming an Advisory Council to work with DDA and report to the legislature and Governor every year on the outcomes and progress and to identify areas where legislation might help alleviate problems.

## 2. Ongoing attempts to keep families from working as staff – Creates definitions that explicitly allow families to work as staff.

In late July 2016, the Developmental Disabilities Administration (DDA) proposed changes to their then-current waiver that would have eliminated the ability of family to work as staff. This sparked a grassroots movement that eventually turned in the Self-Directed Advocacy Network of Maryland, Inc.

Since that time, SDAN members have provided countless input to DDA and attended countless meetings to give input on proposed changes, many of which became part of the waiver or policies despite strenuous objection of stakeholders.

We have been able to preserve the ability of family to work as staff, but there are ongoing attempts to weaken the right of the participant to have his/her family support in a paid capacity, such as a requirement for a designated representative if deemed by DDA to be unable to "make informed decisions" independently. This needlessly would eliminate many of the individuals who living full and successful lives in the self-directed model. SDAN continues to contend that EVERYONE can self-direct given the right supports. EVERYONE is capable of communicating the things they like versus the things they do not. EVERYONE can indicate staff they want to work with versus staff they do not.  EVERYONE is capacity of making and communicating their choices, including whether they want a family member to work for them.

### 3. Re-establish the Support Broker Role as Primary Advocate – Creates definitions that allow support broker to give supports as requested by the participant in a fiduciary capacity

Despite indications in CMS guidelines that, in general, there are not overlaps of support broker and targeted case managers (CCS) work, DDA used that as an excuse to significantly pare down and diminish the role of the support broker in the development of the plan and in assisting participants with the implementation of their plans.  Former tasks completed by support brokers have been turned over to overworked and undertrained CCSes and the result has been incomplete or inaccurate plans with missing services or funds that were not properly documented in the plan and a general chaos on the ground in the day to day and big picture of individuals in self-direction.  People have lost the independent voice who stood up for their rights and needs and the "expert" in self-direction rules and procedures on their team.  People are left confused and unsure about how to get the services they need.  Many have lost needed supports without anyone advocating for them to remain.  Health and safety have been jeopardized.

# Self-Directed Advocacy Network of Maryland, Inc.

# Timeline of Input to and Involvement with DDA

- Formed in August 2016 in response to DDA's Amendment 2 proposed changes to the then-current waiver.
- Attended four DDA "Listening Sessions" in August/September 2016 and provided detailed responses to DDA's questions
- September 22, 2016: Attended meeting with DDA where SDAN presented over 500 petitions to DDA staff asking for Amendment 2 to be stopped (it had been stopped just before this meeting). Work groups that included over 30 stakeholders were established but did not meet until the end of November 2016 after much prodding of DDA by SDAN to schedule – 4 work groups met intently over three months to provide input in the format requested by DDA.
- Attended February 2, 2017, meeting where Deputy Director Simons heard issues directly for the first time; specifically, the request that definitions of services be written differently for self-direction versus traditional services due to the different program structure and implementation; Mr. Simons stated that self-direction would not be able to go back to its own waiver, which has always been SDAN primary suggestion.
- February 17, 2017: work group recommendations due to DDA, which were put into a chart for the entire group to vote on
- February 2017: SDAN members testify in support of DDA's budget while noting concerns for self-direction at DDA budget hearings in House and Senate
- March 30, 2017: work groups met and nearly unanimously accepted all the recommendations of each group yet DDA never responded in any way to these recommendations or shared their positions on them. Very few of these recommendations made it into the waiver renewal document.
- May 2017: SDAN votes in board members but still unincorporated
- May 15 & 16, 2017: DDA holds a symposium asking the same questions from the listening sessions; responses to input from other groups that submitted recommendations in writing but **forgets** that SDAN ever submitted detailed work group recommendations in March.
- June through September 2017: DDA establishes a Steering Committee that has several objectives; SDAN members participate on each subcommittee; no results or reports on these meetings is ever produced; DDA seems to drop initiative. At a July 2018 seminar to provide information on self-direction, DDA staff announced that "subject matter" experts are working to establish policies and guidelines, which will later be shared with stakeholders. This was one of the tasks of the abandoned Steering Committees.
- August 2017: SDAN becomes a nonprofit corporation in Maryland

- Summer/Fall 2017: DDA initiates two new waivers to be effective 1-1-2018; DDA begins quarterly meetings with SDAN

- December 2017: SDAN submits detailed comments on the proposed Community Pathways Waiver renewal

- February/March 2018: SDAN testifies in support of DDA budget at DDA budget hearings while noting concerns related to proposed waiver renewal

- May 3, 2018: Quarterly meeting where DDA promises to provide information and address concerns; indicates they will be willing to have a separate meeting about Transportation concerns

- Mid- June 2018: FMS RFP is posted.

- June 20, 2018: SDAN attends pre-proposal conference at DDA

- June 26, 2018: Conference call with Mr. Simons and other DDA staff regarding concerns with RFP after which SDAN contacted the Governor's office.

- July 8, 2018: SDAN submits questions related to the RFP

- July 13, 2018: After many reminders, meeting regarding SDAN's concerns about how wording in waiver about payment for Transportation will negatively affect self-direction. DDA staff threaten to end meeting multiple times during this meeting and indicate that while Transportation funding for self-direction does not have a cap currently, that was not their intent and that many other amendments are needed to the waiver and will be coming soon

- July/August 2018: Many calls and contacts to legislative reps made about RFP, which is eventually withdrawn; Letter writing campaign to Governor to state concerns about self-direction in general

- DDA cancels August 7 quarterly meeting with SDAN and never rescheduled

- September 11, 2018: Meeting with Governor's staff at which SDAN reps ongoing issues with DDA, concerns about the RFP, and DDA's general disregard of a stakeholder input.

- Governor's Office enlists Secretary Carol Beatty of the Maryland Department of Disabilities to work with SDAN and DDA; Secretary secures SDAN members a spot on the DDA Transformation Committee and the Employment First Committee

- October 9, 2018: SDAN Board meet with Secretary Beatty to review input that has already been submitted to DDA and to explain major concerns; Secretary Beatty arranges for SDAN quarterly meetings to resume

- November 13, 2018: DDA & SDAN Quarterly Meeting with Secretary Beatty in attendance; plan established to move forward, including workgroups with just some DDA staff and SDAN reps to address specific issues

- January 8, 2019: Working group meeting with DDA Staff to review our recommendations and reasons for denials

- January 22, 2019: DDA "Bucket" meeting on policy, LTSS, Budgets & Implementation Dates (Buckets meetings were never held; DDA dropped entire concept of these meetings, which was to be a very detailed review of waiver language and policy discussions).

- February 6, 2019: DDA Workgroup Meeting related to designated rep issues. SDAN had sent detailed feedback on proposed forms and language related to this issue – To this date, still not resolved and recently started over with DDA on this topic

- February 11, 2019: DDA Quarterly Meeting conducted on phone

- March 3, 2019: SDAN submits extensive comments of Amendment 1 of the current waiver

- March 5 and 7, 2019: SDAN testimony in support of DDA Budget at Budget Hearing in Senate while noting continuing ongoing concerns regarding waiver changes

- May 7, 2019: DDA & SDAN Quarterly Meeting

- May 13 to 20, 2019: DDA conducts meetings in regional locations regarding Amendment 2; SDAN members attend all meetings; meetings were hastily arranged and very poorly attended

- June 2019: DDA conducts meetings in regional locations regarding amendments to DDA Statutes; SDAN members attended some of these meetings; again meetings were hastily arranged and very poorly attended

- June 12, 2019: DDA reboot of RFP for FMS services comes out with very little revisions from the previous version

- June 24, 2019: SDAN reps attended RFP meeting at DDA after only learning about it three days prior; via social media; we learned at this meeting that at least two potential bidders did not receive notice from Maryland but rather from a paid RFP services. The Arc of Central Chesapeake and MedSource, concern, were also not informed despite signing up for alerts; one was informed via social media.

- July 12, 2019: SDAN submits extensive comments on Amendment 2 of current waiver

- July 13, 2019: DDA & SDAN Quarterly Meeting

- July 26, 2019: SDAN submits exhaustive questions regarding the RFP to DDA procurement, who indicates they will not respond. Limited response is ultimately received.

- August 15, 2019: DDA announced the formation of a Policy Review Team. Several SDAN members participate and it continues to meet. The overwhelming feeling is that their input is ignored and comments and online conversations are deleted by DDA with no one seeing the final product of the work.

- August 28, 2019: SDAN helped to promote demonstration at DDA offices against the RFP

- September 24, 2019: SDAN arranges for a meeting with legislators to discuss the many issues with the RFP. It was attended by over 50 members of SDAN.

- November 20, 2019: DDA & SDAN Quarterly Meeting

- December 6, 2019: SDAN joins with other advocacy organizations to reach out to Secretary Neall related to ongoing issues and concerns
- December 16 2019: DDA cancels Transformation Meeting scheduled for December 18, 2019.
- All efforts in 2020 have been related to this bill and working with other advocacy organizations to address the many concerns with DDA policies and procedures.

This is not an all-inclusive list of SDAN's efforts, but an attempt to show the level of interaction with DDA since the end of July 2016 to date. SDAN has participated in every initiative and opportunity DDA gave stakeholders to provide input. Our meetings with individuals who self-direct, and their families, have shown glaring issues and frustrations with DDA and their responses to the customers they are charged to support.

# Individuals who Self-Direct as of 12-4-2019

| COUNTY_NAME | Community Pathways Waiver | Family Supports Waiver | Community Supports Waiver | Totals |
|---|---|---|---|---|
| Allegany | 12 | 0 | 0 | 12 |
| Anne Arundel | 66 | 0 | 0 | 66 |
| Baltimore | 168 | 0 | 2 | 170 |
| Baltimore City | 53 | 0 | 1 | 54 |
| Calvert | 22 | 0 | 0 | 22 |
| Caroline | 8 | 0 | 0 | 8 |
| Carroll | 39 | 2 | 3 | 44 |
| Cecil | 17 | 1 | 0 | 18 |
| Charles | 17 | 0 | 0 | 17 |
| Dorchester | 20 | 0 | 2 | 22 |
| Frederick | 51 | 0 | 1 | 52 |
| Garrett | 8 | 0 | 0 | 8 |
| Harford | 79 | 0 | 0 | 79 |
| Howard | 76 | 0 | 1 | 77 |
| Kent | 8 | 1 | 0 | 9 |
| Montgomery | 167 | 0 | 0 | 167 |
| Prince George's | 70 | 0 | 0 | 70 |
| Queen Anne's | 30 | 1 | 1 | 32 |
| Somerset | 7 | 0 | 0 | 7 |
| St. Mary | 12 | 0 | 0 | 12 |
| Talbot | 17 | 0 | 0 | 17 |
| Washington | 24 | 0 | 0 | 24 |
| Wicomico | 50 | 0 | 4 | 54 |
| Worcester | 32 | 6 | 8 | 46 |
| **Totals** | 1053 | 11 | 23 | 1087 |

STATE OF MARYLAND

DHMH

Maryland Department of Health and Mental Hygiene

*Larry Hogan, Governor - Boyd Rutherford, Lt. Governor - Van Mitchell, Secretary*

To: DDA Licensed Service Providers
DDA Coordination of Community Services Providers
Fiscal Management Service Providers
Support Brokers
DDA Families and Self- Advocates

From: Bernard Simons, Deputy Secretary
Developmental Disabilities Administration

CC: DDA Headquarters and Regional Offices

Date: July 8, 2015

Re: Developmental Disabilities Transformation and Communication

Since beginning as the Director of DDA in April of 2014, people have asked me what direction I planned to take DDA. Before I could answer that question, I needed to hear from the stakeholders in Maryland. Through the last year, there have been a number of forums for self-advocate, families and providers to weigh in how things were going and what direction they thought DDA should go. Specific forums on the DDA Waiver, Targeted Case Management, Person-Centered Plan, Self-Direction and town hall meetings were conducted around the state; the input we received in these forums has been very informative and posted on the DDA Website. The culmination of the stakeholder input has guided DDA in the creation of a vision and call to action that I would like to share with you.

**The Vision:** People with developmental disabilities will have full lives in the communities of their choice where they are included, participate, and are active citizens.

**Call to Action:** Create a flexible, person centered, family oriented system of supports so people can have full lives.

I cannot put it any better than American Association on Intellectual and Developmental Disabilities (AAIDD) President, Amy Hewitt, when she wrote: "Everything about services and supports to people with IDD is about community living. Community living has become a complex and evolving construct in this field. What once simply meant ''not living in an institution'' or ''living in the community'' now has different meaning and new contexts. We know more; we have learned and evolved our thinking. Community living is now viewed as people: 1) living where and with whom they choose; 2) working in real jobs of their choice and earning real wages; 3) practicing faiths of their choice; 4) being connected to an array of friends and family with whom they have deep personal and intimate relationships;

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5) growing and developing personally through opportunities for education and lifelong learning; 5) exploring areas of personal interest; 6) experiencing physical and emotional wellbeing; 7) having membership in community organizations; 8) making choices, taking risks, and determining the course of their own lives; and 9) accepting the responsibilities of citizenship (such as paying taxes and voting)."*

We will listen to what people want their lives to look like and we will create the supports and services they need to achieve their own personal vision. We will transform practices, policies and funding processes to create flexibility. We will realign our waiver and provide technical support and training to self-advocates, their families and the providers of services. We will focus on one person at a time.

I have identified five essential focus areas for community living to integrate in the transformation of DDA: Self-Advocacy, Self Determination, Supporting Families, Employment First, and Independent Supported Living. You will be learning more about how each of these focus areas fit into our message of flexibility, person-centered, family oriented system of supports one person at a time.

The transformation of the system will take time and partnership with all stakeholders. I ask for your support, commitment and leadership in communicating our message and call to action.

Thank you!

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*Dr. Hewitt's words can be found in: INTELLECTUAL AND DEVELOPMENTAL DISABILITIES 2014, Vol. 52, No. 6, 475–495.

# Traditional or Self Direction

**Traditional Services** provided by the state of Maryland via DDA Medicaid Waivers and implemented through a network of community service provider agencies.

- Provider agency is selected by the individual to implement the variety of waiver services called for in his/her Person-Centered Plan.
- Provider agency decides if willing/able to accept the individual into their program.
- Provider agency decides who will provide nursing and behavior services
- Provider agency hires, supervises and fires staff.
- Provider agency makes staff assignments.
- Provider agency provides mandated staff training.
- Provider agency that offering residential services may decide where and with whom the individual lives.

*Waiver participants choose how services are delivered…*

**Self-Directed Services** in the State of Maryland are another option for those eligible for DDA Waiver funding. Individuals are supported by a team, as needed.

- Individual chooses their team, which helps complete employer and budgeting processes. Teams always include the CCS and the individual, but can also include family, friends, and a support broker.
- Individual can choose a professional to provide services as needed; including nursing, behavioral, hippotherapy and music therapy.
- Individual is the Employer. He/she interviews, hires, supervises and, when necessary, fires his/her own staff
- Individual decides what training staff needs in addition to any DDA mandated training.
- Individual can choose to hire family to work as staff.
- Individual decides how to spend their budget.
- Individual works with a Fiscal Management Service (FMS) in order to manage the payroll and budget.
- Individual decides their daily schedule and where and with whom they live.
- Individual has the option to hire an independent Support Broker who helps educate and support the individual employer and their team.

For more information
please visit
marylandsds.org

# Why Self Direction?

*Freedom*
*to*
*choose…*

*Freedom*
*to change…*

For more information please visit marylandsds.org

- **Self-Direction is individualized and person centered.**
- **Individuals make choices about their lives.**
- **Self-Direction is cost effective.**
- **Self-Direction is compliant with CMS community rule.**
- **Supported decision making is provided by the team.**
- **Individuals can make changes as life circumstances change.**
- **Individuals find staff which are able to provide custom supports.**
- **Individuals can train their staff about their preferences.**
- **Individuals can elect to hire a support broker who in an independent advocate**
- **Individuals can elect to enter Self Direction as they transition from high school.**
- **Self-Direction is available in all waivers.**
- **Individuals learn about their budget and how to design services using available funds.**
- **Individuals learn how to advocate for their needs as they train their own staff and team.**
- **Individuals select their own team members and vendors.**

# There are Threats to Self Direction

**For the last few years, DDA has been engaged in a system wide transformation which radically changes waiver language and policy.**

**Those in Self-Direction have seen their program diminished.**

- **Risk for adverse health and safety outcomes**
- **Failure to implement Supported Decision Making for teams**
- **Repeated failure to take seriously stakeholder feedback**
- **Participant-chosen staff prevented from working**
- **Individuals no longer supported to work from home**
- **Policy changes limit flexibility**
- **Mandatory use of standardized needs assessments in place of clinical team assessments**
- **Severe administrative delay in processing annual plans and service changes**
- **Unapproved plans delay Transitioning Youth who wait months to years for supports**
- **Recent RFP for a single FMS contractor takes away choice and control of services**
- **DDA Maryland has chosen to be more restrictive than Federal rules allow**

*Stakeholder input has not been considered…*

*Health and Safety of Participants is at risk…*

*Participant autonomy at risk…*

For more information, please visit marylandsds.org

Support with amendments SB0959

Good afternoon, I am Edward Willard an advocate for the rights of Citizens with disabilities. This afternoon I will be representing myself as a citizen of Maryland. I have worked on Self-Directed Services from its conception in 2004. My history includes working at the Developmental Disabilities Administration on and off for ten years as a contractual Employee. My final position at DDA was as the Director of Advocacy Supports, where due to significant health issues I had to retire in 2017. Therefore, my testimony speaks to how Self-Directed Services were intended to be and the gross dilution and failed promises DDA has made over an eleven-year span.

In 2005 when The Center of Medicare and Medicaid Services, CMS, awarded Maryland the New Directions Waiver, they made one point crystal clear: They wanted people with disabilities to craft a life that made sense for them. And Maryland's DDA did just that. Here is one example. An incredible program developed by one participant paid for pottery classes at a community college and that person ended up opening a small business, displaying and selling their beautiful work. A key element in making this successful was that they needed minor support in class, so included in their plan was paying for their tuition and for a classmate willing to support the person, even their textbooks, and mileage. CMS said, "We regularly do not pay for things such as these, but come to us and talk about the justification for these items to be reimbursed, and likely we will grant the usage of the funds." Citizens with Developmental Disabilities made lives custom tailored for themselves. It was truly person-centered and **FLEXIBLE**.

The leadership of DDA at the time established a mindset throughout its Administration for the success of Self-Directed Services. It made the promised changes to the new service delivery system. At the same time, those administrators understood the responsibility for being good stewards of federal and state funds. **Self-directed plans cost no more than, and often are significantly less than, traditional services—often with more powerful results**. Having worked with three previous DDA deputy secretaries, I know firsthand about their passion and commitment to self-direction and self-determination.

However, I saw a significant change beginning in 2009, which accelerated when the New Directions Waiver was merged into the Community Pathways waiver in 2014 and continues through today. Self-Directed Services has been diluted and bureaucratized. There no longer seems to be understanding or compassion. It is not person-centered. It is state-centered. There is no commitment to the intent of people controlling their lives and becoming as independent as possible. Individuals no longer have the flexibility to craft supports that make sense for them and allow them to achieve their goals. No one is asking, like CMS did in 2004, "What do you want to do and we will work with you?" And no one at DDA is listening to the direct stakeholders, their families and their advocates. People with disabilities have been unnecessarily negatively impacted. I hope the establishment of the Advisory Council will allow Maryland to recapture and re-implement the principles of self-direction. Empowering individuals with disabilities to live truly self-directed lives will ultimately benefit all of us.

**In Support of HB 1171 (SB) 0959**

**House Health and Government Operations Committee**

**March 4 2020**

**Joseph Lindemon**

My name is Joseph Lindemon I am Dylan Lindemon's dad. Dylan is a 27-year-old adult who has autism. He has been in self-directed services since graduating from high school. In May 2019, Dylan's therapeutic medications stop working and he spiraled into a period of extreme dysregulation. Dylan's anxieties and self-injurious behaviors exploded out of control so we sought help, through his team, to seek behavioral supports through DDA. On July 6, 2019, a Dr. Klein from Humana came to our home to assess Dylan's level of crisis to determine if emergency respite services could be provided. By July 2019 Dylan's self-injurious behavior had evolved from constant to periods of calm throughout a given day. During Dr. Klein's visit Dylan sat calmly watching his videos in our family room. Dr. Klein reviewed the last two months with us and observed the multiple wounds on his arms. He strongly recommended that we get a behavioral plan in place but did not feel he was a candidate for emergency respite at that time. From July 6, 2019 until March 2020 we have been working through our service coordinator to seek funding from DDA for a behavioral plan. In addition to working through service coordination I have tried reaching out to members of the DDA Central Office for support. Most of my e-mails went unanswered or referred me to Service coordination. None offered concrete ideas or support. During this period of time my son, Dylan continued to injure himself and spiral out of control. His new regiment of drugs was in the tweaking process causing periods of drowsiness, anxiety, rage and significantly interfered with his sleeping patterns. As he continued to spiral out of control, I became more acutely aware that Self-Directed Services were not truly directed by the participant, but by a large bureaucracy that appeared to be indifferent to our requests. Late 2019, in speaking with another parent I got the name of a contact who I reached out to and the log jam began to unravel. When I would e-mail her I would get a same day phone call from my son's DDA representatives. Through those phone calls we finally got a BCBA from Humana to meet with us at our home in early October 2019. My wife and I felt this was going to be the start to get the help our son so desperately needed. We were excited and deflated at the same time after that meeting. We were excited because Ms. Alexander assured us, "That she was supposed to expedite our plan". At the same time she offered us no idea of when any meaningful support would be arriving and months later no meaningful support ever arrived. From October to February all we would get is an occasional draft of a proposed plan that she was developing, with the help of her supervisor. Each time she presented us with a draft plan I would send back corrections within the plan such as the participant's name was not my son's, behaviors that were identified Dylan didn't present with, and mistakes with the identifying disabilities.

Through my contact I was able to get clarity on a question that I asked months earlier," why could Dylan not use a private BCBA to write his plan since he was in self-directed services"? This time I got a different answer. This time we were told we could use a private BCBA to write his plan. Although elated

**Support HB 1171**

**Joseph Lindemon**

by the news I was also extremely frustrated. When I asked my service coordinator months earlier if we could use a private BCBA I was told we cannot.

Months have gone by while my son languishes in the depths of his dysregulation. His quality of life is gone and we are trying to recover small bits and pieces of that life. I work in the field of special education and know many BCBA’s who are quality professionals and could have written his plan within weeks instead of the months it is taking working through the DDA bureaucracy.

The purpose of my letter is not to place blame on anyone or any agency. Instead, it is an indictment to what the concept of self-directed services has become about. In going through this large bureaucratic process it became apparent that lines of communications were not established between the participant, service coordination, the participant’s team and DDA staff. That lack of clear lines of communication directly affected our ability to receive the supports Dylan needed in a timely fashion. As of today we still have no behavioral plan. DDA’s new proposals for self-direction will erode even further the client’s autonomy in making decisions that directly affect their well- being. DDA's proposals will limit the voices of the people who know the client’s best and will put the day-to-day decisions into the hands of people who are ill informed on the unique characteristics defining each participant in self-direction. Please do not allow the erosion of the client’s rights to autonomy and control to be compromised for the needs of a bureaucracy.

I want to thank DDA for providing us with my son's services and wish to make it clear that I am not an adversary of DDA, but instead an advocate for my son and the many other sons and daughters who receive self-directed services. The strength of any decision-making process is the allowing of multiple viewpoints through the lenses of each person who is affected by the process. It is a consensus of those voices that make for the most constructive changes in policies, for all.

Enclosed are three photographs that I hope will give you some insight into the devastation that has befallen our family since May 2019. The old expression goes,” a picture is worth a thousand words” here are 3000 words.

**SDAN Support with amendments SB 0959 Written Testimony**

Craig Mickel March 10 2020

I am writing on behalf of my daughter, Caitlin Mickel, who is currently in Community Pathways - Self Directed Services. I am concerned about the following changes that have been made by DDA: Definitions of Community, Family as paid staff, and the reduction in the role of Support Brokers.

Caitlin has been in Self Directed services for over 8 years. This has helped Caitlin find meaningful and purposeful ways to integrate into the community. Self-Direction also helps her to establish and maintain her identity through her involvement with the community.

Over the last few years Caitlin has decided, on her own, to pursue using our farm and our animals to establish outreach of therapeutic interaction with the public at large ***(free of charge).*** We have a small farmette of 6 acres in Smithsburg Maryland. This includes 2 small miniature horses, 2 ponies, 1 miniature donkey, 2 miniature pigs, and 2 quarter horses .

As the Barn Manager it is Caitlin's job, **with family assistance,** to maintain and integrate our animals into the community. One of the problems is that DDA now defines community as being outside the boundaries of the home. In our case our activities do both – on our property and outside in the community. People come onto our property to interact with the animals, and we take our animals outside in the community . Such restrictions in definitions are unnecessary. Our home is in the community. Caitlin's desire to give back to the community should be supported. The new definition could have a drastic effect on Caitlin's ability to use her Self Directed funds to pursue her desired vocational goal. The definitions stifle creativity, hence Self Direction. I am not implying the intent of DDA is to take this away, but this cookie cutter approach to services is the opposite of what self-direction was intended to do in Maryland.

Family as staff is important for Caitlin. Our family is involved, along with the entire team, to make this programming work for Caitlin. My wife left a highly paid job in the Nursing Profession to assist Caitlin as her employee. I also assist but not in a paid position. This is an "all hands on deck" undertaking by our entire family to make this happen. It is near impossible to find someone who is trained in horses, can drive a truck with a horse trailer to outside public events where we take our animals, work erratic **part time** schedules and time frames, and know the ins and outs of our daughter's medical needs and abilities. Eliminating **family as paid staff** will basically stop what Caitlin has desired to do with Community Pathways – Self Direction.

Finally, neither Caitlin nor our family is versed in the Jargon of government speak, definitions, procedures, policies, and abbreviations. I have found the role of the Support Broker to be of utmost value in helping Caitlin and ourselves to understand how to navigate through this program. I look at the Support Broker as a necessity for her to benefit from the program. The support broker is an Advocate and Bridge in helping families and the individual with the disability work through and understand the process of obtaining supports under the waiver. The Support Broker is critical and families should have the option for as many hours as they need. The Coordination of Community Services (CCS) is our means of interacting with DDA, yet within the last 2 years we are on our 3rd coordinator. Our support broker has remained with us since day one.

I implore you to please make a favorable report on SB0959 to ensure that Caitlin and others can keep doing the great things in Community Pathways – Self Direction program going forward today, tomorrow, and the years to come.

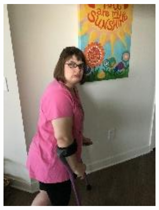
Sincerely,

Craig Mickel, father of Caitlin

## Samples of Caitlin's Community Outreach!!

1. **Hospice of Washington County** – in dealing with Children with grief of the loss of a loved one. We help with yearly picnics and gatherings when requested by the Hospice Social Workers.
2. **Brooks House Hagerstown Maryland** – a residential setting for recovering women with opium abuse. Women come out to our farm and ride horses, during inclement weather we meet the residents at indoor riding facilities out in the community to interact and ride our horses. A tradition was established when someone graduates the program at Brooks House we bring horses out to their residential treatment facility for them to ride around the property in front of family, guests, and other residents signaling there riding off to a New Life addiction free.
3. **Hope Center in Hagerstown Maryland** – participate by bringing our Horses and small animals to their 3 week outdoor camp they have for disadvantaged youth.
4. **FFA** – bring our horse to ride at their annual fund raiser at White Tail Ski Lodge.

I can go on but I think you get the idea!!!



# Testimony in Support of House Bill 1171(SB 0959)
## House Health and Government Operations Committee
## March 4, 2020

My name is Karen Bowers. I am writing in support of HB 1171. My daughter Jennifer is a Self-Directed participant in the Community Pathways Waiver after transitioning from High School in 2012. Jennifer is 29 and has multiple severe disabilities including Cerebral Palsy, Hydrocephalus, and Intellectual Disabilities. Jennifer requires 24/7 support. The Home and Community Based Waiver Self-Direction service was designed to provide Jennifer individualized supports helping her to live in the community and to avoid institutional care.

As a parent new to adult services I searched the DDA website looking for clues about how to obtain what Jennifer told us she needed**. I found the DDA Mission Statement which reads: "Create a flexible, person -centered, family -oriented system of supports"**

However, after eight years we still have not encountered a flexible, person-centered, family-oriented system of supports consistent with that mission statement which first caught my eye.

The recent wavier reauthorization and amendments have further decreased flexibility in Self Direction. Despite DDA emphasis on Person Centered Planning, we are experiencing more restrictions limiting true Person-Centered Solutions. Changes in Service definitions threaten Jennifer's continued progress. What good is a person-centered plan that doesn't align with the individual's vision?

It's once again time to help Jennifer write her plan for FY 2021. The most recent wavier language finalized in Dec 2019 now threatens to remove services despite their approval as part of her Person-Centered Plan since 2013. These services are part of Jennifer's behavior plan and very much needed.

In addition, ***Community Development Services*** has been rewritten to restrict in-home learning, work, and preparation for community activity, which Jennifer needs to be successful when she is out and about in community settings.

What works for Jennifer doesn't seem to matter. The newly revised on line person centered plan format with it's drop down menus and generic goals does not provide a true picture of Jennifer. I don't recognize Jennifer in the plan now.

Waiver language alone can't promote community integration. Well trained teams can. Family education, and more training in Person Centered Thinking can. Real Person-Centered Plans can.

Please support HB 1171 to protect Self Direction in Maryland and require the DDA to fulfill their mission to: ***"Create a flexible, person -centered, family -oriented system of supports"***

Thank you,

Karen Bowers, mother of Jennifer Bowers

**Written Testimony of Latonia Reynolds, March 10 2020**

**Support with amendments SB 0959 before the Senate Finance Committee**

My daughter, Satera, is a self-directed participant in the Community Pathways waiver since 2015. Satera has epilepsy, mitochondrial disorder, cerebellar atrophy. The DDA Mission reads “Create a flexible, person centered, family-oriented system of supports.” In fact, my experience has been quite the opposite.

My daughter is unable to access the community without a specialized collapsible stroller which can be placed in the rear of a car. As part of her plan we began a journey to secure this piece of equipment in the DDA system with help from LISS services. We entered a system which was dysfunctional, chaotic, misinformed and misleading. More importantly, without this needed piece of equipment my daughter was left at home unable to go out into the community to live her life. I worked so hard trying to advocate on her behalf to make the pieces come together, to connect the dots, to talk to the right person, to follow the conflicting directions given to me. We all want to see our children succeed and accomplish their dreams. Without a functional DDA it was difficult for me to help her to work towards the life she wanted. I remember on one occasion I was determined to get her to a play she wanted to see. I decided to try to take her older wheelchair apart to get it into the car. After a while I looked down on the ground and saw the chair in pieces unable to fit into the car and no one to help me reassemble the chair and help with Satera. I’d reached my limit. I was heartbroken.

The next year, Targeted Case Management did not improve our experience. During the PAU for 2018 our PCP meeting was held and the recommendation was for more personal support hours. That need was never addressed. We met on multiple occasions in multiple locations with our CCS and then her replacement. Nine months passed and still it was not submitted. No one took responsibility for this failure. The regional office offered no solutions in spite of months of trying to problem solve. Though it was finally submitted May 23, 2019, I discovered through yet another CCS and subsequent new agency that it was entered into the system incorrectly creating yet more delays in addressing Satera’s needs. This all coincided with the new LTSS PCP process being implemented. For my daughter and our family, the failures of the DDA Transformation in Case Management and LTSS PCP process have been devastating and harmful.

Despite it all, Satera is excited about her future and hopes to one day have her own business baking gluten-free, sugar-free vegan cookies. Currently she’s baking items for gift basket to give to the local Takoma Park Fire Station.

Please support SB 0959. This bill will help to provide desperately needed DDA oversight and address participant and family concerns about DDA failures.

Thank you,

Latonia Reynolds

Mother of Satera Reynolds – Stevenson

**Written Testimony of Jeneva E. Stone, March 10, 2020**
**In Favor of SB 0959 with amendments:**
**The State Advisory Council on Self-Directed Services Bill**
**Before the Senate Finance Committee**

I ask you for a favorable report on the proposed Self-Directed Services Advisory Council, a much-needed source of information moving forward on a vulnerable population, for whom **Maryland does not yet have a thorough and clear vision for adult services**: **Disabled Marylanders who require either delegated or skilled nursing**--"delegated" services are those non-medical persons, with training, may provide, according to Maryland nursing regulations, and "skilled" nursing only by an LPN or RN.

For decades, the Developmental Disabilities Administration (DDA) and the Division of Nursing Services (DONS) have provided comprehensive support for "medically fragile" young adults ONLY in the **DDA's "medical day" programs, which are run using the model of nursery schools**. Other DDA providers may reject our children out of hand, **giving our kids nowhere to turn except to self-directed services**.

A new generation of parents is shepherding their children through the public school system: We are ensuring our children are educated and we expect them to have lives within their communities after graduation. We reject segregation whole-heartedly.

Neither DDA and nor DONS (through its REM and Model Waiver programs) have kept pace with these rising expectations, which are supported by the Center for Medicaid Services (CMS), the Individuals with Disabilities Education Act (IDEA), and the U.S. Supreme Court's 1999 Olmstead Decision. Instead, our children are subject to segregation and isolation through Maryland's residual institutionalization programs. **Our children deserve better—they deserve the same rights as their other disabled peers and the general population**.

I've been asking questions, trying to understand how this system has evolved, and I've discovered that **DONS operates under a series of non-public internal guidelines which are focused on cost containment, not on the needs of the disabled individual**—in fact, provision of nursing in Maryland is based on a parent's need to work, even if their child is 21 or older. I've recently heard DONS personnel testify under oath that **the Department of Health believes disabled Marylanders with skilled nursing needs may be treated as minor children**, rather than adults. I've also heard the Assistant Attorney General for the MDH cast doubt on the Olmstead Decision in a public hearing. I know that DONS will not listen to the DDA; and that the DDA does not press DONS. I know that **CMS guidelines allow state agencies to provide skilled nursing 1915(c) waiver programs, but the DDA declined to do so.**

In addition to resolving and making recommendations on support brokers, family as staff, activities supported by the waiver, and others, the Advisory Council, if established, could provide recommendations on how to fully integrate disabled Marylanders with nursing needs into our communities. We need, as a state, to ensure that no Marylander faces social segregation and restricted community access. Self-directed services gives our young adults the fighting chance to be a part of their communities.

**Testimony in Support of House Bill 1171(SB 0959)**

House Health and Government Operations Committee

March 4, 2020

My name is Kathy Cooper and I am here today with my husband, Jim and our daughter, Melanie who is 34. Melanie was fortunate to be one of the very first to enter the Self-Directed Waiver at 21, back in 2006. Melanie has experienced a life of seizures. Her syndrome is degenerative, but Self Direction allows her to continue to live her best life inspiring others with her courage. In her 15 years self-directing her program, she has impacted hundreds of support staff who have gone on to careers in service to others.

In many ways, Melanie is blessed more than most. I was privileged to be able to afford to leave a teaching career to raise our 4 children and to then coordinate Melanie's Self-Directed life. Her Dad is recently retired from McCormick, and we are both just entering the Medicare ranks at 65. Melanie has 3 siblings and 5 nieces and nephews. She is well loved and has a good life, so some may ask 'why are you here?'

Ninety-nine percent of the individuals in Self Directed Services and their families do not have the privilege of time, money, transportation nor energy to be here today. I see it as my duty to be here today for them, as well as, for Melanie.

I have the following concerns about recent changes in Self Directed Services.

1. **Participants should have the right to choose Family to Work as Staff. Recent Waiver changes threaten this choice.**

   I believe that the premise of Self Direction (called New Directions back in 2005-2006) had its roots in the belief that it was a WIN/WIN/WIN. **The individual** with disabilities deserved respect and had the right to choose a more independent life with the help of a support team of their choosing. Paying **family members** who are already invested and knowledgeable about Melanie makes the team stronger and more person centered.

   Melanie's days with her family and 9 support staff in her apartment and out in the community, is a Person-Centered Solution that works for her.

2. **Recent Waiver changes which will result in the loss of Melanie's awake overnight staff in July 2020.**

   I was told in 2019 that our daughter's staffing hours for awake overnight staff may no longer be funded this coming July because they are not 'habilitative'. After 7 years on the housing wait list, Melanie was given a housing voucher in Harford County. For 6 years, she has lived in her own place and she loves her independence. She requires 24/7 support, so clearly her Dad and I spend many hours a week filling in the gaps. Melanie is at risk of losing her apartment because of this recent change.

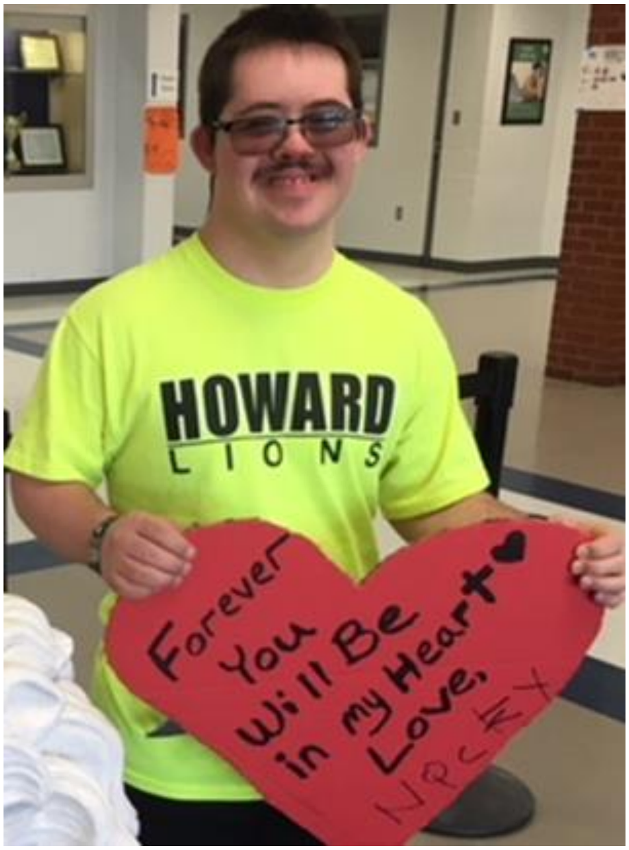
DDA's forethought and courage to implement this waiver has given families like mine the courage to live the lives we have been dealt. **It's important for participants to continue to have Choice and Control over services and that these services be person centered and flexible.**

# Testimony in Support of House Bill 1171
(Senate Bill 0959)
House Health & Government Operations Committee
Submitted by Alvin N. Mineart, Jr. (aka Nicky) – Self-Directed Services (SDS) Participant
03/04/2020

- My name is Alvin Mineart. My son Nicky is here in support of HB 1171; I am here to help him express his testimony. His way of saying thank you is to share a sweet treat – he will leave these M&Ms here at the table for you.

- Nicky turns 23 this month. He has Down syndrome and Type 1 Diabetes. In school, known as "The Mayor," he knew everyone and everyone knew him. In Work Study, he worked Monday through Friday. His employer wanted him to return after he finished school.

- Nicky transitioned into **no services**; with no choice but to stay home with Mom. Mom had to retire early from NSA, giving up her career, to provide for Nicky. Turned down by eleven (11) day programs, he chose Self-Directed Services (SDS). It took DDA over one year to approve him to be in the Waiver. That year was filled with lost opportunities; lost independence, identity, job, three potential employees, and he wasn't out in the community.



- In SDS, he has started regaining his independence & identity. SDS has been the miracle affording him the chance to fulfill his dream to live independently, outside of our home. Although with his staff (sometimes staff as family) he is able to work and enjoy his community, he still struggles with nursing delegation to fully support his diabetic needs, putting him at risk.

- The passing of this bill will enable Nicky, and others, to become more independent and eventually enjoy life outside of their family's homes. The formation of an Advisory Council will strengthen SDS and allow the group to address additional participants needs to include proper medical support/delegation and overnight support; while holding the DDA accountable to the legislature.

- Without SDS, Nicky will be forced to give up his life, his independence and be placed in a medical day program as a diabetic. He will no longer have the joy of being known by everyone while working in his community. His health will be at risk due to lack of activity; he could lose his eyesight, limbs and even die early. He will in essence cease to exist as his own person.

***Thank you very much!***

# Testimony in Support of House Bill 1171 (SB 0959)
# House Health and Government Operations Committee
## March 4, 2020

I am writing in support of HB 1171. My daughter Louisa Serban is in the DDA Family Supports Waiver program. Louisa has very complex needs (described below). DDA approved her services under the traditional model in November 2019, which was a huge relief. Unfortunately she is not yet able to access any of the services that she desperately needs. The provider agency is not able to find a Personal Support caregiver for her in almost 4 months. We feel helpless and are trying to access Self Direction, so we can start receiving the critical services that Louisa was approved for.

Louisa is 5 years old and has Angelman Syndrome, which is a life-long rare genetic disorder as a result of which she has profound intellectual disability, gross and fine motor impairment, hyperactivity, insomnia, behavioral issues, and complex health issues such as seizures. Louisa is non-verbal and is not able to communicate her most basic needs (not even with gestures). For example if she is thirsty/hungry or cold or is tired or if something hurts. She is not able to do any of her daily, basic self-care tasks independently such as eating, dressing, toileting, bathing, and continence. Louisa requires extensive round the clock support and constant supervision for her well being and safety. This is expected to be a life-long requirement.

DDA received our request to transfer to Self-Directed Services in January 2020, which is just the first of several steps to switch to Self Direction. We are still waiting for the approval of this first step and we don't know when we will be able to access Self Direction. Meanwhile, we are not receiving any of the approved services that we so desperately need. We believe that Self Direction will allow us to access these services.

**Please support HB 1171** to protect Self Direction in Maryland. This bill establishes the State Advisory Council on Self-Directed Services. It is extremely difficult to navigate the system. Among other important functions, this Council will provide a forum for information sharing and support, which especially as a new waiver participant, will be an essential support for our family. The bill also requires that waiver services include Fiscal Management and Support Broker services which serve important functions for providing and managing waiver services.

Thank you,
Anna Hovsepyan, mother of Louisa Serban

## IN SUPPORT OF HB 1179 (SB 0959)
## House Health and Government Operations Committee
### Jean J. Weller 2-29-2020

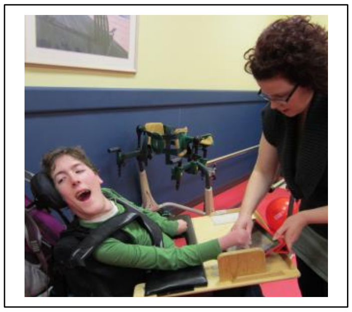
My son Paul Weller has been a participant in Self-Directed Services since its inception. He was born premature with multiple disabilities including Cerebral Palsy and Cortical Visual Impairment, and mild intellectual challenges. He is now 37 years old, very verbal, and uses a power wheelchair to get around. He developed Type I Diabetes in 2006 and has REM nursing 12 hours/day because he is not able to manage his Insulin Pump. Still, he has a great sense of humor, loves music, and wants to go out every day even if it's just for a ride. However, Paul has an anxiety disorder which can become acute in crowded areas where there are a lot of children. If he goes to the Mall, he needs to sit in a quiet area. He needs Personal Support to manage his Diabetes diet for his meals, drive him to his various Dr.'s appointments and Therapies and outings, and to be there for Personal Care when one of our nurses doesn't show up which has been fairly often. There is no duplication of services.

With the New Waiver, DDA has proposed that participants like Paul should spend much of their time out of the house moving toward more Community Integration. It has removed the "Self" out of Self-Direction and replaced it with "DDA" -Directed Services. They have insisted that the only "Meaningful Day" is one in which the participant is working in the non-disabled community gaining skills for Integrated Employment. Paul takes PT and OT twice a week and Counseling once a week. He is only able to volunteer a few hours once a week at his Support Broker's office, but then, again nowhere with crowds or noisy children.

Another change is that since my son requires an accessible van, which we own, the DDA will no longer cover a mileage reimbursement to the family for his travel to his non-medical activities. However, they will reimburse an employee who uses his or her own vehicle to transport SDS participants who do not require accessible vans for Transportation! This is discrimination against those participants who need accessible transportation.

DDA has been very unresponsive to questions about those in SDS who do not fit the profile of their "ideal" developmentally disabled participant who can improve him or herself to the point of earning a minimum wage job. There are plenty who want to live meaningful lives in SDS by choosing their own activities out in the community, whether they choose to be working or not. DDA's answer is to evaluate everyone to see if they are capable enough to self-direct! They have lost the Vision of the original Self-Direction Concept that anyone can self-direct with enough support! **A Meaningful Life is determined not by the State, but by the person living it**.

**SUPPORT: Testimony in Support of House Bill 1171(SB 0959)**
**House Health and Government Operations Committee**
**Mary Grelli, Kenneth Garove**
**March 4, 2020**



Hello, I am Mary Grelli and my husband is Kenneth Garove. I am writing to express my concern that DDA, in the 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, Cortically Blind, Hydrocephalus, and Intellectual Disabilities.

My husband and I have been advocating, and caring for our disabled son in our home son 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 didn't want to speak with me regarding the issues at hand because of HIPPA restrictions. He also said he preferred to speak with 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. 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 strongest caregivers and advocates. The goal or mission statement of DDA for a happy and healthy team based on…" ...provid[ing] support for individuals ***and their families*** to determine what is important to and for them to achieve the 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 1171.

Sincerely,
Mary Grelli, Kenneth Garove
Parents of Francis

Support: Testimony in Support of HB 1171/SB 0959

House Health and Government Operations Committee

March 4, 2020

Genevieve Houston-Ludlam, Ph.D.

I would like to express my support of HB1171/SB0959. I think it is critical that we establish an advisory council to independently report issues regarding self-directed services to the General Assembly, assisting in the oversight of the DDA.

In particular, I would like to speak about clause K.6.I, which has the advisory council reporting directly to the legislature on matters of "(I) COMMUNICATIONS BETWEEN THE ADMINISTRATION AND SELF–DIRECTED SERVICES PARTICIPANTS AND THEIR FAMILIES;"

My experience with the transition of my daughter Carmen from school services to her adult self-directed services this year is consistent with the general opinion of the DDA amongst participant families that it is non-responsive to their participants and families. Oversight in this area is critically important.

Carmen officially transitioned to adult services on July 1, 2019. Despite many attempts to work with the DDA, I ultimately had to "pull the fire alarm" by contacting the Governor's office to get Carmen's waiver services turned on over 6 months later. Since this time, I have been contacted by several other families in the same situation- having been stonewalled by non-responsiveness of DDA, having their child's waiver services languish in a bed of red tape, and determined to do whatever they had to do to get their child's services turned on.

Communication by fire alarm really isn't a workable scenario. It is my hope that the advisory committee can help improve DDA's responsiveness by providing an independent reporting path to the General Assembly.

Supplemental material: A brief timeline of our experience with Carmen's transition.

7/16/2019- approval received, start date of August 1st given by DDA

9/3/2019- Our CCS had been attempting to contact DDA since mid-August about why Carmen's plan (and 2 other clients) was approved but the funding had not been turned on. Carmen's funding had been held up due to "a glitch in the LTSS software." Our CCS recomputed the budget for a new start date of October 1 and re-entered all Carmen's data.

9/13/19- spoke with a friend commiserating, saying that her children's plans had been approved after a long time fighting with DDA, then languished without funding until she contacted the Governor's office and it got approved. I decided that contacting the governor's office was kind of the "nuclear option" and decided to let my CCS work the system first.

9/24/19- email from our CCS stating that the new budget had been approved with a start date of October 1, 2019.

9/25/19- email from our CCS telling me that she had been told that the approval she got the day before was approval for the waiver only, but not for her Self-directed services, so we would not meet the Oct 1 date.

10/8/19 Called our regional office to find out what was happening. Call was returned- left a voicemail to call him. My return voicemail was never returned.

10/28/19- contacted NaToya Mitchell (Self-Directed Services, DDA), Anthony Jackson (Customer Service "fixer"), and Tonia Ferguson (Customer Service "fixer")

"My daughter, Carmen Houston-Ludlam, transitioned from school-based services July 1 of this year. To date, her self-directed waiver services have not been turned on, although we have been told that her budget is approved and we have been given (and now missed) several start dates. My CCS and I have attempted to find out what the holdup is, but cannot get our phone calls returned. Please help me figure out what the problem is and get her services started."

Anthony Jackson responded by email saying he would look into it.

11/13/19 Contacted Anthony Jackson by email telling him that nobody had contacted me. He responded that he would make some calls.

12/4/19 Contacted Anthony Jackson again telling him that nobody had contacted me and Carmen still didn't have her waiver services. He asked me to call, and I did.

He said that her data had not been put into the system and that my CCS had to do that. I told him that I had been working with my CCS, and that she had put the information into the system several times, that "glitches" in the LTSS software had caused that data not to take hold. I asked him to open up Carmen's record and look. Indeed, everything that should have been there was in the system. He said he would work on it.

12/16/19 Attended LTSS transition meeting in College Park. Was directed to a lady (I think it might have been Tonia Ferguson) who said she'd look into it. I did not hear back, although Tonia Ferguson said she sent an email Dec 23. I did not receive it and it was not in my spam folder.

12/27/19 I contacted Anthony Jackson again and got an out-of-office reply.

1/8/20- Over 6 months past Carmen's transition date, having given up, I emailed Secretary Beatty, copying Secretary Neall, Director Simons, Senator Elfreth, and Delegate Howard

Thanks to the work of Nan Brittingham of Secretary Beatty's Office, Tara Hargadon of Secretary Neall's Office, and Johntel Greene of Senator Elfreth's office, Carmen's services were turned on within a week of my "fire alarm" email.

# SB0959/HB1171 – SUPPORT WITH AMENDMENTS

## Public Health – Demonstration Program and Developmental Disabilities

Testimony of Martha Gabler
Mother and Legal Guardian of 23-year old son with severe autism
Before the Senate Finance Committee
March 10, 2020

Thank you for this opportunity to testify in support of this bill.

My family resides in District 20. We have a 23-year old son, Douglas, who has severe autism and is nonverbal; he has self-injurious behaviors such as hand-biting and head-hitting. He will need round-the-clock care and supervision, including skilled behavioral supports, for the rest of his life.

We ended up in Self-Directed Services by happenstance. During the transition process, Douglas was rejected by traditional agencies because they could not meet his needs. This thrust us into Self-Directed Services.

We immediately found ourselves in a perfect storm of incomprehensible acronyms, hundreds of pages of regulations, rule changes, conflicting information, obstruction, multiple and continuous hoops to jump through, and, when all is said and done, unbelievably poor support for our son.

Under the current Self-Direction system, we don’t have a program for our son: we have a house of cards, and every single day we cross our fingers and wait to see if it will hold up or collapse. People have no idea of how “down-the-rabbit-hole” this system is.

We feel that the excellent proposals in SB0959 would make Self-Directed Services a viable system for supporting individuals with developmental disabilities.

For example, the proposed changes to Support Broker Services would give individuals with developmental disabilities, and their families, the information they need to set up appropriate services and staffing. We recently experienced how good Support Broker services can make a big difference.

Like everyone else in Self-Directed, my son experiences high staff turnover. However, in our last round of hiring we had help from a Support Broker with a lot of experience in hiring. Because of her expertise, we had a better set of candidates and were able to hire a better staff person. Also, I felt confident that we were not unwittingly violating laws about non-discriminatory hiring practices.

No individual or family can be expert in all the areas we have to deal with in Self-Directed Services. Participants in Self-Direction need these vital supports restored to the program. Good support services lead to better outcomes for individuals with disabilities.

Thank you for this opportunity to comment.

Respectfully submitted,

Martha Gabler

Martha Gabler
Mother and Legal Guardian of Douglas Gabler
10125 Markham St.
Silver Spring, MD 20901
Martha.gabler@gmail.com

# WRITTEN TESTIMONY OF MINDY JOHNS FOR HB1171/SB0959

How has DDA failed my son, Daniel, who has been a Self-directed participant since 2013?

(1) We waited nine months for approval of his FY 2019-2020 Budget, despite submitting all documents and requested clarifications in a timely manner. After many inquiries about this delay, we were finally told that it was due to his HRST not being approved. We learned that one nurse did the initial review, then another nurse took over his case, then DDA fired the agency that did the reviews and told us -- just before Christmas -- that we should contact one of DDA's approved HRST reviewers and take care of it ourselves! We also had to add an emergency line item to Dan's budget to pay for the review. This is one of many examples of DDA's shortsighted, ill-conceived actions that are detrimental to families and participants.

(2) We have been trying to change Daniel's Fiscal Year dates back to the preferred dates of July 1 to June 30 for almost two years…ever since we were randomly assigned a new FY date by DDA. Apparently this random date assignment occurred during DDA's LTSS Transition. Again, DDA instituted a new system/policy without ironing out all the "wrinkles" and it has caused many problems for the family and the participant. We have also waited about 6 months (and counting) for approval of a pay increase for an excellent employee, despite the fact that Daniel's budget will support this increase, all documentation has been submitted, all clarifications have been provided, and several inquiries have been made to DDA about this issue.

(3) Over the past 7 years, DDA has repeatedly changed major policies and procedures without effectively communicating these changes and how to implement them. This lack of transparent communication causes delays, confusion, frustration and crisis situations for Support Brokers, CCSes, families and participants.

(4) DDA has not sought -- or has outright ignored -- valuable stakeholder input on crucial issues, including: major Waiver Amendment revisions, allowable CLS activities, family as staff, stand-alone mileage reimbursement, limits on employees' hourly wages, and moving FMS services to a single provider.

(5) One of the many DDA policies that adversely impact Daniel is that respite care is limited to 8 hours per day. When he needs respite care, he isn't able to pay his employee for a full 24-hour day of care due to limits on the number of hours per day that can be billed for personal supports, CL and respite. Six hours of each 24-hour day of respite are not billable, even though his employee is working a full 24-hour day.

(6) We had an excellent Support Broker who was a very valuable member of Daniel's team, but she quit in frustration when she tried to get re-certified in 2019. Despite following all instructions and procedures, and making every effort to comply with DDA's ever-changing requirements, she was denied admission to the training class. She copied me on her emails with DDA and I was dumbfounded by the DDA employees' lack of clarity and consistency, inability and unwillingness to solve problems, and lack of communication among themselves (the right hand didn't know what the left hand was doing).

(7) In summary, DDA must be held accountable for their actions. They are not fulfilling their Mission Statement, and are harming the people they are supposed to be serving. Self-direction is the *only* viable, cost-effective option for many disabled people, like my son Daniel. Self-direction has allowed him to be safe and healthy, to make progress towards his goals, to be active and engaged in his community, and to truly live his best life. DDA needs to stop putting up roadblocks to Self-direction, and start working hand-in-hand with stakeholders to strengthen, expand and improve Self-Direction in Maryland.

# My Story

I started in self-direction 2006 after being with a traditional agency. If I had stayed there, I probably would not be alive. I am healthier and happier. My live is so much better!

*Choice and Control Matter Matter to Me!*

Rickey Brown, Jr.
1615 Glen Keith Blvd.
Towson, MD 21286
Contact: Robin Jeffries
410-842-3629

Self-Direction is important to me because…

- I am supported by my aunt who makes sure I get what I need.
- I rarely get sick like before and get to all my appointments
- I am out in my community and meeting my neighbors.
- I go to church and volunteer there.
- I also volunteer at a nursing home.
- I visit my family where they live; they could never get to the agency to see me before.
- I sing at karaoke.
- I go skating.
- I am living my best life.

## I AM Ryan Gerhold – Age 34

Running Hare Cookies with Santa with my family

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

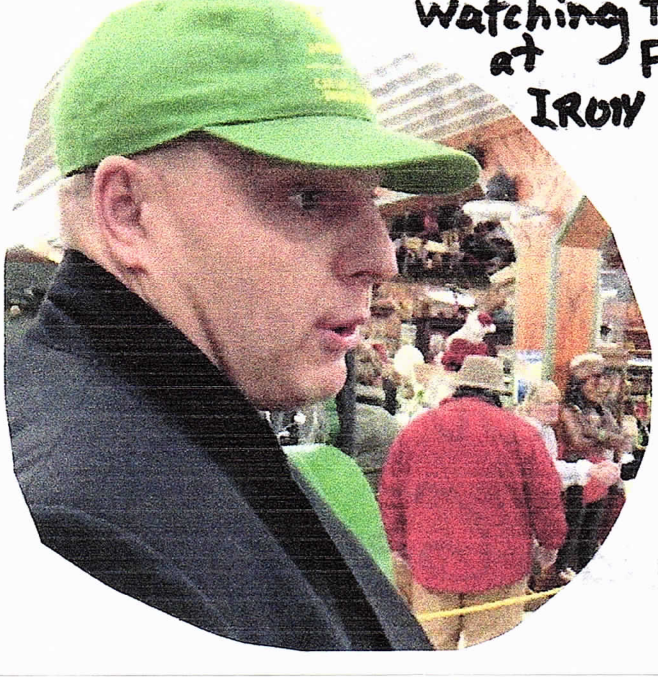
MY LIKES:
My girlfriend and going out with her
Movies, Restaurants, Concerts, Live shows, the beach
Sleeping with my dog, Jax
Hanging with family, especially mom
Helping around the house
Being able to decide who works for me as staff
Staying busy

**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!

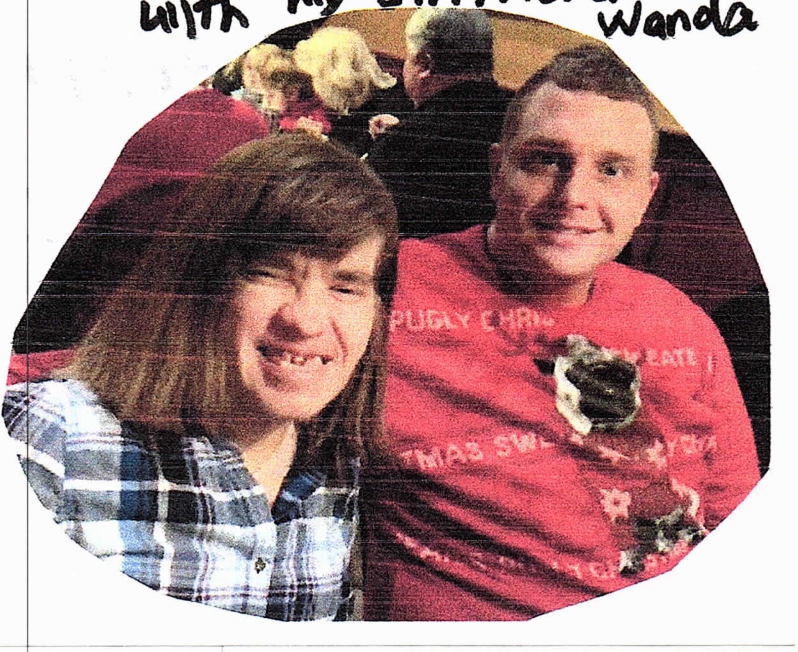
**Self Direction** is important to me because I am

1. 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

watching trains at FLAT IRON FARM



Christmas Eve Dinner with my Girlfriend Wanda



I support HB1171 and SB959.
I support HB984 and SB796.

# My Successes in SDS

Self-Direction is important to me because...

**I don't really like strangers very much. I value my time alone with my music and my toys, and going to movies, parks and restaurants when it is very quiet. I love my staff. They are kind and understand me. When I have behaviors, they know how to help me. When I am anxious, they know how to calm me. I was in two residential homes and I was overmedicated and sleeping all the time, and I gained a lot of weight. My parents tried to be very involved in my care, but it didn't matter what they wanted for me, or what I needed. My dad died from complications of diabetes and heart disease. I don't want to die from that too.**

## *Choice and Control Matter to Me!*

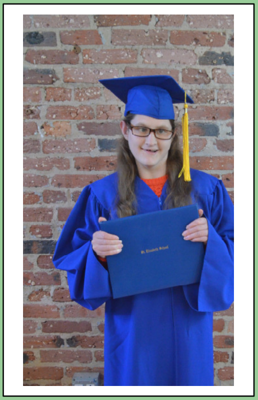
My concerns about self-direction include...

**That somehow the law is going to change, and it will be eliminated. I do not understand how the lawmakers refuse to see me as an individual. My disabilities do not allow me to work. I have to be home full-time with staff coming in because I cannot stay by myself. When I lived in residential care, I had some nice staff and some awful staff. I had staff who pretended to like me. I was prescribed way too much medicine because of the reports given to psychiatrists from staff I only met one or two times, and they reported me. The report was "refused pysch medication" and "had a behavior." The result was a higher dosage of psych medication or an additional one. I had terrible experiences. I cannot go back to residential care.**

Elliott Shull
1302 Oak Hill Ave.
Hagerstown, MD 21742

I support HB1171 and SB959.
I support HB984 and SB796.

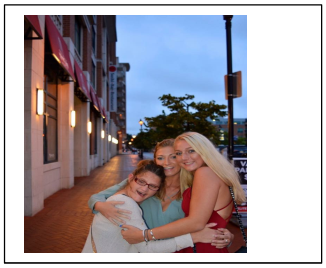
# My Successes in SDS



## Self-Direction is important to me because…

I wanted to choose where I lived and not have to move into a group home and I wanted to be able to hire my own staff so that I can hire people that enjoy doing the same activities that I do. I'm afraid if I move into a group home my staff may not be kind to me and let me make choices and decisions. If I choose where I live, I can be near my family and friends so they can visit me and help me, I applied for 20 extra hours of personal supports April, 2019 as I was moving into my own home and DDA has yet to approve the hours I desperately need to support me. I am frustrated with the lack of timely response I receive from DDA. In addition, SDS is important to because I am a very active person. I attend church, social groups, Independent Living classes as well as other activities and my staff is able to drive me to these activities so that I can have a fulfilling life.

*Choice and Control Matter Matter to Me!*



## My concerns about self-direction include…-

-Personal supports being limited to 82 hours per week as I need 24hour care. I am non-verbal and have very poor motor skills

-transportation being wrapped into services and not separated as it has been in the past

- CDS no longer provided for Self-employment, I work very slowly, and it has been determined that I do not meet the standards of integrated competitive employment but I still want to work and be a contributing member of society

-The new proposed role of Support Brokers I definitely need a Support Broker to help me hire and fire my staff, review timesheets, and to help me write my plan

-The change of not having a choice in my FMS

-DDA not being held accountable to respond to me in a timely respectful manner

Elizabeth "Ellie" Smith
2436 Lakewood Road
Carney, MD 21234

# My SDS Story

My name is Andrew Maerzke. I am 31 years old, and I have been in Self Directed Services since 2013. I am completely unable to speak, and incapable of traditional sign language. Over the last 31 years, my family has learned to translate my small gestures and eye gaze, so that they understand what I want and need. I am able to communicate my needs and wants to my family, but will not attempt to communicate with people I do not know. Self-Direction has been wonderful for me, because I am can now spend my days in a way that I find fulfilling. I am healthy, because I am not forced into a crowded room full of other clients and continually sick!

My happiest days are the ones where I can get into my own van, and go out for a shopping trip, or to a park. When I've had seizures at night, and need to stay home and be monitored, I can do that. While I was in a strict program, it was terrible for me. I had trouble conforming to the rigid bus schedule, the crowded rooms, etc. Self-direction changed my life 100% for the better, because my family is better able to help me do what makes me happy and safe each day of my life!

To me, it seems that Maryland DDA is trying their best to take away the freedom and flexibility that I have enjoyed with Self-Directed Services. They are becoming more strict about family members being paid as our staff. My family cares for me 24/7 365 days of the year. I can only pay them as staff for 40 hours a week for their tireless attention. Paying them as staff makes my life better, because we are better able to afford basic necessities like groceries and clothes, etc. Why is DDA trying to isolate us away from our best caregivers?

*Self-Direction has changed my life 100%*

They seem obsessed with taking away so many things that were good about Self-Direction in Maryland. Our Support Brokers, our wonderful ARC Fiscal Management Service. I cannot speak, and will not try to communicate with others, but with the help of my family, I am living the best life I can, in spite of my disabilities.

Please help me and others like me to keep our lives happy, safe and self-directed. Help us keep our family as staff members and helpers. We and our families need to have a voice in Self-Direction. DDA cannot be allowed to dictate to me what will be in my best interest, because they do not know.

I Support HB 1171 and SB 959.
I Support HB 984 and SB 796.

Andrew Maerzke
You can reach my family here: 8517 New Cut Road
Severn, MD 21144
debbie.maerzke@gmail.com

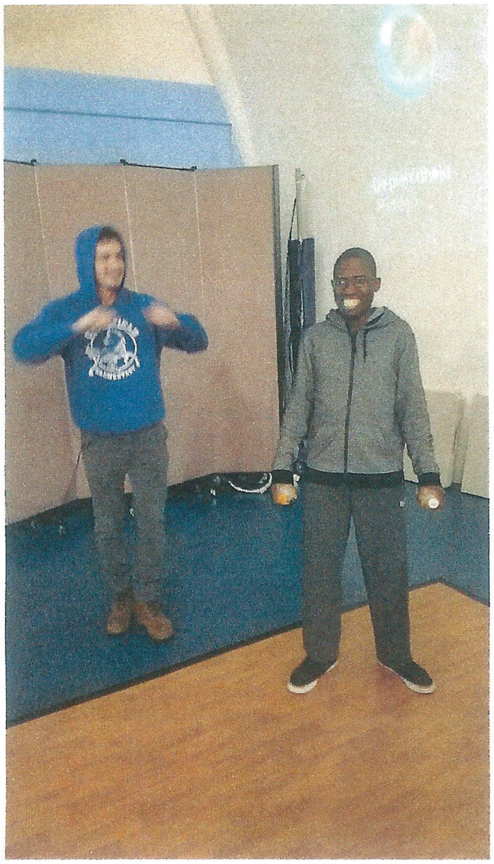
My name is Faith Pasko

I am 26 years old and I have Down Syndrome, Apraxia of Speech and Autism. I have chosen to Self-Direct my Medicaid Waiver Support Services in order to achieve greater control over my life choices. I use no verbal communication, I have a vulnerable nature and because of my intellectual limitations I need support staff to accompany me in the community to keep me safe. I can't be left alone at any time. If I become frustrated and anxious I may become non-compliant. If I have the right staff along side of me I can be a part of my community. Because I have support staff I am able to go to two volunteer jobs and to a local disability ministries programs. Because I have some health problems, my support staff monitors me to keep me safe and healthy. I don't know what I would do without the Self-Directed Waiver. I am always working towards independence to promote self confidence .

## Self-Direction is important to me because.....

- I can hire staff who understands my needs
- I can have flexibility in my day
- If I am not able to follow through with my responsibilities because I become overwhelmed, my staff will respect my need to return home
- I can live independently from my family while living in my home
- I able to hire a sign language interpreter to assist me with communication
- I can choose my own schedule

Faith Pasko
Harford County, MD



# I AM JOSHUA COONEY

I am Joshua Cooney and I am 32 years old. I have late onset autism. I self-direct my Medic Aid Waiver support services. I need my own routine, my space, and choices. I love to be out in the community but hate being forced to stay out when I am ready to go home or forced to go when I am not ready. I get upset when people act out or babies cry. I need great flexibility of movement. Self Direction has made great positive changes in my life.

**Self Direction Lets Me Live the Life I Love**

Joshua M. Cooney
[redacted] Bel Air, MD
terri.cooney@verizon.net

Self-Direction is important to me because…

- I have the staff I want and like
- I choose how I will spend my days
- I come and go when I need to
- I can make changes to suit my needs and wants
- I can keep the routines that are so important to me
- I can live in my home but be independent of my family
- I have not been in the hospital for behaviors for 10 years

# My Story

Paul Weller
10869 Hilltop Lane
Columbia, MD 21044

Hi! My name is Paul Weller. I am 37 years old. I Self-Direct my Medicaid Waiver Support Services. I have Cerebral Palsy and I am Visually Impaired. I also have Type 1 Diabetes and use an Insulin Pump.

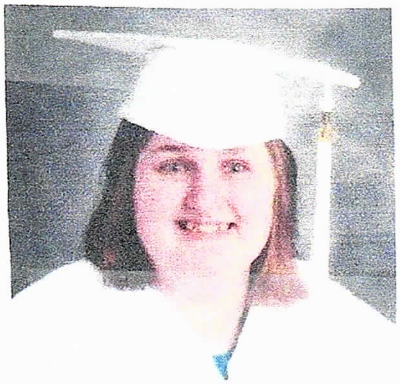
## Choice and Control Matter to Me!

I love Music and Art. The picture above shows me holding a piece of Fused Glass which I made. I wake up every morning to my "Alexa" playing "The Hallelujah Chorus" at least once, followed by "Lean on Me" or "Who Let the Dogs Out". I need help with all activities of Daily Living. Self-Direction gives me the support I need to enable me to go out every day and do the things that will keep me healthy and happy.

## Self-Direction is Important to Me because..

- I hire staff I want
- I choose how I wish to spend my day
- I go home and rest when I need to
- I make changes to my program and staff
- I go to PT and OT as much as I need to.
- I have a team of supports who understand me

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



My name is Courtney Litzenberger. I am 26 years old. I Self-Direct my Medicaid Waiver Support Services.

I have severe autism. I have a certificate of completion from the 12th grade at Forbush School.
I have a voice, but have limited language skills. I am capable of making choices in my activities of daily living and who I want to live with.
I can read and I can print my name. I also print pages of Disney movie titles, all spelled correctly.

I spend some time on the computer searching YouTube movies, shopping at Amazon and the Disney store.
I am out in the community with my staff every day, usually at commercial establishments.
In nice weather I like picnics and going to a park.

I have volunteer job at my church, assembling the bulletins every Friday. I really enjoy going. I am very friendly with anyone I meet.

Staff helps me accept new situations and works to expand my activities in the community.

**Self-Direction is important to me because...**

I hire staff that works well with me

I can keep a calendar in my notebook which helps me focus

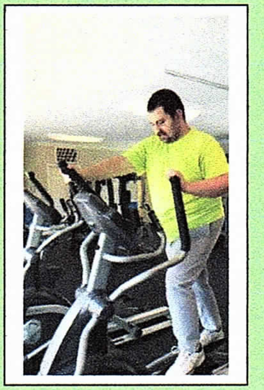
I can count on a routine that my staff and I agree on

I have supports that have learned to work with my autistic behaviors

I can make changes in my staff and use as many hours that are budgeted

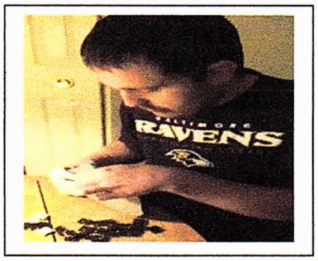
Courtney Litzenberger, 8033 Fair Breeze Drive, Severn, MD 21144 ruth.litz@comcast.net

# All About Me



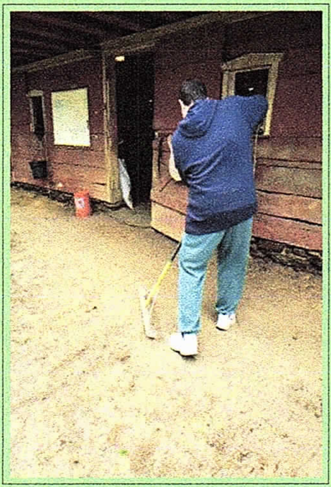
Hi, my name is Justin Sauter. I am 29 years old and have autism. I have been in the Self-Directed Home & Community Waiver Support Services going on 6 years now. With staff, I participate in many community outings, whether its volunteering at several horse farms learning new skills, walking at the community park, working on mosaics, other activities, and continuing to increase skills, these items are what I like to do. Because I have a lot of behavior issues, the need for staff that I choose is very important to me. Also, being non-verbal, I use an IPAD with a communication app on it, to speak for me.

*Choice and Control Matter*
*Matter to Me!*



## 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 make my own hours. I often work on my mosaic designs in the wee hours of the morning.
- I have a support system of my choosing.
- I am the boss!

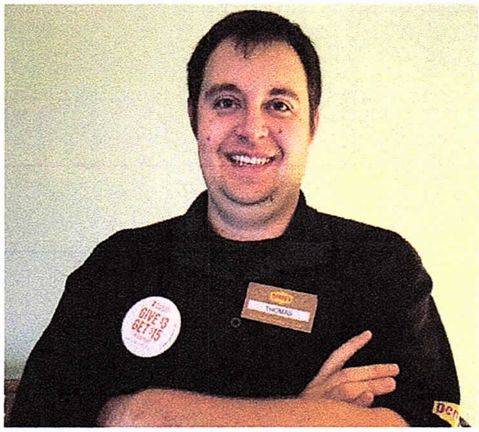


Justin Sauter
100 Brookebury Drive,
Apt. B1
Reisterstown, MD 21136
tp@slatehillrabbitry.com

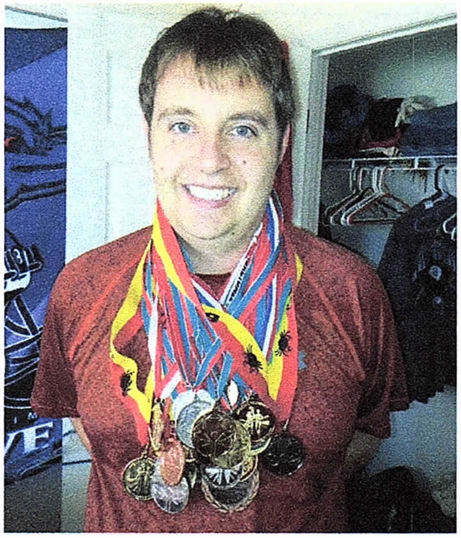
## Thomas R. Livingston 294 Garrison Way Fruitland, Maryland 21826.

**I was born deaf and autistic. I struggle with receptive and expressive communication and daily life skills. I need 24 hour staff support for safety. I do not hear smoke alarms when I am sleeping and require over night staff.**

**Self Direction Services SDS has enabled me to hire caring staff and gain more independence. I am a bus boy at Denny's and I am proud that I have a meaningful career.**
**Through SDS I am able to participate in many community activities.**

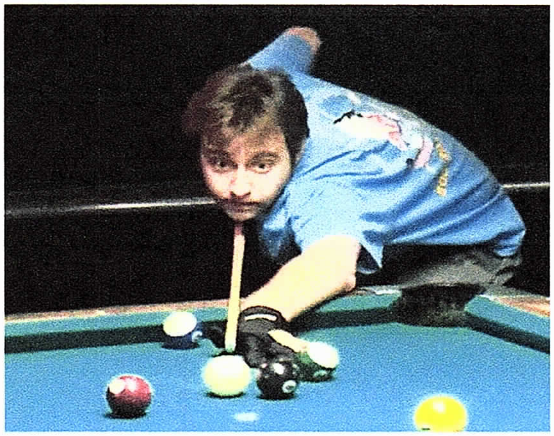


My father helped me find a job at Denny's as a bus boy. I love my job, it has given me purpose in life. I earn money and I am a tax paying citizen of Maryland.
I have many friends at work and love my customers.



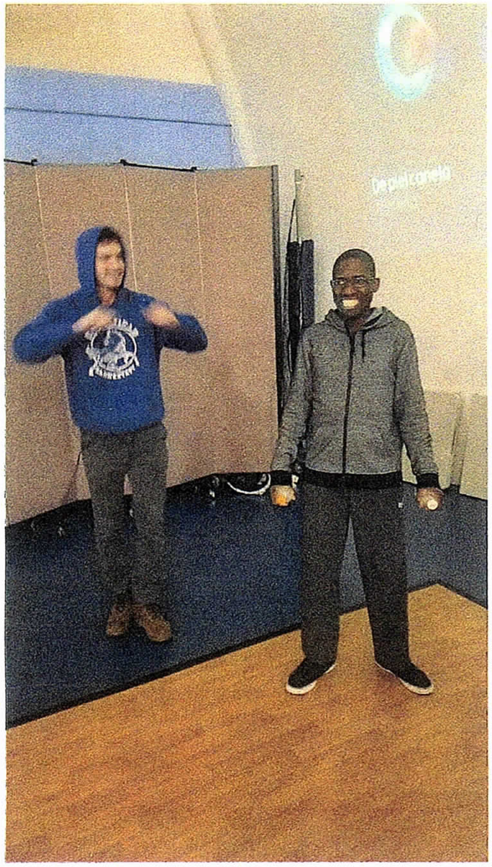
I love Special Olympic (S.O.), I play many sports; softball, basketball, bowling, etc. I have many friends in Special Olympics, together we participate in different activities in our community, dinners, movies, Ocean City, Church etc. Staff takes me to S.O. practices & other activities with my friends.

The Project Read Program at the Library has taught me to read. This skill has helped me with my job, enables me to use a smart phone, read menu's, create grocery list, Uber and more.



I am a Las Vegas pool champion, and a member of the American Poolplayers Association, APA. I play pool in the community and have many friends in pool leagues.

Contact: Mother – Maureen Curran, 443 -365-3952



# I AM JOSHUA COONEY

I am Joshua Cooney and I am 32 years old. I have late onset autism. I self-direct my Medic Aid Waiver support services. I need my own routine, my space, and choices. I love to be out in the community but hate being forced to stay out when I am ready to go home or forced to go when I am not ready. I get upset when people act out or babies cry. I need great flexibility of movement. Self Direction has made great positive changes in my life.

## Self Direction Lets Me Live the Life I Love

Joshua M. Cooney
128 East Lynbrook Place Bel Air, MD
terri.cooney@verizon.net

Self-Direction is important to me because…

- I have the staff I want and like
- I choose how I will spend my days
- I come and go when I need to
- I can make changes to suit my needs and wants
- I can keep the routines that are so important to me
- I can live in my home but be independent of my family
- I have not been in the hospital for behaviors for 10 years

My name is Daniel Johns. I am 28 years old and live with my Mom, Dad and younger sister in Upperco. I was diagnosed with Autism when I was 5 years old. I have a history of Epilepsy, Anxiety and OCD. I also have Apraxia, so I can't communicate by speaking. I recently found out I have a genetic mutation (CDKL5 Disorder), which is the cause of my disabilities. My Mom is my primary caregiver and advocate, and gave up a promising career due to my 24-7 needs for care and supervision. I am blessed to have the unconditional love and support of my family, because I want to live with them as long as they are able to care for me.

# *Choice and Control Matter to Me!*

Self-Direction is important to me because there is no traditional program in my area that can provide the 1-to-1 care and support I need in order to stay safe, healthy and engaged in activities that are meaningful to me. SDS allows me to hire my own staff, plan my own schedule, allocate funds from my budget, and go out into the community every day. I enjoy doing errands, volunteer work, Special Olympics sports, bowling, mini golf, going to parks, restaurants, movies, nature programs, and Rec. and Parks activities.

**Self-Direction allows me to truly live my best life!**

Daniel Johns
16007 Trenton Road
Upperco, MD 21155

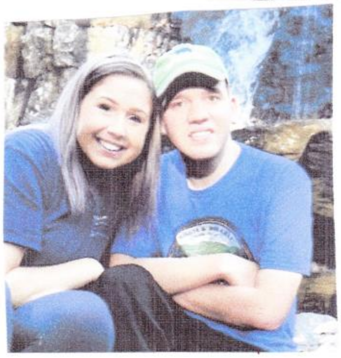
CONTACT:
Mindy Johns
410-218-4908
omrc.tennis@yahoo.com

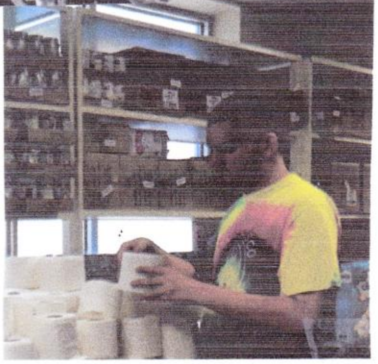
My name is Patrick Good. I am 27 years old. I Self-Direct my Medicaid Waiver Support Services. I have Autism. I am a friendly person and I like to be out and about in my life. Many things are hard for me. I need to be monitored 24/7 because I have no fear of danger and I need guidance in being out in community. I can't be on my own at home. I need help with personal care and staying safe. I love music, Movies (Barney, School House Rock, Magic School Bus, & Disney Princesses), hiking, bowling, ice skating, and going to parks. I like to ride horses for the therapy to calm me down. I like to be helpful in the community by doing some volunteer jobs. I need help with cooking and cleaning. I do not like to sit around all day.

## Self direction gives me freedom and a say in what I do every day of my life

Self Direction is Important to me because....

. I hire the staff I want
. I choose how I wish to spend my day
. I go home and rest when I need to
. I make changes to my program and staff
. I stick to a routine that works for me
. I go to horseback therapy to help me manage anxiety
. I have a team of supports which understand my needs

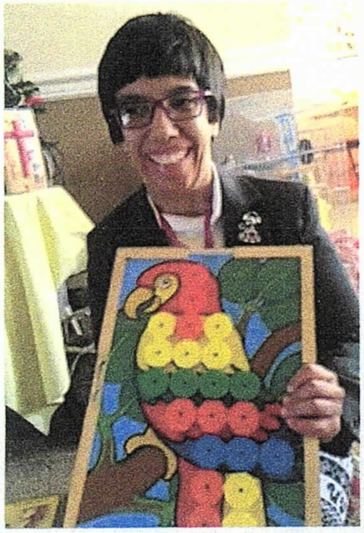




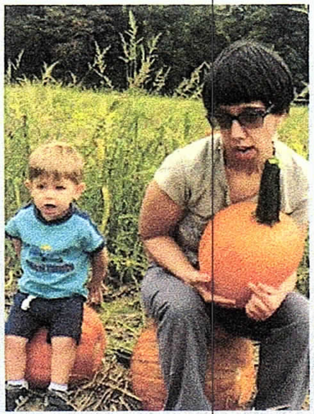
Patrick Good

Bel Air, MD 21014
Bkgood@comcast.net

**My name is Melanie Cooper.** I am 34 years old. For 13 years I have enjoyed Self Direction through the Medicaid Waiver. I have lived in my very own apartment for the last 6 years. I have a rare seizure disorder (LGS) and autism. 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.*

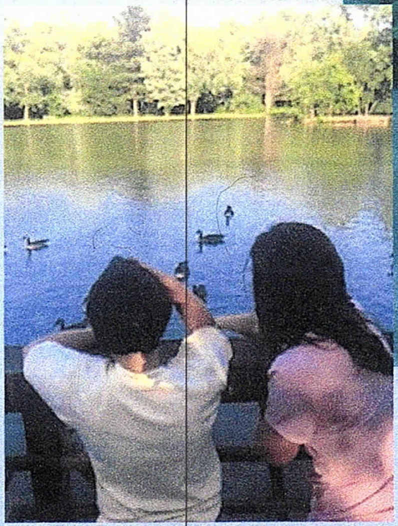


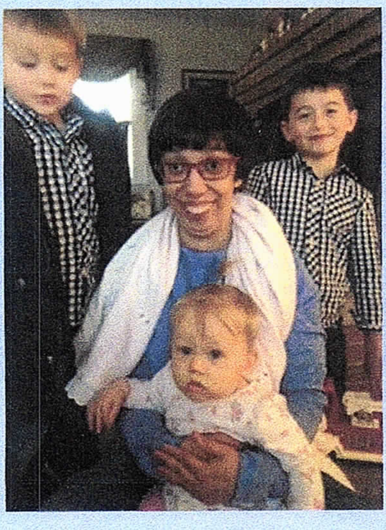
# *Self Direction Gives me Self Worth through Independence*



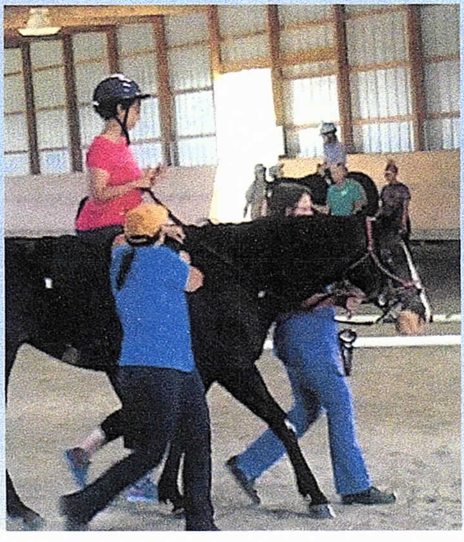
Self Direction is Important to me because…

- **(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 9 years.

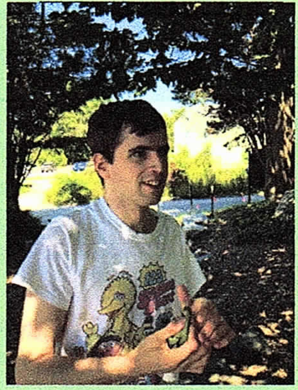




**Melanie Cooper**
**126 N Hickory Ave Apt #20**
**Bel Air, MD 21014**
**kathykcooper@gmail.com**



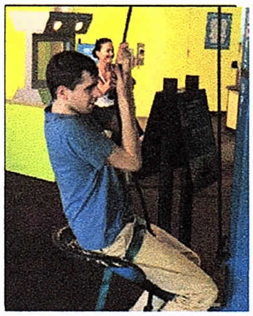
# My Story

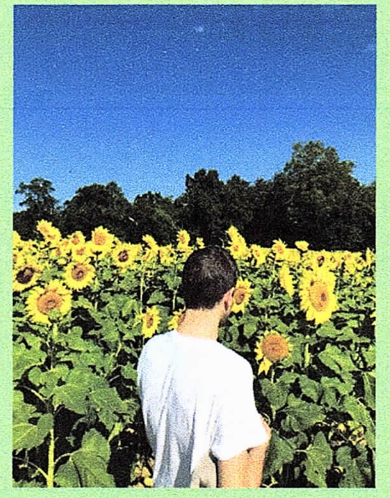


My name is Al Wopat. I am 25 years old. I Self-Direct my Medicaid Waiver Support Services. I have autism and I sometimes have difficulty communicating my needs and wants. Sometime crowds are difficult for me because I have to wait and sometimes all of the sensory input is too much. When I have good support and feel well, the world is a wonderful place.

I often need some assistance to take care of myself and I cannot stay in my home alone. I do love going out into my community but I also like my quiet time. Controlling how I spend my day makes me happy.

*Choice and Control of my day really Matter to Me!*





Self-Direction is important to me because...

I choose where I go and what I do each day.

I choose who I spend my day with.

I can have new experiences in the community when the timing is right for me.

Everyday can be unique.

I can learn to be more independent at home and in the community and that feels great!

I can change my program as I gain more independence because I have a team who supports me!

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

# My Story

My name is Francis Garove. I am 28 years old. I self-direct my Medicaid Waiver Support Services. I have multiple disabilities but Cerebral Palsy is my primary diagnosis. I need 24x7 care. I need help with eating, toileting and hygiene. I cannot stay in my home alone. I like meeting new people but I also love my routine. I love music therapy the most. I also like to swing in my wheelchair swing, go to bingo and participate in physical therapy as well as swim therapy. I also like to play music and games on my computer using a special needs switch. I am wheelchair dependent. I am non-verbal but can express myself by smiling. I need support to try new things.

## *Choice and Control Matter Matter to Me!*

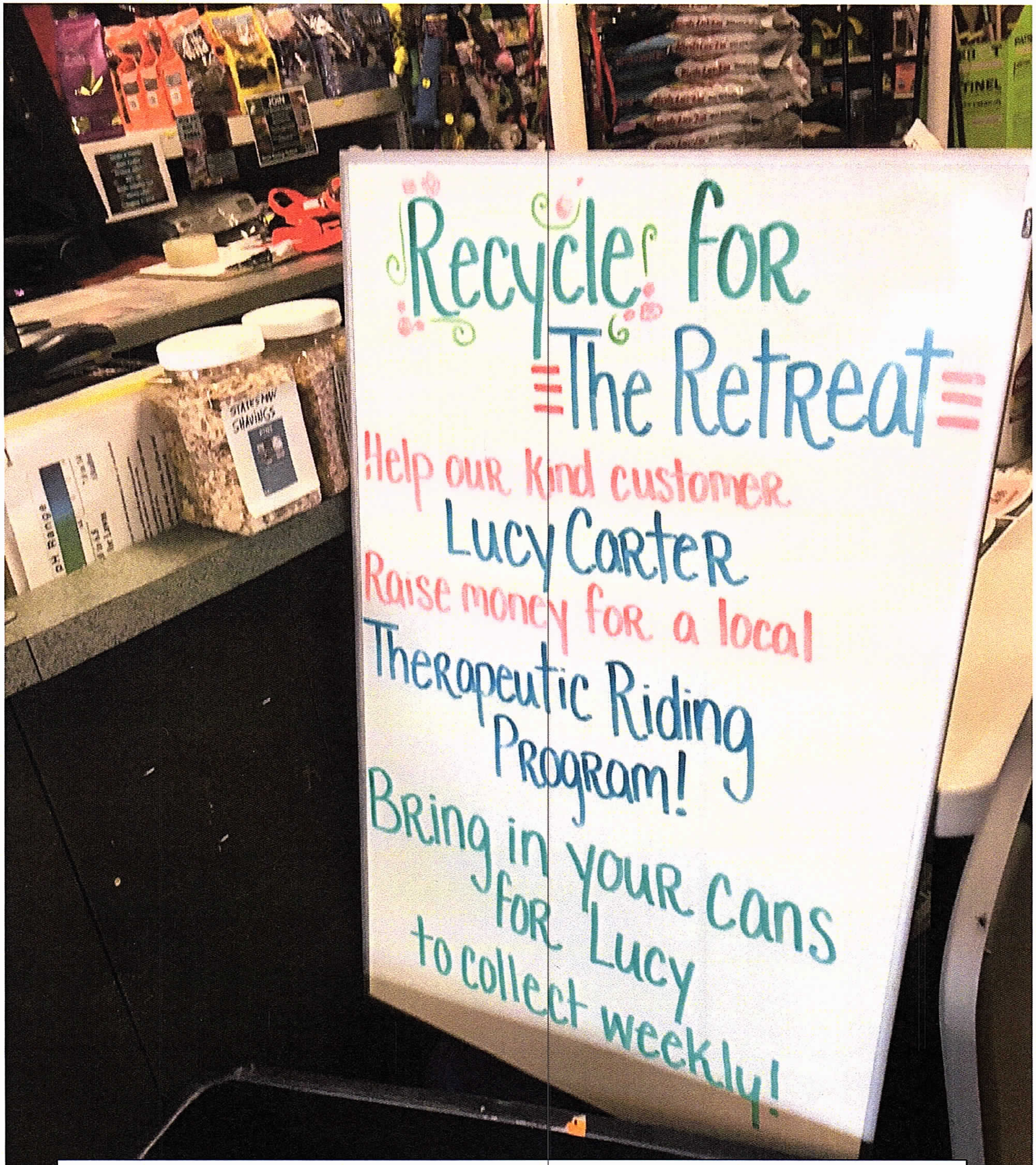
### Self-Direction is important to me because…

- I hire the staff I want
- I choose how I spend my day
- I can make changes to program and staff
- I stick to a routine that works for me
- I go to music and swim therapy to help me manage stress
- I have a team of supports that understands my needs
- My personal support staff is a med tech who can give me my regular medications and can care for me if I'm sick

Francis Garove
18 Flintlock Court
Perry Hall, MD
21128
rgrelli@verizon.net

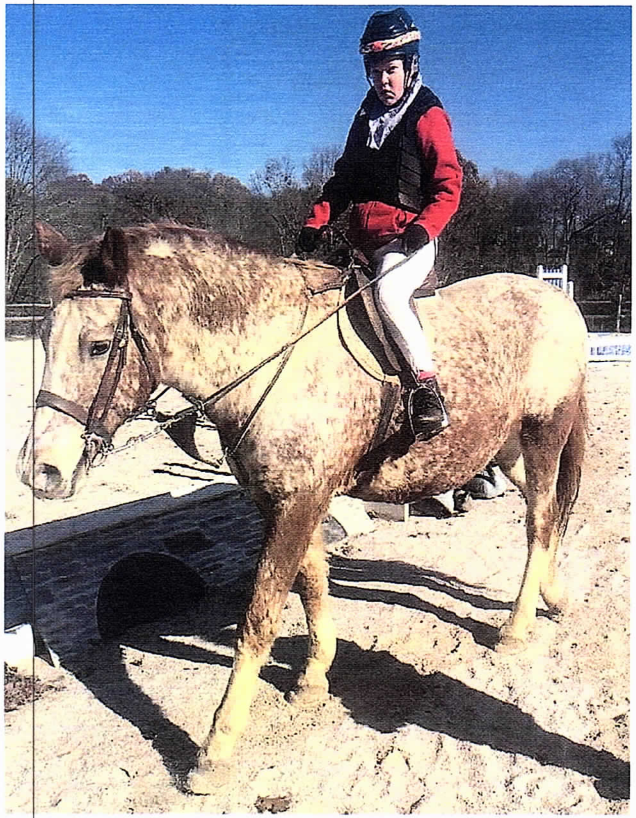
DDA Self-Directed Services WORK!

Our services can be customized to meet the unique needs of people with intellectual and developmental disabilities to LIVE the lives they choose, often for much less than traditional services.
PLEASE HELP US **PRESERVE OUR SELF-DIRECTED SERVICES**



Lucy has her own home-based recycling business. Not only is she doing what she loves, she is building community and helping her environment. With recent changes made by DDA to the Self-Directed Services Waiver, Lucy, and many others with home-businesses will no longer be able to participate in activities like these out of their home with supports they need and have had in the past.

# Recycle for the Retreat



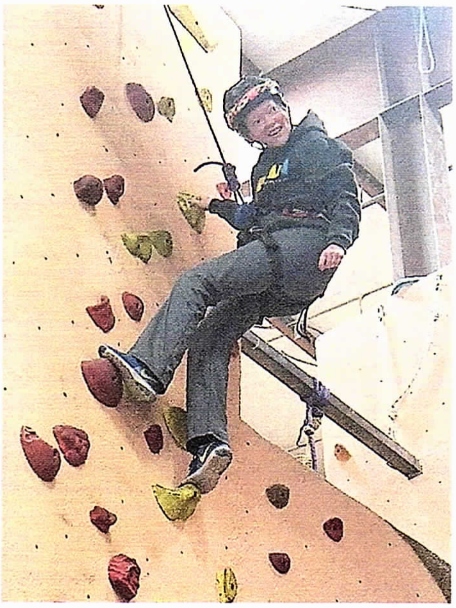
**Help Lucy Carter raise money for the Retreat at Beckleysville, Hampstead's fantastic therapeutic riding program.**

**Lucy will collect your aluminum cans every week, process them, and donate the proceeds to the Retreat.**

Contact Lucy at 410.790.4375 to receive a collection bag and to arrange a weekly pickup day.

To learn more about the Retreat and the remarkable service it provides, please visit retreatatbeckleysville.org.

## Community Integration Assistant for Cool Young Woman with Developmental Disabilities



## Weekdays and/or weekends and evenings

## Hampstead, Md.

## $18-$20/hr

Seeking a proactive and well-organized person to provide community integration supports for a fun and active young woman in Hampstead, Md.

- Must enjoy working with horses and dogs and engaging in physical activities.
- Some personal care required.
- Flexible schedule: 1-5 weekdays: Hours approximately (9:00a.-4:30 p.) Some evening and weekend hours also available.
- Must demonstrate a strong commitment to helping people with developmental disabilities engage in their communities and realize their potential.
- Volunteer experience strongly preferred.
- College coursework in special education, physical education or behavioral sciences preferred.
- Climbing experience preferred.
- Must have a reliable car and an excellent driving record.
- Excellent references.
- Must have or be willing to get CPR/First Aid Certs.
- Generous mileage reimbursement.
- Wage dependent on credentials.

Send resume and letter of interest to supportbroker@meggcarter.com

# 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!*

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.

**John Phillip**
**Woodhead**
**443-280-1096**
crwoodhead@hotmail.com

# My Successes through Self-Direction!

**Caitlin Mickel works with a student at her family's farm.**

**Things important to me and how self-direction helps me get them …** I love working with horses and hope to be trainer one day. In the meantime, I am working with staff at my family farm to acquire, improve, and maintain skills in caring for the animals and keeping up a facility. Together with my staff, I have created a Western Town and dressed up my animals so that we can host birthday parties for individuals with and without disabilities and community groups, such as Girl Scout Troops. I give lessons to children at our farm. I also take my animals into the community to assisted-living facilities and inner city churches. I needed help from others as I struggled with multiple brain surgeries much of my live. It is important for me to give back to others in the community now that I can.

## My concerns about how the new waiver will affect my program …

**Narrow Definition of Community Development Services** – When updating my plan last year, I was told that having people come to my farm was "reverse integration." My farm and the services I provide to the community there were not considered appropriate under the new definition of community development. I believe that my farm IS part of the greater community and the work I do there to care for my animals and maintain our facilities allows me to give back to my community, which is very important to me. Without the staff supports provided through the waiver, I would not be able to host events at our farm or get out into the community with my animals to share them with those who cannot come to me.

# My Successes through Self-Direction!

**Meet Carol'Ann Alphin - She was interviewed on television while choosing a dress to wear to the Night to Shine Prom event in 2017.**

## Things important to me and how self-direction helps me get them:

I love to be out in the community. I love to make things to give to veterans and people in nursing homes. My self-direction staff takes me where I need to go, helps me create the things I donate, and supports me as needed throughout my day.

## My concerns about how the new waiver will affect my program:

1. **Narrow Definition of Community Development Services**

Currently my staff works with me on craft and cooking products in my home. I then give these products to members of the community at Veteran's centers and assisted-living facilities. While CMS allows these kind of supports to be provided in my home by my waiver staff, ***Maryland has chosen*** to exclude all participants' homes, as a location where community supports can be provided. I enjoy giving my products away. Without staff supports to create these products, my community involvement will be reduced.

2. **Directing my services** –

I understand what it means to be an employer and what responsibilities that involves. I do not need a designated representative, but I would like to retain the ability to receive supports with some tasks from my support team. **Maryland's choice** to establish a new "criteria" to be able to self-direct is a concern to me. All individuals with disabilities are capable of self-directing with the right supports, yet new restrictions are putting that in jeopardy.