

FAQs Self-Direction Act HB318 & SB441

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

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

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

2. What will the Self-Direction Act do?

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

3. Why does the Act specifically stipulate the family members can work as staff?

In 2016 DDA attempted to completely eliminate the ability of participants to hire family members as support staff. Only an SDAN petition drive to Governor Hogan stopped that proposal. Since then DDA has continued to place limits on this ability. CMS permits family members and legally responsible adults to work as staff. SDAN asserts that the decision to hire family members should be made by the participant with support from their team.

4. Why does the Act mandate that anyone eligible for DDA funding can self-direct?

In its 2018 and 2019 Request for Proposals (RFP) for a fiscal management service (FMS) Maryland Department of Health (MDH) included an unusual duty for the FMS provider: the obligation to determine whether an applicant for self-direction was "competent" to self-direct. DDA administrators have also publicly suggested that not everyone is capable of self-directing. SDAN "presumes competence" and believes that with the right supports, anyone can self-direct.

5. Why does the Act stipulate that fiscal management services be provided under the waiver?

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

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

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

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

7. Why does the term Designated Representative appear in the Act?

SDAN has opposed the concept of the Designated Representative (DR) since DDA introduced it three years ago. SDAN affirms that the DR detracts from the autonomy of the participant and the ability of the participant team to assist the person realize their goals and desires. When people do need assistance, SDAN believes that the team approach, using supported decision making, is best. However HB318/SB441 does allow participants to choose the SB as a designated representative (DR) in order to spare family members from being disqualified as staff members in case the Department forced the choice of a DR. Nevertheless, the DR role presents issues for both participants and for anyone who assumes it. It is possible that this aspect of the bill will be amended to eliminate any reference to the DR. The DR issue would then be left the Advisory Council.

8. Why does the Act specifically refer to the Cost of Living Adjustment (COLA)?

More than halfway through FY21, the majority of SDAN members report that they have had difficulty accessing the COLA—despite DDA assurances that it has been allotted. The Act will ensure that participants receive the COLA in the future.

9. What is the role of the Advisory Council created by the Act?

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

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

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

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

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

11. Who supports the Self-Direction Act?

The Act is supported by the following organizations:

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