



**Final Report of the Workgroup to
Review and Recommend Policies for the
Maryland Self-Direction Program**

Annapolis, Maryland
March, 2022

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**Maryland General Assembly
Office of Delegate Karen Lewis Young
Annapolis, Maryland**

March 7, 2022

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March 7, 2022

The Honorable Shane Pendergrass, Chair
Health and Government Operations Committee
Room 241
House Office Building
Annapolis, MD 21401

Chair Pendergrass:

Enclose is the report of the Workgroup to Review and Recommend Policies for the Maryland Self-Direction Program.

The workgroup spent the interim thoroughly evaluating the complex system of programs and waivers contained within the self-direction program. During our seven public committee meetings and six public subcommittee meetings, we heard testimony from dozens of expert witnesses, advocacy organizations, participants in self-direction, caregivers, and representatives from The Maryland Department of Health (MDH) and Developmental Disabilities Administration (DDA).

In addition to our workgroup, I organized two subcommittees. One subcommittee reviewed the application of Center for Medicare and Medicaid Services (CMS) waiver services to ensure that Maryland was accessing all the funds available for self-direction participants. The second subcommittee provided participant analysis and suggestions to strengthen the self-direction program. Each workgroup meeting studied written materials, presented best national practices, and provided equal opportunity to present and debate various aspects of the self-direction program.

As a result, the workgroup has put forward nine recommendations set forth on pages 3 through 5 of this report. I am proud of this work product and believe that these recommendations are sound, necessary, and consistent with the original intent of self-direction. In response, I have filed HB 1020 – The Self-Direction Act of 2022, which incorporates each of these recommendations.

It has been a privilege and pleasure to serve as chair of the workgroup, and I thank you for giving me this opportunity to guide the work of this important body. I look forward to a productive legislative session incorporating much of this work to strengthen our self-direction program.

Sincerely,

A handwritten signature in blue ink that reads "Karen Lewis Young".

Karen Lewis Young

**Workgroup to Review and Recommend
Policies for the Maryland Self-Direction Program
2021 Interim
Membership Roster**

Delegate Karen Lewis Young, Chair

Senate Members

Susan Lee

Delegate Members

Heather Bagnall

Lisa Belcastro

Harry Bhandari

Nicholaus Kipke

Kirill Reznik

Geraldine Valentino-Smith

Public Members

Ken Capone

Laura Howell

Ande Kolp

Rachel London

Serena Lowe

Megan Rusciano

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Esther Ward

Alicia Wopat

Maryland Department of Health Members

The Honorable Bernard Simons

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Workgroup to Review and Recommend Policies for the Maryland Self-Direction Program

Introduction

In 2005, the Maryland General Assembly passed House Bill 988, which included the creation of self-direction for participants with developmental disabilities (titled in 2005 as New Directions). The bill's passage was considered a national model for providing a participant-centered approach to healthcare that ensured the individual's treatment plan values and interests were respected and they are able to avoid institutionalization.

Over the last few years, advocacy organizations and participants have reported changes to the services available to people practicing self-direction. After submitting a formal request, House Health and Government Operations member Karen Lewis Young was notified on April 1, 2021, of authorization to form an interim workgroup. The Workgroup would comprehensively review the existing policies for the self-direction program and make recommendations to restore and strengthen the program for its participants. Delegate Lewis Young was appointed to chair the Workgroup.

The Workgroup was charged with:

- Reviewing and understanding the self-direction model for participant-led healthcare.
- Determining if program accessibility and flexibility have decreased.
- Identifying and collating the needs and gaps for individuals practicing self-direction.
- Investigating financial concerns by reviewing existing CMS waivers for participants

Meetings

The Workgroup met from June through December during the 2021 interim. Thirteen public meetings were held where experts and participants presented data on various policies, procedures, and regulations impacting the self-direction program. The Maryland Department of Health discussed existing processes and answered committee members' questions. In addition, dozens of citizens provided testimony. Every meeting included the opportunity for public comment. Every workgroup member actively participated in a thoughtful and robust discourse throughout each session, resulting in comprehensive recommendations.

Recordings of the following meetings were published through youtube:

- August 25, 2021: <https://youtu.be/3Q2biAsSic0>
- September 28, 2021: <https://youtu.be/zfPhnCoyXgo>
- October 27, 2021: <https://youtu.be/dqS3l3Au6rk>
- December 29, 2021: https://youtu.be/Q_jGt_priT4

June 30, 2021 Meeting

At its first meeting, Health and Government Operations Vice-Chair Joseline Pena-Melnyk and Workgroup Chair Karen Lewis Young welcomed everyone. The committee's composition was outlined, and the initial review of our Workgroup's mission. A video developed by the Self-Direction Advocacy Network of Maryland, Inc. (SDAN) was shared to understand the benefits of the self-direction program.

As the final agenda item, the Maryland Department of Health was finalizing a Request for Proposal (RFP) application for Fiscal Management Services (FMS) for self-direction. The committee and MDH discussed the various components of the RFP for potential updates.

July 28, 2021 Meeting

The Workgroup hosted an expert from the Administration for Community Living (ACL) to discuss the federal framework for self-direction. Specifically, they discussed available federal waiver options available to participants of self-direction. Next, a long-term support broker in Maryland presented a history of self-direction from its introduction in 2005 to today. MDH also briefly updated the committee on the status of the FMS RFP.

August 25, 2021 Meeting

Chair Lewis Young announced the formation of two new subcommittees. One subcommittee will review the existing CMS waivers and identify potential waivers that Maryland does not currently utilize. The second subcommittee will be a participant-led committee to help identify and provide solutions to gaps in the self-direction program.

Next, a panel of self-direction experts presented challenges and options with various components of self-direction. These components included challenges with competency testing, designated representative requirements, allowances for house managers and administrators, access to overnight supports, the process by which participants may hire family members to provide supports, and allowances for the administration of medications.

September 28, 2021 Meeting

The Participant's subcommittee reported to the general Workgroup on the meeting minutes of their first meeting. The committee outlined challenges they identified, including shortages of direct support professionals and support brokers, the desire to remove or minimize the role of designated representatives, a need to re-evaluate the transportation fee schedule, and the need to recruit and retain new people to the field.

Additionally, the CMS subcommittee reported their first meeting, including the CMS response letter to an inquiry filed by Representative David Trone. The committee reviewed the CMS waivers for overnight supports, support brokers, and habilitative supports.

October 27, 2021 Meeting

The fifth meeting focused on the experiences of various people working within the self-direction program. The panel consisted of a support broker, a former Maryland Coordinator of Community Services (CCS), a family member caretaking for a person in self-direction, and a self-direction participant. MDH provided data on the growth of self-direction. CMS subcommittee provided an overview policy matrix of various policies, federal guidance, and recommended reforms.

November 24, 2021 Meeting

At the November meeting, the committee began framing out a list of recommendations for the Workgroup to consider. Utilizing the feedback from the CMS and Participants subcommittees, the Workgroup built a list of requested changes to current policy and discussed what policies needed to be addressed on an administrative level versus a legislative level.

December 29, 2021 Meeting

SDAN provided guidance on a few additions to the Workgroup's recommendations at the final meeting. The Workgroup reviewed and discussed the definitive list of recommendations and built a final matrix outlining the suggested changes to various programs available to self-direction participants. Chair Lewis Young also reported meeting with MDH representatives regarding the committee recommendations. She said that MDH has agreed to one recommendation and would change that policy internally. Finally, Chair Lewis Young informed the committee that she had forwarded the recommendations to Legislative Services (MLIS) to draft them into a bill for the 2022 session.

Recommendations

The Workgroup issued nine recommendations to provide greater access and flexibility to self-direction participants. These recommendations have been incorporated into House Bill 1020 and are set forth below.

Recommendation 1 – Overnight Supports and Personal Supports

- Reinstatement full employer authority for all personal supports to self-directed participants.
 - Include those with an established need for overnight supports.
 - Include those living independently or in their family homes.
- Amend the current Community Pathways Waiver to allow the State to receive Medicaid federal matching funds.
- Remove the 82-hour limit on personal supports under the current CPW waiver.
 - Personal supports would be determined *based on individual needs*.

Recommendation 2 – Support Brokers

- Increase Support Broker hours from ‘up to four hours per month’ to ‘up to forty hours per month.’
- Restore support brokers’ responsibilities to match the federal CMS position description.
- Enact a policy that requires a third-party support broker to be hired if the individual hires a family member or guardian as paid staff.

Recommendation 3 – Coordinator of Community Services

- Invest in increased training for the Coordinator of Community Services.
 - Training includes proper policies, resources, and roles.
 - How to work with transitioning youth, individuals without strong family supports, and historically disadvantaged communities.
 - Budget allocations whenever self-direction is changed through legislation to ensure proper education training about the changes.

Recommendation 4 – Transportation

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

Recommendation 5 – Individual and Family Directed Goods and Services

- Create more flexibility with Individual and Family Directed Goods and Services
- Remove the five-thousand-dollar cap on IFDGS
 - IFDGS would be determined *based on individual needs*.
- Allow participants to self-identify their IFDGS without constraints
 - Ensure the participant stays within their budget
 - Ensure their budget matches the provider-based model

Recommendation 6 – Competency Testing

- Eliminate competency assessment in any form from all DDA policies and proposals.

Recommendation 7 – Budget Transparency

- Allow participants to access the Long-Term Services and Supports Computer System (LTSS)
 - Ensure plans and budgets are easily accessible.
 - Ensure the funding is consistently updated for tracking.

Recommendation 8 – Provider Managed and Self-Direction Parity

- Codify in regulation the parity in budgets and compensation for individuals participating in the self-direction program, so they align with the budgets and compensation for individuals utilizing a provider-managed program.

Recommendation 9 – Annual Report

- The Developmental Disability Administration (DDA) will provide an annual update to the Maryland General Assembly for three years outlining its implementation and relevant outcomes of the Workgroup's recommendations.

Conclusion

The Workgroup extends its appreciation and gratitude to the Maryland citizens who participated at each Workgroup meeting. Your input and involvement are invaluable to identifying the self-direction program's strengths and the opportunities to increase participants' positive outcomes. The Workgroup would also like to thank the Health and Government Operations staff, Maryland Department of Health, and the following individuals who assisted by providing testimony or serving on the Participant's subcommittee:

- JP Shade
- Carmen Hudlud
- Mat Rice
- Thomas
- Rob Stone
- Jeneva Stone
- Sunny Cefarratti
- Carol Custer
- Susan Goodman
- Barbara Reff
- Alarice Vidale de Palacios
- Irene Souada
- Karina Jones
- Karen Blanchard
- Patricia Eisenberg
- Marla Hollander
- Beth Monroe
- Gail Goodwin
- Kate
- Paulette
- Lisa Lorraine

The Workgroup members look forward to working on the legislation incorporating its recommendations and seeing that legislation through to passage and enactment.