Findings and Recommendations of the Maryland Department of Health Related to the Expansion of Self-Directed Services as Required Under Section 1 of the Self-Direction Act of 2022

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Maryland Department of Health

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Executive Summary

Self-direction is a service delivery model which allows participants in Medicaid waiver programs to exercise budget authority and employer authority over some or all of the services that they receive. This model is one way by which states can promote self-determination and personal freedom for individuals with intellectual and developmental disabilities. In Maryland, Self-direction options are available under the three waiver programs operated by the Developmental Disabilities Administration.

This report highlights several key findings related to the implementation of Self-Directed Services (SDS) in Maryland, including:

- **Disparities in staff wages.** Staff wages in SDS are exceptionally high, out-competing wages offered by providers in the traditional service delivery model. Specifically, when compared to market norms for similar types of employment, customary wages paid under the SDS model can be up to 62 percent higher than the market average as measured by relevant Bureau of Labor and Statistics (BLS) data. When wage exceptions are requested, wages paid under the SDS model can be over 150 percent higher than the market average.
- **Rapid growth compared to the traditional service model.** SDS is experiencing rapid per-capita cost growth, outpacing the traditional service delivery model. Specifically, per-capita cost growth of 43.3% year-over-year was observed in the Self-Directed Services model from FY 2023 to FY 2024, compared to 22.3% in the traditional model.
- **Balancing caregiver and participant interest.** In some instances, there are unresolved conflicts of interest between caregivers and participants, including financial conflicts of interest. The DDA has received multiple reports of entire families consisting of parents, siblings, and extended family members becoming paid workers for a single SDS participant. In some situations, these arrangements are in conflict with the participant's welfare, independence, and full integration in the community.
- **Limited pathways for concerns related to abuse and neglect.** Under the traditional model, the Office of Health Care Quality (OHCQ) is the licensing and monitoring agent for the DDA. Through periodic surveys, the unit oversees community-based providers serving individuals with developmental disabilities. The unit completes on-site surveys and administrative reviews of complaints and reportable incidents. In short, OHCQ ensures providers act in accordance with minimum health and safety requirements. In the traditional model, Coordinator of Community Services (CCS) quarterly monitoring and followup is only one component of a complete system of monitoring in partnership with OHCQ, which helps to ensure participant health and welfare. In the SDS model, CCS quarterly monitoring and followup is one of the only regular contacts between participants and external parties. When CCS monitoring is refused by the participant or their caregivers, there are significant unresolved pathways for participant abuse and

neglect through isolation. Moreover, many individuals providing services via self direction are unlicensed caregivers, rather than licensed or certified providers.

- **Scope of staff.** There are a variety of entities that operate under the SDS model and there are conflicts between service scope for various participant staff, particularly Day-to-Day Administrators, Support Brokers, and Coordinators of Community Services. Among other things, these conflicts can result in duplicative activities occurring across these entities.
- **Disparities in access.** The SDS model is accessed at a far lower rate by minorities than the traditional model. Specifically, participants in the Traditional model are 52% White and 39% Black, while participants in the SDS model are 62% White and 25% Black.

The Department is taking ongoing steps to safeguard participant health and welfare, prevent fraud, waste, abuse, and exploitation, and ensure integrity and sustainability for the Self-Directed Services model. On Thursday, October 24, 2024, the DDA released a new comprehensive policy and manual for Self Directed Services, which clarified existing guidance about this model. Updates were also made to forms used to request: (1) Wage Exceptions; (2) Individual and Family Directed Goods and Services; and (3) Family as Staff Overtime. These updates are meant to more clearly articulate what is needed in order for a service to be approved and ensure that services are delivered in accordance with federal and state authorities.

Introduction

Self-Directed Services (SDS) are a service delivery model available to participants in the 1915(c) Home and Community-Based Services (HCBS) Medicaid waiver programs operated by the Developmental Disabilities Administration (DDA) of the Maryland Department of Health (MDH or "Department"). In comparison to the DDA's traditional service delivery model, SDS provide participants with a greater degree of flexibility and control over the services which they receive, particularly through participant authority as employer for the staff that provide services, as well as participant authority over the State and federal funds allocated to services through a personalized budget. SDS are a mechanism for enhanced self-determination, and fill an important role in enhancing service flexibility.

In Maryland, as of November 2024, approximately 3,900 participants self-direct their services, alongside approximately 16,800 participants receiving "traditional" services. In the Traditional service delivery model, services are coordinated through a provider agency, rather than directly by the participant. The two models are similar in many respects. In particular, participants in both models utilize the same service authorization and planning process, known as Person-Centered Planning, which results in a detailed authorization of services and funding which are targeted to the participant's needs and goals. Additionally, participants in both models receive case management services through a Coordinator of Community Services (CCS), who provides assistance in developing the annual Person-Centered Plan (PCP), helps to coordinate support from various sources, and completes quarterly monitoring visits. These monitoring visits assess the participant's health and safety, delivery of services, and satisfaction with services.

There are several structural differences between Maryland's Traditional and SDS models. First, only Traditional participants may receive community residential supports (such as licensed group homes), and therefore Maryland's population of approximately 7,000 participants receiving residential supports is located entirely within the Traditional model. Second, participants in SDS receive certain kinds of unique services and supports which do not apply in the Traditional model. First, all participants in SDS must complete payment, tax, and billing related tasks through one of the Department's three Financial Management and Counseling Services (FMCS) vendors. Additionally, participants in SDS have the ability to reallocate unused funds in their budget to purchase additional goods and services via Individual and Family Directed Goods and Services (IFDGS), which is unavailable in the Traditional model. Participants in SDS also have the ability to receive employer-related information, guidance, and human resource support through Support Broker Services, as well as a Day-to-Day Administrator to assist with administrative tasks and assist with managing the participant's home and staff.

Self-Direction History, Purpose, and Policy Goals

In a national context, self-direction (also known as participant-direction or consumer-direction) is supported by the federal Centers for Medicare and Medicaid Services (CMS) at the Department of Health and Human Services (HHS) and by many national advocacy organizations. Self-direction has been broadly implemented by many state Medicaid programs (National Council on Disability, 2013). National advocates point to self-direction as a means of realizing community integration goals, as well as a means of achieving cost-savings for Medicaid programs, as SDS programming exhibits fewer overhead costs than traditional services. Versions of the self-direction model have been applied to services for a variety of populations under

HHS's purview, including individuals with intellectual and developmental disabilities, elderly individuals, and individuals with physical disabilities. Self-direction has been broadly applied to HCBS such as those overseen by the DDA, as well as to personal care services and Medicaid State Plan services.

Self-direction has its roots in the independent living movement of the 1960s and 1970s, but came into its modern form in the late 1990s with a series of demonstration programs carried out by the Robert Wood Johnson Foundation and HHS, evolving from a series of time-limited grants in 1995 (the Self-Determination program and the Independent Choices program) to the 1998 rollout of a full-scale randomized trial known as the Cash and Counseling Demonstration Program (National Council on Disability, 2013). The Cash and Counseling model proved to be a notable success, with a Mathematica analysis of randomly-assigned participants in three states (Arkansas, Florida, and New Jersey) revealing that direct control by participants over their services resulted in increased quality of life and increased independence, while not significantly increasing Medicaid expenditures or the rate of reported Medicaid fraud/waste/abuse (Brown et al., 2007).

It is important to note that the Cash and Counseling demonstration remains one of the only large-scale scientific studies (and the only large randomized study) of the effects of self-direction on satisfaction, health/social outcomes, and expenditures for Medicaid participants. The typical modern model for self-direction differs significantly from the Cash and Counseling model. Nonetheless, many present-day studies and reports about self-direction continue to cite the Cash and Counseling experiment as primary evidence for the positive effects of self-direction (Applied Self-Direction, 2021). Re-exploration of these findings is becoming increasingly critical, as self-direction programs continue to expand rapidly following initial acceleration during the COVID-19 pandemic.

In the 2000s and 2010s, adoption of self-direction programming expanded rapidly in both personal care services and HCBS through the support of CMS and other funding agencies. The application form for 1915(c) Medicaid waivers was modified in 2005 to encourage states to implement self-direction options, and many states did so (National Council on Disability, 2013). Since the COVID-19 pandemic, many states, including Maryland, have seen rapid growth in both enrollment and costs for their self-direction programs. Some states, such as New York, have recently announced significant changes to certain portions of their self-direction programming to attempt to reign in costs, particularly related to overpayment of persons providing services (Nahmias, 2024). These concerns have coincided with ongoing HHS Office of Inspector General (OIG) attention towards a heightened prevalence of Medicaid fraud in personal care programs, which include both self-directed and traditional approaches to personal care (Murrin, 2021). However, these OIG findings have been disputed by self-direction advocates as being not significantly above baseline, and not significantly associated with the self-direction model itself (Applied Self-Direction, 2021; Metraux, 2024).

It is important to note that Medicaid waiver applications in most states assume that self-direction will achieve cost-savings versus traditional services, as self-directing participants incur lower overhead costs. Most states implement this assumption by capping self-direction expenditures at a defined fraction (such as 90%) of traditional costs (Walker et al., 2009). Nonetheless, evidence

for self-direction as a means for Medicaid programs to achieve cost-savings is fairly limited. In the original Cash and Counseling demonstration, Medicaid expenditures increased by 8% during the first two years of enrollment in the self-directed model, largely due to increased utilization of authorized services (Kemper, 2007). In a smaller Michigan study of 70 self-directing participants, inflation-adjusted cost-savings of 14% were identified over the course of three years (Head & Conroy, 2005). At present, there is no conclusive evidence for self-direction either substantially raising or substantially lowering the total cost of Medicaid services, although many states impose mandatory caps, or managed care/capitated approaches, which ensure that self-direction spending cannot exceed traditional spending (National Council on Disability, 2013).

Self-direction programming has also been criticized in the context of racial and income equity, as self-direction is accessed at a significantly higher rate by White, middle-to-upper income families than by others (Bradley, 2023). In particular, according to recent National Core Indicator (NCI) data, Black recipients of services for intellectual and developmental disabilities are roughly half (52.6%) as likely to access self-direction as recipients of all other races (Bradley et al., 2021). In Maryland, this dichotomy is worse than the national average, with Black participants roughly one-third (32.74%) as likely to access self-direction as participants of all other races. In Maryland, participants in the Traditional model are 52% White and 39% Black, while participants in the SDS model are 62% White and 25% Black.

Maryland currently faces many challenges in the context of its SDS model, particularly related to accelerating and unpredictable costs; lack of safeguards for participant safety and community integration; significant pathways for Medicaid fraud, waste, and abuse; improper rates of pay for staff; racial and income disparities; and legal flexibilities which prevent MDH from exercising certain types of oversight. Some of these challenges are unintended consequences of flexibilities created by the Self-Direction Act of 2022, while others arose in the broader national context of rapid SDS model growth that followed the COVID-19 pandemic.

The policy goals of the Department towards self-direction are straightforward: a well-built SDS model will enable the Department to enhance independence, increase flexibility, promote self-determination, support families, create equity, and build thriving, diverse communities in a fiscally responsible way. However, in the context of a service system in which more than 4,000 people qualify for services but must remain on a waiting list due to insufficient funding, it is unconscionable to operate a system which does not carefully assess its own efficacy and cost-efficiency. Without expanded oversight over self-directed services, Maryland will worsen the direct support professional and nursing shortages, exacerbate participant vulnerability, fail to prevent unethical and illegal behavior, and fail to reduce or eliminate waiting lists for services.

SDS Model Changes as a Result of the Self-Direction Act of 2022

The Self-Direction Act of 2022 (CH0736/CH0737) served multiple purposes, including modernizing statutory definitions related to self-direction in Maryland, establishing new kinds of services, and expanding the scope of existing services. At the time of the Act's passage, a fiscal analysis was not performed to fully quantify the cost of several of the expanded services under the Act. During review of the Act, the Department of Legislative Services noted that expansion of services such as Individual and Family Directed Goods and Services (IFDGS) would have an

"indeterminate but likely significant" effect on spending (Holcomb & Department of Legislative Services, 2022). Additionally, the effects of other requirements, such as provision of overnight personal supports, creation of the new Day-to-Day Administrator position, and participant access to LTSS*Maryland*, were not quantified. Because the DDA budget, like all Medicaid services, is based on utilization, components of the Act which would produce increased utilization should have received closer attention during the 2022 session. In general, the DDA's budget has not increased concomitantly with the increased spending requirements under the growing SDS model, creating a series of unfunded mandates within Maryland SDS law.

In general, requirements resulting from the Act are as follows:

1. Md. Code Health - General §7-408a requires the DDA to train CCS on the SDS model, in consultation with stakeholders.
2. Md. Code Health - General §7-408b and §7-408c require CCS to educate recipients on the models of service delivery.
3. Md. Code Health - General §7-409a(1) and §7-409c remove the prior cap on IFDGS.
4. Md. Code Health - General §7-409a(2) requires the DDA to provide access to the Plan of Service and recipient budget in the LTSS software system.
5. Md. Code Health - General §7-409a(3) and §7-409b expand the definition of Support Broker Services and increase the number of available Support Broker Services hours up to 30 hours/month.
6. Md. Code Health - General §7-409a(4) allows family members and legal guardians to provide services.
7. Md. Code Health - General §7-409a(5) requires the DDA to provide mileage reimbursement for use of accessible vehicles in certain contexts.
8. Md. Code Health - General §7-409a(6) creates a new service (Day-to-Day Administrative Supports) which assists with household and personal management.
9. Md. Code Health - General §7-409a(7) and §7-409c allow for the provision of overnight support through personal support services and prohibit a limit on the number of personal support hours received.
10. Md. Code Health - General §7-409a(8) requires the Department to contract with a minimum of three vendors for FMCS.
11. Md. Code Health - General §7-409a(9) clarifies that recipients have the option to employ a support broker/brokers, or other representatives, in directing services.
12. Md. Code Health - General §7-409a(10) requires that the DDA provide training for representatives, support brokers, or a team of individuals on self-directed services.
13. Md. Code Health - General §7-409d prohibits competency assessments prior to the authorization of self-directed services.

Maryland SDS Budgets

Annual budgets for all DDA participants are constructed in a similar manner, regardless of service model. All underlying Medicaid rates are identical for Traditional and Self-Directed services. This means that participants in SDS receive budgets calculated using rates based on the same cost components as traditional services. However, participants in SDS do not have the same cost components when hiring employees or vendors.

Participants in SDS hire employees, vendors, or DDA providers to provide supports based on the needs identified in their PCP. The DDA sets Reasonable and Customary (R&C) wages and rates for employees, vendors, and providers to aid participants in choosing a rate that is aligned with market norms. Participants can exceed the maximum R&C wage through the wage exception process, which allows participants to pay an hourly employee a rate as high as the full provider rate minus 14%. This 14% difference is due to the presence of traditional provider overhead cost components in the traditional rate model which are not experienced by individual employees in the self-directed model. It is important to note that SDS participant budgets are always developed *without* this 14% differential – therefore, the full amount of funds remains in the participant's budget as unallocated funds when the participant hires an employee, vendor, or provider at a rate lower than the fully-loaded traditional provider rate, and such unallocated funds can be reallocated for other purposes.

One major distinction between SDS budgets and Traditional budgets is that participants in the SDS model may access up to 100 percent of their total approved annual budget due to the Self-Direction Act of 2022. In the traditional model, this is generally not possible, as budget lines are approved for specific services, and the participant cannot receive more than a maximum number of hours of each specific service over a specific unit time (for instance, 40 hours per week). Funds which are unused in the Traditional model are reverted to the Department.

Meanwhile, in the Self-Directed model, participants can access these unused funds in all budget lines and reallocate those funds to additional purchases of optional goods and services through Individual and Family Directed Goods and Services (IFDGS). As a result of the Self-Direction Act of 2022, the Department's pre-existing spending cap for IFDGS was removed. The IFDGS request process, which is available only under the SDS model, makes it possible, and in some cases likely, that self-directing participants will expend 100% of their annual budgets. This delta between budgets and actual utilization has been referred to as "cost-savings," even though DDA's annual appropriation is based on actual utilization, and therefore no "cost-savings" actually exist in terms of the Department's budgeting process. The blanket provisions in Maryland law prohibit many forms of restrictions on IFDGS, however the Department does seek to enforce guardrails and assurances for IFDGS as outlined in its federally-approved waiver applications.

In most years, budget utilization for all DDA participants is between 50% and 60%, as Maryland's established PCP process authorizes more supports than are typically needed. This practice does not create a risk of overuse in the Traditional model due to the hour-based restrictions on service delivery described above, and did not create a risk of overuse in the SDS model before the removal of the IFDGS cap. However, now that participants in the SDS model can convert all authorized services into their equivalent monetary value through IFDGS requests, there is no genuine legal or programmatic restriction prohibiting these funds from being spent.

Of note, over the past year, SDS per-capita spending has grown very rapidly, at more than double the rate of per-capita traditional spending. Budget utilization is rising in both models, but MDH expects self-directed utilization to outpace traditional utilization in the near future, as participants continue to increase wages, increase benefits, and increase IFDGS purchases. In FY 2024, if 1,000 participants in SDS had spent 100% of their approved budgets, the Department would have

expended an additional $94,196,816. If all participants in SDS had spent 100% of their approved budgets in FY 2024, the Department would have expended an additional $342,122,837.

SDS Model Statistics

The tables and figures below demonstrate recent program history within the SDS model in Maryland. Since the COVID-19 pandemic and passage of the Self-Direction Act of 2022, both enrollment and per-capita costs in the SDS model have increased markedly, with particularly rapid per-capita cost acceleration in FY 2024, in which the SDS model reached 43.3% per-capita cost growth. FY 2024 coincided with the introduction of many flexibilities required by the Self-Direction Act of 2022, as the Department amended the relevant 1915(c) Medicaid waiver programs on July 1, 2023 to introduce the new program elements required by the Act.

Table 1. SDS vs. Traditional Services Populations, PCP Approved Budgets, and Expenditures by Date of Service[1]

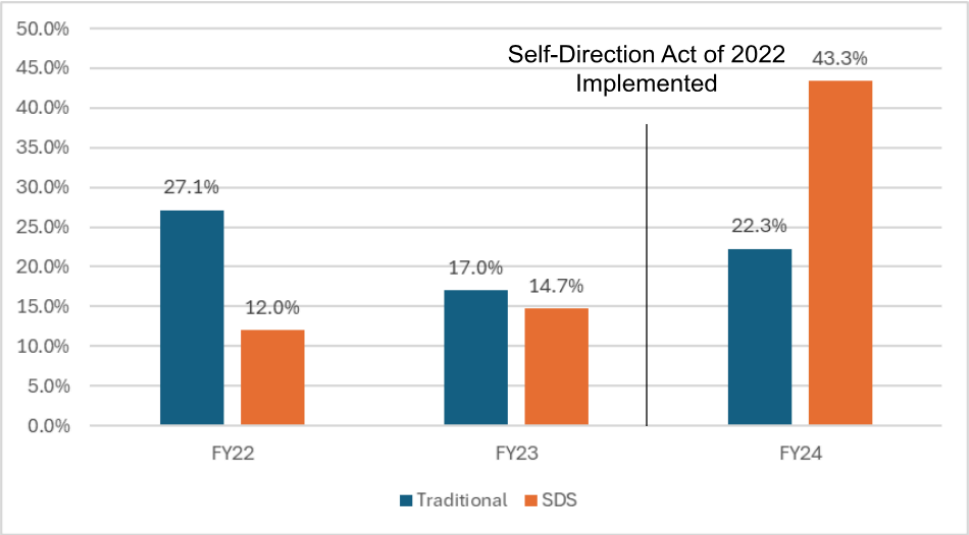
Fiscal Year	# of people	Total PCP Budgets	Avg. PCP Budget	Total Spending	Total Yearly Growth	Avg. Spending	Per-Capita Yearly Growth
Self-Directed							
FY 2021	1,618	$175,879,855	$108,702	$88,731,580	n/a	$54,840	n/a
FY 2022	2,042	$257,157,600	$125,934	$125,421,870	41.35%	$61,421	12.00%
FY 2023*	2,777	$488,351,971	$175,856	$195,686,024	56.02%	$70,467	14.73%
FY 2024*	3,632	$708,983,674	$195,205	$366,860,837	87.47%	$101,008	43.34%
Traditional							
FY 2021	16,259	$2,109,604,293	$129,750	$1,116,071,398	n/a	$68,643	n/a
FY 2022	16,754	$2,494,058,608	$148,863	$1,361,704,397	22.01%	$87,276	27.14%
FY 2023*	16,776	$3,160,103,057	$188,370	$1,713,290,194	25.82%	$102,127	17.02%
FY 2024*	16,827	$3,465,385,774	$205,942	$2,101,142,464	22.64%	$124,867	22.27%

* Additional claims and adjustments were received for FY 2023 dates of service since the March 18, 2024 report containing the prior version of this table. The effects of claims lag also apply to FY 2024, and FY 2024 claims values are expected to rise in the following months as a result of this lag.

Within the total figure of 43.34% per-capita cost growth in FY 2024, certain services accelerated far more quickly. For instance, IFDGS claims (excluding claims for the purpose of funding a Day-to-Day Administrator) increased from $977,990.13 in FY 2023 to $4,679,090.95 in FY 2024, an absolute increase of 378.44%, or 171.36% per-capita.

[1] Source: DDA Fiscal Unit and Office of Data Analytics Management, 20 August 2024. Spending data is current as of 31 July, 2024, and is derived from MMIS reports. Please note that claims data from MMIS is based on date of service, and therefore does not always align with expenditure data in the Maryland Financial Management Information System (FMIS).

Figure 1. Annual Per-Capita Spending Growth by Service Model



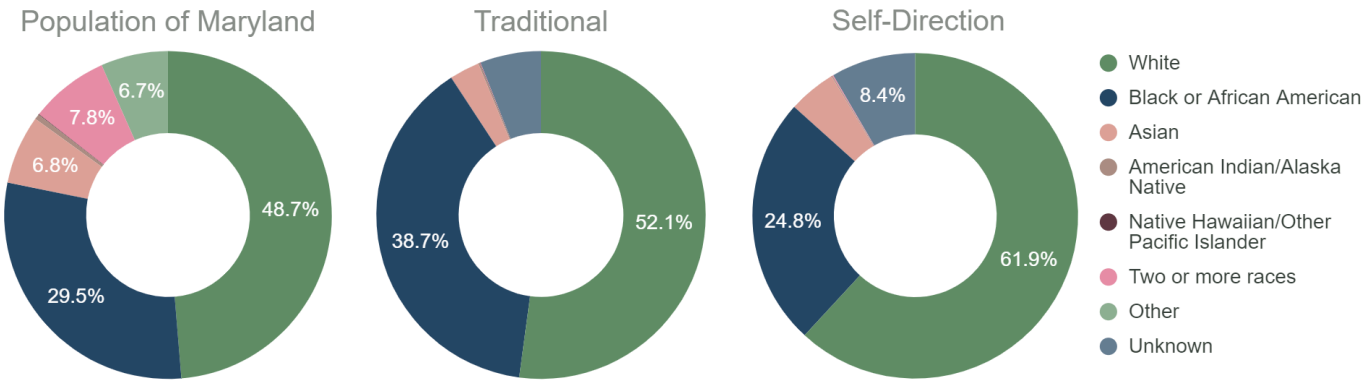
SDS model demographics are an additional source of concern. Maryland SDS participants are more likely to identify as White or Asian than Traditional service participants, and are substantially less likely to identify as Black. SDS participants are far more likely to identify as White than the average Maryland resident, and are less likely to identify as any other race (U.S. Census Bureau, 2020). In FY 2023, Black participants were one-third (32.74%) as likely to select the SDS model as participants of all other races, the sharpest difference between models among any racial identity. Racial disparities in self-direction may be attributable to lack of outreach to minority communities, as well as to the general association of self-direction with higher-income and higher-education families, which are also characteristics associated with White racial identity (Bradley, 2023). Data regarding Hispanic/Latino ethnicity is not well-captured in the Department's current dataset, with unknown ethnic identity for a majority of participants.

Table 2. Racial Identity by Service Model, FY 2023[2]

Race	DDA Population	Traditional Model	Self-Directed Model	Maryland - 2020 Census
White	53.13%	52.00%	61.62%	48.69%
Black or African American	36.95%	38.60%	24.67%	29.47%
Asian	3.16%	2.95%	4.71%	6.81%
American Indian/Alaska Native	0.15%	0.16%	0.10%	0.52%
Native Hawaiian/Other Pacific Islander	0.01%	0.01%	0%	0.05%
Two or more races	0.06%	0.05%	0.10%	7.80%
Other	n/a	n/a	n/a	6.65%
Unknown	6.27%	5.99%	8.38%	n/a

[2] DDA Data: DDA Office of Data Analytics Management, October 27, 2022. Census Data: U.S. Census Bureau, 2020.

Figure 2. Racial Identity by Service Model, FY 2023



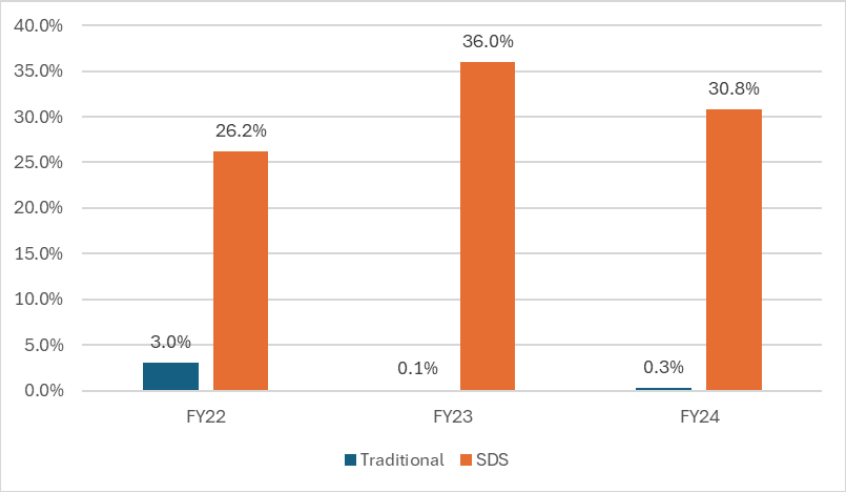
In recent years, the SDS model has thoroughly outpaced the Traditional model in terms of annual growth, with the Traditional model remaining nearly flat, while the SDS model has grown rapidly. One of the strongest reasons for this pattern, as discussed under "SDS Wages and Rates" below, is the economic attractiveness of the SDS model's substantially higher-than-market wages, which allow SDS participants to outcompete traditional provider organizations for a scarce population of direct care staff and nurses. When traditional provider organizations are unable to hire sufficient staff, they must refuse admittance to new participants desiring their services.

Table 3. Self-Directed Services Program Growth[3]

Month	SDS Participants	Traditional Participants	Proportion SDS	SDS Spending	Traditional Spending	Proportion SDS
June 2021	1,618	16,259	9.05%	$88,731,580	$1,116,071,398	7.36%
June 2022	2,042	16,754	10.86%	$125,421,870	$1,361,704,397	8.43%
June 2023	2,777	16,776	14.20%	$199,180,194	$1,663,585,752	10.69%
June 2024	3,632	16,827	17.75%	$366,860,837	$2,101,142,464	14.86%

[3] Source: DDA Fiscal Unit and Office of Data Analytics Management, 20 August 2024. Spending data is current as of 31 July 2024, and is derived from MMIS reports.

Figure 3. Annual Enrollment Growth by Service Model



SDS Wages and Rates

As described under "Maryland SDS Budgets" above, participants in SDS must follow an established Reasonable & Customary (R&C) standard when paying employees. Similar R&C standards also apply to vendors and providers. At present, Maryland's established R&C wages for the eight services which may be provided by employees are set at a level substantially higher than market norms for similar types of employment, as measured by relevant Bureau of Labor and Statistics (BLS) data for the state of Maryland, as measured by National Core Indicator surveys of the DSP workforce, and as measured by data collected by the Maryland Rate Review Advisory Group.

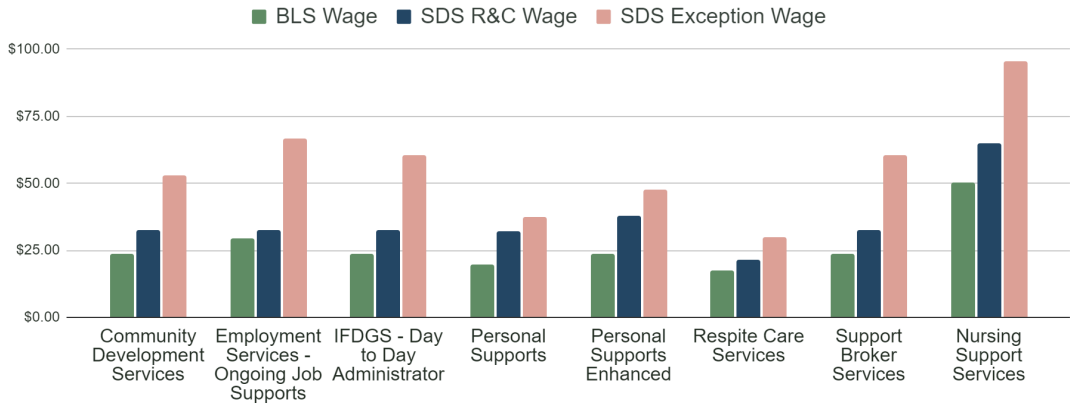
Additionally, by applying the Exception Wage Rate instead of the established R&C Wage, participants may further boost payments far beyond market expectations, in some cases more than doubling the expected market wage. In almost all cases, R&C wages available to employees under the SDS model are greater than the 90th percentile of wages for similar work in the state of Maryland (Bureau of Labor and Statistics, 2023).

Table 4. Comparison of SDS Wages and BLS Wages[4]

Waiver Service	BLS Code	Percentile - BLS Wage	R&C Wage	% Above BLS	Exception Wage	% Above BLS
Community Development Services -- Group, 1:1, 2:1 (per employee)	21-1093	75th - $23.69	$32.45	36.98%	$53.04	123.89%
Employment Services - Ongoing Job Supports	21-1012	50th - $29.67	$32.45	9.37%	$66.91	125.51%
IFDGS - Day to Day Administrator	21-1093	75th - $23.69	$32.45	36.98%	$60.46	155.21%
Personal Supports	21-1093	50th - $19.91	$32.18	61.63%	$37.53	88.50%
Personal Supports Enhanced 1:1 and 2:1 (per employee)	21-1093	75th - $23.69	$37.86	59.81%	$47.54	100.68%
Nursing Support Services	29-1141	75th - $50.32	$64.90	28.97%	$95.43	89.65%
Respite Care Services	31-1120	75th - $17.57	$21.63	23.11%	$29.79	69.55%
Support Broker Services	21-1093	75th - $23.69	$32.45	36.98%	$60.46	155.21%

By offering wages so significantly misaligned with the market, SDS employers have become far more attractive to direct support professionals and nursing staff than traditional provider organizations. By allowing State and federal funds to be spent on wages that are so widely divergent from those offered by traditional providers, the Department is directly contributing to market inefficiencies which are likely to worsen the direct support professional and nursing shortage. This misalignment of funding and policy goals additionally works against the Department's long-standing objective of building provider capacity and raising DSP wages among traditional providers.

Figure 4. Comparison of SDS Wages and BLS Wages



[4] SDS wage data: DDA Reasonable & Customary Rate Charts, July 1, 2024. BLS Data: BLS May 2023 Occupational Employment and Wage Data.

According to data collected in 2022 by the National Core Indicator State of the Workforce Survey, direct support professionals employed by traditional providers in Maryland earn an average hourly wage of $16.50. This is considered an accurate estimate, as Maryland reached a 90.7% response rate in the 2022 survey year, with a margin of error of 2.09% (National Core Indicators Intellectual and Developmental Disabilities, 2023). Recent data collected by the Maryland Rate Review Advisory Group align with the NCI survey, indicating an average wage of $16.22 among traditional provider DSPs, and a median wage of $15.79.

When compared with services in the SDS model offering more than double this amount, as well as more attractive benefits such as health insurance, retention incentives and bonuses, and more paid time off than typically offered by traditional providers, DSPs will naturally pursue employment in SDS. DSPs may additionally encourage service participants to transition their services to the SDS model in order to financially benefit from the model. These artificially-created economic pressures can counteract participant choice and complicate service delivery for providers and participants in the Traditional model.

Table 5. Maryland General Ledger Data - Traditional Provider DSP Wages[5]

Metric	DSP Base Wage	FTEs and Contractual/Temp Staff
Median	$15.79	$16.77
Mean	$16.22	$16.89
Max	$24.19	$24.46
10th Percentile	$12.91	$15.42
25th Percentile	$14.80	$16.03
75th Percentile	$17.76	$18.41
90th Percentile	$20.47	$19.74

It is additionally important to note that the inflated wages offered to employees under the SDS model are frequently offered to legally responsible family, relatives, or friends of the participant, who generally have minimal specialized training or qualification related to the provision of services. One of the greatest strengths of the self-direction approach is its ability to offer compensation to typically uncompensated caregivers, but this advantage disappears when the wage being offered is far higher than the market value of the services provided. Offering exorbitant wages is additionally a pathway for fraud, waste, abuse, exploitation, and loss of participant independence, as described below under “Fraud, Waste, Abuse, and Exploitation.” In FY 2024, $142,610,156 were paid directly to family members in gross wages, accounting for approximately 39% of total SDS model expenses during the fiscal year, and also accounting for a majority of wages for participant employees.

[5] Source: MDH-DDA Rate Review Advisory Group General Ledger Data Collection Tool

Table 6. FY 2024 Gross Wages Paid to Family Members[6]

Relationship	Total Paid FY 2024	% Total SDS Model Expenditures FY 2024
Parent	$121,313,667	33.07%
Grandparent	$2,469,218	0.67%
Sibling	$16,818,019	4.58%
Extended Family	$2,009,252	0.55%
Total	$142,610,156	38.87%

Fraud, Waste, Abuse, and Exploitation

Both self-directed and traditional intellectual/developmental disabilities services must be carefully monitored for fraud, waste, abuse, and exploitation, due to the vulnerability of the population being served, as well as the Department's obligation to meet federal Medicaid waiver assurances (i.e., Administrative Authority, Financial Accountability, Health and Welfare, Level of Care, Service Plan, and Qualified Providers). Many required elements of Medicaid HCBS, such as case management monitoring visits, or the verifications performed by fiscal intermediaries (FMCSs) in self-direction, are directly focused on prevention of mistreatment of participants and misuse of funds. National advocacy organizations have rejected the claim that self-directed services are uniquely susceptible to compliance failures, focusing on evidence related to the relative infrequency of fraud convictions in personal care services, as well as evidence from the Cash and Counseling demonstration program which found that participant-directed funds were rarely used fraudulently (Applied Self-Direction, 2021).

However, despite the strong national evidence for the benefits of self-direction, weaknesses in Maryland's SDS model create significant unresolved pathways for fraud, waste, abuse, and exploitation which the Department is actively working to address. These are briefly described below. Additional perspectives are also offered in Appendix A, which presents four case studies of both positive and negative experiences within the Maryland SDS model.

Participant Isolation

As described in Case Study 2, the least successful implementations of self-direction often involve participants losing independence and becoming isolated from their community. Loss of independence is typically associated with underperforming staff or fraudulent staff behavior, such as the community development staff in this case study who failed to help the participant engage with activities in his community. While the SDS model is focused on enhancing independence, if independent sources of support such as Support Brokers and CCSs allow the participant's needs and goals to be subsumed by the needs and goals of caregivers or employees, the self-direction model can be significantly isolating. Isolation is also a concern when multiple family members are employed as primary staff, as the participant's contact with non-family sources of support can be reduced.

[6] Source: Combined data from Maryland FMCS entities (The Arc of the Central Chesapeake Region, GT Independence, Public Partnerships LLC), various retrieval dates in August 2024.

Refused CCS Monitoring Visits

The DDA has received reports of self-directing participants, or their caregivers, refusing to participate in mandatory quarterly in-person monitoring visits with their CCS. Participants and families cite a variety of reasons for not wanting to comply with monitoring requirements, including health concerns related to COVID-19 (though SDS monitoring visit refusals were occurring prior to the pandemic). Aside from being a significant violation of federal requirements and of the participant's rights, monitoring visit refusals also stand in the way of practical checks and balances on the various persons who may wish to influence the participant's planning process and services. For participants who do not employ a Support Broker, the CCS is often the participant's most significant independent source of support and guidance, and less-than-quarterly CCS contact can be detrimental to participant health and welfare, as well as reducing the likelihood of participants meeting their identified goals.

In the overall context of SDS, there is substantially less monitoring than is typical for traditional providers. In traditional services, providers must be licensed or certified, which involves regular contact with authorities at the DDA and at the MDH Office of Health Care Quality (OHCQ). OHCQ completes periodic on-site surveys and administrative reviews of complaints and reportable incidents. In short, OHCQ ensures providers act in accordance with minimum health and safety requirements. Because most service providers within the SDS model are unlicensed caregivers, similar oversight is often not available. In the context of refused CCS monitoring visits, there are exceptionally few checks or balances on the activities of participant staff, and there is exceptionally low visibility into many pathways for fraud, waste, abuse, or exploitation.

Family Conflicts of Interest

In cases where family members provide paid services to the participant, and particularly in cases where multiple family members are providing services, there is often a distinct conflict of interest between these family members' economic interests (which would favor the most intense and frequent types of support) and the participant's independence (which should favor flexibility in the intensity/frequency of supports depending on the participant's needs and goals). This conflict of interest is not insurmountable–the vast majority of self-directing participants have highly positive experiences through paid family caregivers–but it is not always simple to resolve. Particularly in the context of Maryland's R&C wages, which allow for very high payments to family members, the DDA has received multiple case reports of entire families consisting of parents, siblings, and extended family members becoming economically dependent on a single participant. Such situations are significantly dangerous to the participant's welfare. Additionally, many family caregivers also qualify for the federal live-in caregiver difficulty of care tax exemption, leading to significantly higher take-home pay than would be available to staff who are not live-in caregivers (Internal Revenue Service, 2014).

In Maryland, Support Broker Services are mandatory for participants who employ family members as staff. In most cases, the presence of a Support Broker and CCS is sufficient to eliminate family conflicts of interest. However, in cases with unusually intense family involvement in the provision of services, or in cases where the Support Broker or CCS has limited access to the participant, conflicts can persist.

Support Broker Conflicts of Interest
Support Broker Services are partially intended as a mechanism to reduce conflicts of interest, by providing independent support for the resolution of human resources issues and other concerns that may arise when self-directing. However, Support Brokers also have significant economic interest in participant selection of the SDS model, and may also fill inappropriate roles which are intended to be filled by the CCS, FMCS, or Day-to-Day Administrator. Related to the former, the DDA has received reports of Support Brokers attempting to influence participants in the Traditional model to switch their services to the SDS model. The DDA has also received reports of Support Brokers attempting to influence participants' choice of CCS providers. This includes a Support Broker threatening to end their services if the participant did not change CCS providers. Additionally, the DDA has identified Support Brokers who improperly provide other services outside of the scope of Support Broker Services, leading to other conflicts of interest.

Support Broker Services in Maryland are affected by several provisions in the Self-Direction Act of 2022, particularly the Act's widening of the scope of the service to encompass "any services that are authorized by regulations adopted or guidance issued by the Centers for Medicare and Medicaid Services," a phrasing which largely prevents the Department from mandating deconfliction of service definitions for Support Broker Services and other waiver services.

Employee Conflicts of Interest
All employees of SDS participants are to some degree invested in the participant's choice of service delivery model, and this is largely unavoidable. However, in certain circumstances, employees' interests may substantially conflict with participants' interests. The DDA has received multiple reports of potential employees attempting to convince Traditional model participants to switch models. These reports have included both DSPs employed by traditional provider organizations, who may wish to increase their own pay by working for an SDS participant, and friends or family of participants, who may see the participant as a means to earn money. Conflicts like this can be resolved through strong, independent case management, but are not always easy to detect.

Day-to-Day Administrator Scope
The Day-to-Day Administrator position created by the Self-Direction Act of 2022 is broadly defined in Maryland statute, with a focus on "managing the recipient's home, staff, and other administrative duties." Services provided under Medicaid waiver programs are required to be non-duplicative of one another. Given the concurrent expansion of Support Broker Services under the same Act, tasks of staff management and administrative duties are difficult to distinguish from the role of a Support Broker, which includes "developing staff supervision and evaluation strategies" and "developing strategies for managing employees, supports and services," as well as other similar tasks. The combination of these dual provisions in Maryland law – that the scope of Support Broker Services may not be narrowed, and that a Day-to-Day Administrator must be allowed to complete certain management tasks – generates conflicts, as well as potential for duplicate billing of the same service. Beyond conflicts with Support Broker Services, the DDA has also observed duplicative activities between the Day-to-Day Administrator service and the Personal Support Services and Housing Support Services waiver services, generating further risk of improper duplicate billing.

Individual and Family Directed Goods and Services
The Self-Direction Act of 2022 notably reduced guardrails on IFDGS. By removing the Department's prior cap on IFDGS, the Act allowed most participants to access tens of thousands of dollars of unallocated funds for the first time. No DDA participant budget – in the SDS model or the Traditional model – is ever constructed with the expectation that all authorized funds will be spent within the plan year, as most services are capped to a certain number of hours per week. An unrestricted mechanism by which all unused funds can be funneled to direct purchases of a wide variety of services or items is ripe for significant abuse, with potential growth up to hundreds of millions of dollars of Medicaid expenditures typically paid for by personal or other resources. Additionally, allowing IFDGS to capture all unallocated funds creates an incentive for participants to avoid spending these funds on genuine assessed needs. Authorized funding is based on participants' individualized needs and goals, and attempts to reallocate funding to IFDGS by underutilizing other services can harm participant health and welfare.

Spending in IFDGS nearly quadrupled (378.43%) from FY 2023 to FY 2024, even without most participants approaching 100% budget utilization. The availability of large amounts of unallocated funds through IFDGS is additionally a significant source of inequity between the Traditional model and the SDS model.

Conclusion
MDH is presently focused on responding to constituent concerns, collecting data, and ensuring the proper functioning of the SDS service delivery system within the constraints of existing federal requirements and State law. However, it is clear that action must be taken to resolve inequities, protect participant welfare, and restore the proper function of the SDS model. When operating in accordance with its stated goals, the SDS approach can be a powerful engine for promoting human rights, enhancing independence, and building strong communities. When operating poorly, the SDS approach can easily do the opposite, opening pathways for abuse, restricting independence, and reducing community integration.

Maryland presently faces many challenges in SDS. It is important to ensure that all participants receive services which meet their needs and protect their interests, including by addressing financial conflicts of interest, ensuring appropriate monitoring, and addressing racial disparities. Additionally, MDH must ensure an equal choice of service delivery model between traditional and SDS for all participants, which is difficult to achieve when employees in the SDS model commonly receive more than double the market rate typically available to employees in the traditional model. Finally, in order to meet federal requirements, MDH has a responsibility to ensure that waiver services are delivered in a cost-neutral manner, which is difficult to achieve in an environment which has recently experienced significant cost growth, as well as presenting significant risk for variability in future budget utilization.

Through 2024 and 2025, MDH is focused on building out new initiatives to enhance training for all SDS stakeholders and participants, improving the function of FMCS services, reviewing rates, increasing outreach to minority communities, and preventing fraud, waste, abuse, and exploitation within the SDS model. These initiatives will be conducted with a consistent focus on independence, dignity, and equity for all Marylanders with intellectual and developmental disabilities.

Appendix: Case Studies of SDS Utilization and Support Broker Services

As described throughout this report, there are a wide variety of experiences, and a wide range of quality, experienced by Maryland program participants who choose to self-direct. For many individuals, self-direction achieves all of its promised qualities with few downsides, including enhanced independence and community integration. For others, self-direction is a mechanism by which independence and community integration are lost, and the needs and goals of others are prioritized above the needs and goals of the participant.

This appendix contains four case studies. All four studies are based on real individuals, with names and identifying details changed to protect privacy. The first two case studies focus on overall participant experiences in self-direction. The second two case studies focus on the role of Support Broker, particularly focused on this role's ability to either enhance or detract from participant success. These real-life examples are typical of many hundreds of cases seen daily by DDA Regional Office staff.

Case Study 1: Positive Experiences in Self-Direction

Olive has been a self-directed participant since 2019 and is enrolled in the Community Pathways Waiver. She uses her budget to receive personal supports, assistive technology, support broker services, and transportation in case of emergency due to using a wheelchair. She lives independently in Washington County, accessing the community while attending church and volunteering. She has a full-time job that she has maintained since 2010. Olive uses her assistive technology funding for a laptop to work on her own brand, as well as to access timesheets, invoices, and schedules that she uses to manage her self-directed services. Along with the services mentioned above, she also uses funding for Individual and Family Directed Goods and Services for a gym membership with personal training to remain healthy and create relationships within the community. She has a close relationship with her family and friends that act as natural supports when needed.

Case Study 2: Negative Experiences in Self-Direction

John has been a self-directed participant since 2021 and is enrolled in the Community Pathways Waiver. John's person-centered plan includes community development services, nursing, personal supports, respite, transportation, and support broker services. John has many interests such as wrestling, shopping at the mall, and going to the gym that he would like to participate in if given the opportunity. He is an animal lover and cares for several pets. However, John does not access the community unless it is for doctor appointments. His family does not have an accessible vehicle. He lives with his father who is also paid staff. He has shared with his CCS that his father has been abusive towards him. He is able to advocate for himself and communicates with his CCS the problems he has within his home, but he has limited natural supports in his life at this time. John has shared with his CCS and Support Broker that staff will clock in when they are not working, or will leave him unattended while clocked in, or will clock in for community development services but do not ever actually take him outside the home. His CCS and Support Broker along with DDA Regional Office staff have offered to support him in addressing these issues with his staff (one of whom is his father) but he has declined as he is fearful of retribution against him. Since he is not taking part in community integration although

he would very much like to do so, John's services do not meet the requirements of the Community Settings Rule.

Case Study 3: Positive Experiences with Support Broker Services

Mark has been a self-directed participant since 2022 and is enrolled in the Community Pathways Waiver. Mark's Support Broker helped to set up all of his staff in the Electronic Visit Verification system, assists with advertising and hiring staff, and helps to monitor Mark's budget. While monitoring his budget, the Support Broker helps Mark make sure that there will not be any budget deficits and communicates with Mark and Mark's FMCS when issues arise, such as staff not getting paid on time. Mark's Support Broker also assists him with communicating with the FMCS as issues arise related to human resource tasks. Mark's Support Broker completes quarterly meetings to check with how self direction is progressing and helps Mark to monitor his services with his CCS. Mark reports that his Support Broker has been very helpful with making sure staff are paid through the EVV system and that his Support Broker has always been very responsive with any questions and concerns.

Case Study 4: Negative Experiences with Support Broker Services

Jane is a Support Broker who supports several people. There have been numerous complaints regarding Jane's work over the past year. One has been her overstepping her role as a Support Broker. This complaint described an incident in which Jane took a participant's log-in and password for the FMCS portal, and used these for over a year to review and approve timesheets without the participant's permission or knowledge. Another complaint indicated that Jane has made threatening comments to a person receiving services, suggesting that the person needed to be institutionalized. Additionally, other complaints indicated that Jane has incorrectly advised multiple CCSs and participants regarding the wages and rates available for various services, and has encouraged incorrect submission of materials related to changes in employee pay.

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