



INNOVATION WORK GROUP RECOMMENDATIONS

Disability Services Reform

Department of Health and Human Services
Office of Aging and Disability Services
January 2022

Introduction

During 2019, the Office of Aging and Disability Services (OADS) participated in numerous stakeholder group meetings. OADS used the feedback from those meetings and developed a reform plan with the goal of addressing high priority topics. To accomplish our goals, OADS established four primary work groups: Communication, Community Membership, Innovation, and Quality Assurance and Quality Improvement. These work groups are made up of a cross representation of individuals who are invested in improving developmental disability services in Maine including representatives from agency providers, family members, advocates, and state agency staff from the Developmental Disability Services unit at OADS. The recommendations in this report are a culmination of work that has been undertaken this past year, from the Innovation Work Group, a part of the DS Reform Initiative. These recommendations embody and support OADS as we seek to truly embrace our mission to improve and “promote the highest level of independence, health, and safety for older adults and adults with disabilities throughout Maine” and our vision to “promote individual dignity through respect, choice and support for all adults.” OADS would like to thank the following participants in this Innovation Work Group for their enthusiasm and dedication to participating in this work group and contribution to the development of meaningful recommendations for OADS to consider.

Innovation Work Group Members

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Housing Work Group

Recommendations to Meet Maine's Urgent Need for Housing for People Who Use Home and Community Based Services (HCBS)

1. Increase Home and Community Based Services (HCBS)-compliant supportive housing options across Maine for people who use HCBS.

- Establish a temporary position using 9817 ARPA funds initially with the goal of implementing a permanent HCBS Housing Specialist position within the Office of Aging and Disability Services (OADS), tasked with developing a collaborative partnership between OADS and the Maine State Housing Authority to work toward systemic housing innovations statewide for people who use HCBS, such as:
 - Requiring a portion of affordable housing apartment developments to welcome people who use HCBS within larger multifamily developments, including people needing permanent supportive housing.
 - Incorporating point incentives in the Qualified Allocation Plan for Low Income Housing Tax Credits to include permanent supportive housing for people who use HCBS.
 - Requiring incorporating universal design in new/renovated Maine State Housing projects to increase accessible housing stock and facilitate aging in place.
 - Communicating directly with affordable housing developers and consulting and financing organizations to demonstrate OADS' commitment to partner in expanding supportive housing options for people who use HCBS.
 - Exploring housing development and financing opportunities through USDA Rural Development housing assistance programs.

2. Provide information resources regarding essential elements of housing and community life for people using HCBS in Maine.

- Establish a permanent Housing Resource Information Specialist position within OADS, tasked with developing, updating, and maintaining a digital resource center for people who use HCBS, family members, interested community members, service providers, and housing developers.
- This digital resource center would provide information regarding essential elements of housing and community life for people who use HCBS, including:
 - Locating, developing, and choosing HCBS-compliant housing options. A digital Housing Choices Toolkit would offer "how to" materials on such topics as:
 - Housing 101: Terminology, funding options, affordability programs, rental vs. home ownership (with information sufficiently detailed to meet all interested audiences' needs)
 - Streamlined home ownership procedures
 - Finding a home
 - Finding a housemate
 - Connecting housemates to a relationship coach (to assist housemates and their staff)

- making meaningful connections in and contributions to community life.
- A digital Creating Supportive Communities Toolkit would offer examples and strategies to use within inclusive apartment developments and other residential communities to build helping, social, vocational, and lifelong learning relationships.
- Networking and interconnecting with the Maine Coalition for Housing and Quality Services (and other groups as applicable) for broad information sharing.
- Exploring new models/enhancements/alternatives to the current “vendor call” system to share current housing availability information. One such enhancement might be to develop a listing of available housing options that people using HCBS and their families could access. For example:
 - If someone wanted to become a shared living provider, they could post some general information about themselves for families who might be considering shared living; or if someone who uses HCBS is looking for a housemate, they could post information about the housemate opportunity, so others could contact them.

3. Provide people using HCBS in Maine with the opportunity to direct how to spend MaineCare waiver funding, to enable more housing opportunities and expand staffing choices and possibilities.

- Establish and implement a robust self-directed services option for people who use HCBS who have Medicaid/MaineCare waiver funding. Essential components of this self-directed services option would be:
 - Full budget authority
 - Full employer authority
 - State-provided supports to assist participants per Federal guidelines:
- Information about how a self-directed care program works; and
- Resources, counseling, training, and assistance—such as use of supports brokers and financial management services.

Innovation Needed for People Using HCBS Who Seek Their Own Homes: Self-Directed Services Option



Self-Directed Support: Definition

“An individual who needs long-term services and supports (LTSS) is given a budget to spend on their LTSS based on assessment of their support needs. They are responsible for recruiting, hiring, training, scheduling, and firing support staff.”

From A Place in the World: Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities, Denise D. Resnik & Desiree Kameka Galloway, Eds. (2020)

Self-Directed Services Option: Essential Component #1 = Full Budget Authority

Full Budget Authority means giving participants the ability to manage an individual budget in dollars to:

- Select the rate of pay for their support staff,
- Purchase home and community-based support services and respite services, and
- Purchase individual-directed goods and services with budget dollars, including the ability to hire someone to help with the paperwork/computer forms.

(Note: MaineCare covers some goods and services—e.g., assistive technology, mental health services.)

Self-Directed Services Option: Essential Component #2 = Full Employer Authority

Full Employer Authority means giving participants the ability to:

- Direct the implementation of an individual’s person-centered plan via staffing and staff supervision.
- Recruit, hire, train, schedule, terminate, and direct home and community-based support staff and respite staff.

Self-Directed Services Option: Essential Component #3 = State-Provided Supports to Assist Participants

Federal Medicaid [guidance](#) requires states to provide or arrange for “a system of supports ... in developing the person-centered service plan and budget plan, managing the individual’s services and workers, and performing the responsibilities of an employer.”

Examples of such supports (taken from Federal guidance):

- Information regarding how a self-directed care program works;
- Available resources, counseling, training and assistance, such as use of:
 - Supports Brokers, and
 - Financial Management Service.

Key Supports 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.

Additionally, because supports brokers are often steeped in knowledge of a geographic area's community offerings, they can serve as community developers for the participants in locating and identifying such connections as garden clubs, humane societies, nature-based volunteer opportunities, cooking classes, knitting circles, karaoke gatherings, and music- and sports-related activities.

How can self-directed services enable more housing options?

People who use HCBS:

- Can receive supports paid for with their waiver funding even if no agencies provide support services in their communities.
- Are not vulnerable to provider agency's operational continuity (or decisions) in order to receive support in their homes.

How can self-directed services expand staffing choices and possibilities?

People using HCBS can use their waiver funding to:

- Spend on a menu of services (rather than being restricted to support offered in programs). Examples: direct support & personal care, goods & services (stove auto-shut off, YMCA membership), transportation, paid neighbor.
- Address crisis staffing shortages and limited local provider options with creative incentives (e.g., higher pay, flexible scheduling, gas & mileage).
- Avoid support program "silos" and thus (for instance):
 - Receive various supports at home, in the community, and/or at work from one trained direct support staff who knows and works well with that person.
 - Enable direct support staff to also act as personal care assistant as needed.
- Pay for person-specific staff and family training, including modules on mental health (e.g., strategies to support a person with anxiety, motivation support for a person experiencing depression, etc.).
- Cut across MaineCare "silos" to access psychiatric, psychological, communication, and behavioral support services for the person using HCBS and their family, support providers, and staff supervisors/trainers.
- Locate and connect with regional centers for those who have chosen to self-direct their HCBS, as connections may spark the creation of community classes at YMCAs/YWCAs, yoga studios, music and dance schools, and nature walks (such as "slow yoga or karate," sensory-aware dance classes, etc.) that may attract people across ages and communities.

For more about self-directed services option recommendations, see the Maine Developmental Disabilities Council's [report](#).

4. Once available, OADS should explore the proposed new Federal Housing Resource Center which is under development.

Prevention and De-escalation of Crisis Work Group

1. OADS should complete a Systems Analysis of its crisis services and supports programs.
 - This Systems Analysis should include stakeholder input and recommendations for how OADS could put alternative positive behavioral supports in place that would allow the state to eventually eliminate the use of physical restraints and behavior management plans for adults with Intellectual and Developmental Disabilities (IDD) or Autism Spectrum Disorder.
2. Implement Maine's membership with the START program model, particularly to provide training community-wide, including the general public, families, people receiving services, and those providing services and law enforcement.
 - Utilize the START program model to review complex cases.
3. Provide Training for Direct Support Professionals (DSPs) that is rooted in the biopsychosocial model and Trauma Informed Care, such as the Mental Health, Intellectual & Developmental Disabilities (MHIDD) training offered through the START program.
 - Utilize START program resources. Reinforce training and offer ongoing support and information through the use of communication programs such as [Quillo](#).
4. Support Service Providers to develop self-care training for DSPs, to aid in coping with experienced trauma, decreasing burn-out, and preserving positive regard and relationships with the people they support.
 - Share Quillo with Service Provider agencies. Utilize the messaging function available through Quillo to support the objectives of this recommendation.
5. Support Service Providers, people receiving developmental disabilities services, and their families by creating Support Service Liaison positions in each of the eight OADS districts, to assist in accessing training and support resources.
 - Create new Support Service Liaison positions or assign to existing positions within OADS.
6. Increase availability and access to clinicians that practice within a biopsychosocial model to offer emergency, ongoing, and long-term mental health supports. Clinical supports must be easily accessible to all people with IDD/Autism, not only those with waiver services. A person in mental health crisis should not have to wait for clinical services to be authorized.
 - Increase the numbers of clinicians by having dedicated funding. Explore ways that OADS can attract Mental Health clinicians by nurturing closer partnerships with Mental Health providers across the state. Find ways to make it easier for clinicians to contract with and provide services for people receiving services from OADS.
 - An ongoing commitment to making quality, easily accessible clinical services to all people with IDD/Autism across the state.

7. Increase availability and ease of access to clinicians specializing in Physical Therapy, Occupational Therapy, Speech and Specialized communication. These supports must be easily accessible to all people with IDD/Autism, not only those with waiver services. Inability to communicate effectively, and sensory issues that interfere with how a person experiences their world, result in fear and frustration that often lead to Crisis situations. Provision of these supports must include ongoing intervention and follow-up to ensure that each person, their family, and support staff can be continually trained in communication techniques, programming and use of various communication devices, sensory needs, and interventions.

8. Increase the number of available clinicians in these areas of expertise by having dedicated funding. Within provider agencies, utilize “Train the Trainer” programs. Knowledge of needed supports isn’t lost as staff leave. If “Behavior Management plans” continue to be a part of our service system, such plans should be considered “Therapeutic Support Plans.” Words have power and influence our approach to providing support to people with IDD/Autism.
 - Include this change in the revision of Maine’s behavior regulations. Change the perspective of “managing a person’s behaviors” to one of providing “therapeutic, positive, trauma-informed human interactions” that prevent people going into crisis by using Quillo.
 - Commit to developing a cultural shift throughout OADS and across Maine’s communities that promotes providing trauma-informed, positive supports to people with IDD/Autism.

A Trauma Informed Organizational Structure

Building a culture of recovery in the work we do with people with IDD requires an enhanced focus on individual strength and resilience, empowering people we serve, maximizing their self-determination, enhancing their autonomy, and fostering their healing through community integration (Jacobson & Greenley 2001).

(Trauma-informed toolkit for providers in IDD services, Center for Disability Services, 2017)

9. Require Therapeutic Support Plans to include a person's trauma history, including the following:
 - List of known triggers and how to prepare for or address them,
 - List of known difficult anniversaries and how to prepare for or address them,
 - List of people whom the person is connected to positively and how they can help, and
 - List of factors required for this individual to feel/be safe.
10. A commitment within OADS to promote services based on Systems of Trauma Informed Care and the Biopsychosocial model of care.

Technology Work Group

1. Increase the system's capacity for providing people using HCBS both timely assistive technology assessments and follow-up support. (This might be done by creating incentives for agency personnel to obtain an assistive technology assessment credential.)
2. Create a website that can be accessed by providers, family members and people using HCBS with resources and links to resources related to the following topics:
 - Using remote support to create more opportunities for people using HCBS to live independently;
 - Use of assistive technology to help people using HCBS complete daily living skills more independently;
 - Use of assistive technology to help people using HCBS navigate their community more independently (for example AbleLink's GPS-based app for using public transportation or with the University of Maine VEMI lab's app for accessing ride sharing services); and
 - Archived webinars on the use of assistive technology.
3. Provide training and ongoing technical assistance to providers, direct support professionals, and people using HCBS on safely using the Internet and social media to increase community connections.
4. Provide training and ongoing technical assistance to providers, direct support professionals, and people using HCBS on the rights of people using HCBS to technology and information access.
5. Work with existing resources within the state (such as smart home designers, Maine Cite, or the VEMI lab) to develop and test innovative technologies that can be used to promote both a higher quality of life and greater independence for people using HCBS.

Self-Directed Services Work Group

1. Allow for a participant to self-direct a budget using full budget authority to hire staff, set qualifications of staff, and direct how staff will provide support to meet the participant's goals.
2. Create Support Brokerage as an operational service to support the person using HCBS self-directing in hiring staff, setting expectations, leveraging community resources to meet needs, and maximizing the budget.
3. Allow for Goods and Services to pay for things related to community integration, access to employment, and health and safety items not paid for by MaineCare.
4. Allow the participant self-directing or authorized representative to have full employer authority.
5. Allow self-direction of employment services.
6. Allow self-direction of live-in caregiver models.

Standardized Needs Assessment Work Group

We received the following recommendations on the implementation of a Needs Assessment tool from stakeholders, which guided the needs assessment selection process.

1. Assessors need to be respectful and knowledgeable about people with intellectual and developmental disabilities and autism.
2. To create a more positive experience, the assessment should focus on a strengths-based approach (what the person can do) and the supports needed to be successful in each activity.
3. The assessment should be included as one source of information among others to create a person-centered plan for services.
4. Gathering information from those who know the person well is important to understand the support a person needs at home, in the community, or at work.
5. If necessary, an additional assessment or exceptions process should be used to capture a person's unique or extraordinary support needs.
6. Some supports are proactive or preventative and the assessment should capture this type of support need.
7. Understanding how OADS plans to use the information from the assessment tool is important.
8. Clear communication during this process is key.

See Final Standardized Needs Assessment [Report](#) online for further information.