



Self-Directed Advocacy Network of Maryland, Inc.

Participant Choice and Control of Services

**RECOMMENDATIONS TO
SUMMER STUDY
WORKGROUP HR318 of 2021**

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

Overnight Supports (ONS) and Personal Supports (PS)

The Issue:

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

Implications of Current State Policy:

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

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

Recommendation:

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

Competency Assessments, Designated Representatives (DR) or Authorized Representative

The Issue:

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

Implications of Current State Policy:

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

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

Recommendation:

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

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

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

Support Broker (SB)

The Issue:

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

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

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

Implications of Current State Policy:

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

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

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

Recommendations:

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

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

The Issue

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

Recommendation:

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

Transportation

The Issue:

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

Implications for Current Policy:

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

Recommendation:

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

Individual and Family Directed Goods and Services (IFDGS)³

The Issue:

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

Implications of Current State Policy:

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

Recommendation:

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

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

Transparency in the Person-Centered Planning Processes

The Issue:

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

Implications of Current State Policy:

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

Recommendation:

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

Parity between Provider-Managed Services and Self-Directed Services

The Issue:

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

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

Recommendation:

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

Nursing

Introduction:

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

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

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

The Issue:

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

Recommendations:

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

Workgroup Goals:

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

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

The workgroup should consist of a minimum of:

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