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Maine Developmental Disabilities Council

Program Recommendations for a Maine Self-Directed Option

PREPARED BY THE MAINE DEVELOPMENTAL DISABILITIES
COUNCIL AND APPLIED SELF-DIRECTION

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Introduction

For the past ten months, the Maine Developmental Disabilities Council has facilitated a series of stakeholder meetings to develop recommendations for a Maine self-directed option for adults with developmental disabilities. The group included self-advocates, family members, leaders of related organizations on disability issues, representatives from the state of Maine, and consultants from Applied Self-Direction, a national technical assistance and training organization for self-directed services.

This report includes a summary of the group's key recommendations that have resulted from months of discussion and deliberation. These recommendations are intended to inform DHHS program and policy decisionmakers as waiver and Medicaid rules are drafted.

Overall Recommendations

Stakeholders strongly agreed that self-direction

- should not be a cost cutting strategy
- should be available for any type of waiver service (employment supports, community supports, in home supports, etc.)
- should not be uniquely subject to assessments or service limitations
- should not be the only reasonable or meaningful service alternative
- should be available and accessible to all individuals who want to use it

Participant Choice and Control

Recommendation: *Both employer authority and budget authority should be included as part of Maine's self-directed option for individuals with developmental disabilities.*

The group agreed that employer authority—i.e., the ability to select, train, and manage staff—should be offered as part of Maine's self-directed option. The group also concurred that budget authority, or the ability of participants to manage an individual budget in dollars, select the rate of pay for their support staff, and purchase individual-directed goods and services with budget dollars, is also necessary.

As part of budget authority, the group cautioned that the state should permit employee wage ranges that are large enough to be meaningful. For example, having the ability to pay from \$11.00 to \$12.00 per hour is unlikely to offer participants adequate flexibility to be able to recruit and retain high-quality staff. Participants should have flexibility and choice to balance paying competitive wages and ensure they receive sufficient hours of care from their individual budget.

The group also recommended that no matter what budget development methodology the state selects, it should be equitable and transparent to stakeholders. No matter what budget methodology used, unused budget dollars should be permitted to roll over from period to period. For example, if budgets are assigned on a monthly basis, unused dollars from February should be permitted to roll over into March.

Individual-Directed Goods and Services

Recommendation: *Participants should be able to purchase goods and non-employee services with their individual budget. These goods and services must be reasonably related to helping the participant manage their disability or enhancing the participant's community integration.*

Having the ability to purchase goods and non-employee services can help participants mitigate care needs and enjoy greater access to their community. ("Non-employee services" refers to intermittent services performed by an independent contractor or vendor, such as snow removal or installation of an environmental modification.)

The group also largely agreed it is preferable that this service category be open-ended to allow maximum choice, flexibility, and creativity. In other words, there should not be a limited list of "allowable" purchases from which participants can select. Instead, while the state may include a list of "non-allowable" purchases, any purchase that is *not* on the "non-allowable" list could be approved provided there is a documented justification for why this purchase will enhance the participant's safety, independence, and/or community integration. Common individual-directed goods and services purchases in states that offer this service category include computers and tablets, public transportation passes/tickets, and gym memberships. Participants should be able to easily understand what types of purchases are (not) allowed and obtaining approval to utilize self-direction benefits for goods or services should not be time consuming or burdensome.

Information and Assistance

Recommendation: *Information and assistance in support of self-direction should be offered as a separate, standalone service and should not be included as part of the case manager role.*

There was strong consensus within the group that supporting and educating individuals who self-direct requires a specialized skillset that is distinct from that of the case manager. The group preferred that support brokerage be made available as a standalone service to support people managing responsibilities unique to self-direction. Key support broker responsibilities typically include coaching participants and families on recruiting and hiring staff, managing a budget, and being an effective employer, as well as assisting with the development of service plans that best position participants to achieve their long-term goals.

Across the country, support brokerage is currently offered in different ways, including by independent brokers, specialized agencies, and by Financial Management Services entities. No matter what structure used, however, the group agreed it is essential that support brokers receive rigorous training on both policy and practice of self-direction. In other words, they should be experts not only on the philosophy of self-direction, but also have a deep knowledge of program rules. They should be available to the participant as a trusted resource and advocate. Last, the group agreed that support brokers' responsibilities should not be subsumed by case managers.

The group also discussed whether support brokerage should be a required service or be optional. While strong consensus did not emerge, support brokerage could potentially be included during the first twelve months after a participant's enrollment in self-direction to ensure participants and families are adequately supported during the transition and are not left to "figure it out" on their own.

However, this report recognizes that different participants will experience different levels of ongoing need for support brokerage. After the initial enrollment period, individuals should have the required flexibility to purchase additional amounts of support brokerage depending on their needs and preferences. Some participants who seek greater support may purchase larger amounts of this service, while other participants may use a support broker relatively rarely.

Financial Management Services

Recommendation: *For maximum choice, Maine should offer both models of Financial Management Services (FMS) models authorized by the Center for Medicare and Medicaid Services: a Fiscal/Employer Agent (participant as sole employer) model and an Agency with Choice (participant as co-employer) model.*

Given that initial program enrollment may be limited, having both models may not be feasible. In this case, the Fiscal/Employer Agent option should be selected.

There was consensus among the group that having more choice is always preferable. Some group members indicated they would be more comfortable in a co-employer role with an Agency with Choice, while others indicated that the increased overhead of the Agency with Choice model would result in a lower effective wage for support staff. This could potentially inhibit participants' ability to recruit and retain high-quality caregivers.

The group emphasized that the ability to pay a reasonably competitive wage was essential for recruiting and retaining high-quality staff. Because the Fiscal/Employer Agent model includes the lowest administrative overhead cost, the group decided that this model could potentially offer

participants greater choice in caregivers as participants would presumably be able to offer more competitive wages.

The group also indicated that should this model be used, ample training must be provided to participants and families to educate them on their roles and responsibilities as employers. This training could be provided by the support broker or a combination of FMS and support broker.

Finally, the group noted that having multiple FMS entities from which participants can select is preferable to having a single vendor statewide.

Next Steps

Important program design and implementation questions still remain open.

At the time of writing this document, the Maine Developmental Disabilities Council, Applied Self Direction, and the Maine DHHS' Office of Aging and Disability Services are developing a collaboration that is intended to provide OADS with access to technical assistance with expertise in Medicaid self-direction policy to expedite the availability of a working program that represents stakeholder values.

The stakeholder group will develop a set of implementation recommendations for a Maine self-directed option that would address but not be limited to the following issues:

1. What types of education and outreach are needed for waiver participants and their families find out about self-direction? (E.g., for example, who would notify them about the self-directed option? How much information or background would the notifying party be able to share about self-direction? Where could families go to learn more?)
2. What kind of support will individuals and families need to effectively use self-direction?
3. How will support brokerage be structured: how will brokers be trained and considered qualified? How can support brokerage be protected from attrition, such as by being subsumed by in the case management role, or by being defunded. How will participants be able to find support brokers?
4. How will the quality of self-directed services be assessed?

MDDC appreciates the time, interest and energy of the people who have participated in the stakeholder meetings and the opportunity to provide this input to the Department.