

**Unified Long Term Care Budget
ULTCBC Consumer Direction Workgroup Plan
REVISED PER UNIFIED LONG TERM CARE BUDGET COMMITTEE
January 2008**

Introduction

Ohio's Uniform Long Term Care Budget Committee (ULTCBC) has been charged with responsibility for developing a single long term care service budget that achieves the following objectives:

- (1) Provides a consumer with a choice of services that meet the consumer's health care needs and improve the consumer's quality of life;
- (2) Provides a continuum of services that meet the needs of a consumer throughout his or her life;
- (3) Consolidates policymaking authority and the associated long term care budgets of state agencies into a single entity for the purpose of simplifying the consumer's decision-making and maximizing the state's flexibility in meeting the consumer's needs; and
- (4) Assures the State has a long term care service and support system that is cost effective and links disparate services across agencies and jurisdictions.

The ULTCBC Consumer Direction Workgroup was formed for the purpose of exploring Objective (1). It consisted of representatives from state agencies that participate in the long term care service and support system, provider organizations, local sub-recipient entities, and members of the long term care advocacy community, including consumers and family representatives (*see appendix for complete list of participants*).

In accordance with its charter, the workgroup was charged with making recommendations and producing a plan for consideration by the ULTCBC that:

- o Incorporates consumer direction tenets into all facets of Ohio's long term care service and support system; and
- o Includes innovative consumer direction components in appropriate parts of the long term care service and support system.

The ULTCBC Consumer Direction Workgroup met approximately once every 2-3 weeks during which time members reviewed documents and shared information about different consumer direction models underway around the state and the country. Brainstorming sessions resulted in the overarching recommendation that consumer direction should be implemented throughout Ohio's long term care service and support system, regardless of funding source, provider type or care setting. Doing so affords consumers of any age

and/or their authorized representative education about choice of and control over the full range of long term services and supports that are available to meet their own diverse needs. Consumer direction has a place in all long term care settings as evidenced by person-centered care programs in nursing facilities; ODA's Assisted Living Waiver; services provided in community development centers and ICFs-MR; home and community-based services (HCBS) provided via ODJFS' Ohio Home Care, Transitions MR/DD and Transitions Carve-Out waivers; ODA's PASSPORT and CHOICES waivers; and ODMR/DD's Individual Options and Level One waivers; and the county levy-funded consumer directed care program in Cincinnati.

When acting upon this recommendation, several key concepts must be considered:

1. The Consumer's Perspective about Consumer Direction

The ULTCBC Consumer Direction Workgroup believes that participation in consumer directed care opportunities must be voluntary, flexible enough to meet the consumer's needs, and contingent upon whether the consumer and/or authorized representative can adequately direct his/her own care. The concept of "dignity of risk" and the consumer's right to make bad decisions is inherent in the concept of consumer direction and must be embraced in any consumer-directed care endeavors implemented by the State. For the latter to be possible, and to assure ongoing consumer participation, a comprehensive set of tools and resources must be created at the state level, and provided to interested consumers and/or their authorized representatives for the purpose of developing the skills necessary to direct their own care and services. The ULTCBC Consumer Direction Workgroup recommends that state agencies collaborate to develop tools that take into account the different populations served within the long term care service and support system. Moreover, for consumer direction to be effective, it must be designed as simply as possible.

Every consumer should be able to direct as much of his/her care as he/she has the desire and ability to direct. To do so, the consumer should:

- Be able to communicate his/her specific needs to the provider.
- Possess the judgment and skills necessary to manage his/her specific needs.
- Select his/her team members and participate in the development of service plans and plans of care.
- Successfully complete training about how to hire, supervise, dismiss and evaluate a worker, complete/approve timesheets, and resolve conflicts, etc.
- Direct his/her care while staying within a budget or under a cost cap established for the consumer as part of the specific program in which he/she is enrolled.

- Work with his/her case manager to establish a back-up plan for situations in which the primary provider is unable to deliver services at the scheduled time.
- Play a major role in monitoring the provider to determine if care is being provided in accordance with the consumer's service plan and/or the consumer's plan of care as mutually agreed upon by the physician, the consumer and/or authorized representative and the provider.

Additionally, the ULTCBC Consumer Direction Workgroup recommends that consumers have greater choice regarding who they can choose to be their paid provider.

Specifically, legally responsible family members (i.e., spouses and parents of minor children) should be permitted to be paid Medicaid providers of personal care services in the State's 1915(c) HCBS waivers. A number of other states are allowed to pay legally responsible family members to provide Medicaid services through 1115 waivers, and CMS recently approved a request by Minnesota to do the same as part of its 1915(c) waivers. In order for this to be allowed under a 1915(c) waiver, a State must provide a definition within the waiver application of what it considers to be "extraordinary care", i.e., care that is beyond what parents would normally do/would be expected to do for their child, or what spouses would be expected to do for each other. For parents of minors to participate, the service must be necessary to meet at least one assessed need that is identifiable when the child is determined waiver eligible. Legally responsible family members must meet all provider qualifications, conditions of participation and training standards as do all other providers. The consumer may furnish or direct the training, and the provider must provide return demonstration of his/her competency.

The ULTCBC Consumer Direction Workgroup also recommends that consumer-directed programs offer budgets or cost caps that allow consumers the flexibility to purchase other needed services (i.e., home modifications, goods and services, etc.) with unused service dollars, during the authorized service period. Finally, it also recommends that the state investigate and address legal issues around the consumer's employer status (i.e., employer of record, managing co-employer, etc.) and liability.

2. Administration and Oversight

Medicaid HCBS waivers are the traditional models for allowing consumers with disabilities and chronic conditions to receive care and services in a community setting. An alternative means of providing long term care services to many individuals, HCBS waivers allow consumers with disabilities and/or chronic conditions to have more control of their lives and to remain active participants in their community. There are several HCBS models:

- 1115 waivers --- Experimental, pilot, or demonstration projects likely to assist in promoting the objectives of the Medicaid statute. Flexibility under Section 1115 is sufficiently broad to allow states to test substantially new ideas of policy merit. These projects are intended to demonstrate and evaluate a policy or approach that

has not been demonstrated on a widespread basis. Some states expand eligibility to individuals not otherwise eligible under the Medicaid program, provide services that are not typically covered, or use innovative service delivery systems. Cash and Counseling demonstrations are examples of 1115 waivers.

- Independence Plus Waivers --- Waivers that are based on self-direction principles. Can be either an 1115, a 1915(c), or a 1915(b)/(c) combination waiver. Designation for a waiver to be an Independence Plus waiver must be specifically requested in the waiver application, as certain additional requirements apply. CMS defines a self-directed program as "a state Medicaid program that presents individuals with the option to control and direct Medicaid funds identified in an individual budget." The CMS requirements for an Independence Plus waiver include person-centered planning; individual budgeting; self-directed services and supports; and quality assurance and quality improvement (QA/QI). ODMR/DD is in the process of completing a 1915(c) Independence Plus waiver application.
- 1915(b) Managed Care/Freedom of Choice Waivers --- Waivers that allow states to implement managed care delivery systems, or otherwise limit individuals' choice of provider under Medicaid. Although 1915(b) waivers may limit the size of the consumer's provider pool, they may offer a larger benefit package that would otherwise not be available to the consumer.
- 1915(b)/(c) Concurrent or Combination Waivers --- States may opt to simultaneously utilize sections 1915(b) and 1915(c) program authorities allowing states to use the 1915(b) authority to limit freedom of choice of provider, and the 1915(c) authority to target eligibility for the program and provide HCBS. By doing this, states can provide long term care services in a managed care environment or use a limited pool of providers.
- 1915(c) Home and Community-Based Service Waivers --- Waivers that allow long term care services to be delivered in community settings. This program is the Medicaid alternative to providing comprehensive long term care services in institutional settings. Ohio's HCBS waivers administered by ODJFS, ODA and ODMR/DD are examples of 1915(c) waivers.
- 1915(i) Medicaid State Plan Option for Home and Community-Based Services --- Enacted as part of the Deficit Reduction Act of 2005 (DRA), States can provide HCBS as a State plan option, e.g., case management; homemaker; home health aide, personal care, adult day health; habilitation; and respite care. In addition, the following can be added for individuals with chronic mental illness: day treatment or partial hospitalization, psychosocial rehabilitation, and clinic services.
- 1915(j) Medicaid State Plan Option for Self-Directed Personal Assistance Services --- Also enacted as part of the DRA, States can offer a self-directed

service delivery model for personal assistance services (i.e., cash and counseling programs) as a State plan option.

Ohio has operated a wide range of 1115, 1915(b) and 1915(c) waivers as part of its Medicaid service delivery system for more than 20 years. Sometimes they have been pilots, demonstrations or model waivers that are small in scale, offer specific services, target specific populations and/or geographical areas and limit risks. Based upon the State's knowledge and experience, the ULTCBC Consumer Direction Workgroup recommends exploration of a coordinated approach to consumer direction that makes use of the most appropriate model(s), and/or elements of these models across all long term care service and support systems.

As a means of making consumer direction more widespread in the State of Ohio, the ULTCBC Consumer Direction Workgroup also recommends:

- Development and use of innovative methods to pay for goods and services and other selected services (i.e., vouchers and/or debit cards, etc.).
- Establishment and maintenance of a statewide registry of providers that lists providers' training, certification and/or approval, as well as information about qualifications, criminal record check requirements, monitoring and sanctioning, etc. The ULTCBC Consumer Direction Workgroup also recommends exploration of the potential use of the existing ODMR/DD registry of certified providers and/or the long term care consumer guide as the basis for the statewide provider registry system. Consumer input should be sought in developing the system.
- Review of Medicaid eligibility requirements in all existing Ohio waivers to assure consistent application, as appropriate, and to explore the expansion of opportunities for consumer eligibility (i.e., Medicaid buy-in, and allowing consumers to set aside patient liability for self-payment of goods and services, and rent assistance, etc.).
- Expansion of opportunities for consumer direction within the Medicaid state plan using the 1915(j) Medicaid state plan option for self-directed personal care assistance services (reference previous page).
- Expansion of person-centered care programs within nursing facilities.
- Expansion of opportunities for consumer direction through Ohio's current 1915(c) waivers, and/or implementation of new Medicaid waivers based upon consumer direction practices.
- Expansion of opportunities for consumer direction within non-Medicaid-funded programs funded or provided by other state and local entities (i.e., levies and grants, etc.).

- Access to an independent consumer-focused advocate that can assist consumers receiving long term care services and supports.
- Implementation/coordination of quality assurance mechanisms across all systems for the purpose of minimizing unnecessary risks, providing quality services, monitoring consumer outcomes (and reporting negative outcomes) and assuring the consumer's health and welfare.

3. Care Management

The ULTCBC Care Management Workgroup defines care management as "a holistic, collaborative, consumer-driven process for the provision of quality health and supportive services through the effective and efficient use of available resources in order to maximize the individual consumer's quality of life based on his/her capacity and preferences."

In Ohio, care management is defined and provided in many different ways depending upon the population served and the system providing it. Care management must be flexible enough to recognize the consumer's unique needs.

Regardless of whether or not care management is being provided to a consumer who is self-directing, and consistent with the ULTCBC Care Management Workgroup's definition, it is recommended that the service embrace person-centered planning as an integral component (i.e., the needs and preferences of the consumer and his/her family must be the primary consideration when developing the consumer's care plan). Care management must also include monitoring of and communication with the consumer and/or authorized representative to assure the consumer's health and welfare.

The ULTCBC Consumer Direction Workgroup also recommends that HCBS waiver consumers who are self-directing be granted budget authority in which he/she is assigned a budget within which funds can be used to purchase needed waiver services identified during the assessment process. Consumers would be permitted to negotiate rates up to the Medicaid ceiling for these services and any savings accrued over the budget period could be carried over in order to afford the consumer the flexibility to purchase other needed services (i.e., home modifications, goods and services, etc.) while still enrolled in the program.

4. Financial Management

CMS, in its HCBS waiver application instructions, underscores that financial management services (FMS) are "a critical support" for consumer direction. 1915(c) waivers do not permit direct payment to consumers, whether for reimbursement of consumer expenses or to allow the consumer to directly pay his/her service provider. Instead, CMS requires that financial transactions be made through a fiscal intermediary.

FMS entities generally function similar to a bank for the purpose of receiving and disbursing public funds, and tracking and reporting on the consumer's budgeted funds; process and pay invoices for goods and services in the consumer's approved care plan; prepare and distribute reports to the consumer and other approved entities; assist the consumer in verifying providers' legal work status; collect and process providers' timesheets; and operate a payroll service that includes appropriate withholdings. FMS entities are intended to assist the family or consumer to direct and manage their own care and services.

The ULTCBC Consumer Direction Workgroup recommends that the State examine the various types of FMS entities used in the delivery of consumer-directed care around the country (and the legal implications of each) to (a) determine the model that is best suited to accommodate the needs of Ohio's long term care service and support system (i.e., vendor agent, agency with choice, etc.), and (b) ascertain the feasibility of allowing an FMS to execute Medicaid provider agreements as part of consumer direction, thus expediting the ability of the provider to furnish services to the consumer.

The ULTCBC Consumer Direction Workgroup also recommends that the State study and determine the various types of employer status available to the consumer (i.e., employer of record, co-employer of record and managing employer, etc.). Further, the state should explore whether the concept of employer status should be uniformly applied across all long term care systems.

In addition, the ULTCBC Consumer Direction Workgroup recommends that the State study the feasibility of utilizing organized health care delivery systems (OHCDS) as another means for offering opportunities for service delivery in the long term services and supports system. According to 42 CFR 447.10(b), an OHCDS is a public or private organization that operates under an agreement with the state Medicaid agency and provides at least one Medicaid service directly (i.e., using its own employees) and subcontracts with other qualified providers to furnish other services. When the OHCDS provides the service directly, it is reimbursed by the Medicaid agency; when a subcontractor provides the service, it is reimbursed by the OHCDS. Both the OHCDS and the subcontractors must meet all of the applicable provider requirements. Examples of OHCDS entities include, but are not limited to clinics, FMS entities, group practices and health maintenance organizations.

Additional recommendations from the ULTCBC Consumer Direction Workgroup include:

- Use of Limited Medicaid Provider Agreements as a way to execute the purchase of goods and services (e.g., one-time agreements to purchase goods at retail establishments, etc.).
- Exploration of the legal implications of consumer direction (i.e., employer status, taxation, and unionization of independent, non-agency providers, etc.).

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- Establishment of consumer protections that assure that providers cannot change timesheets after the consumer and/or authorized representative has signed them and before they are submitted for reimbursement.
- Establishment of safeguards against consumer and provider fraud.
- Assurance of uniform due process for consumers and providers alike.

Conclusion

Consumer direction describes programs and services in which people are given maximum choice and control over the arrangement and provision of the services they receive. Consumers can choose how and where to receive their services; select, train and direct the providers who will work for them; and dismiss them, as necessary. Consumer direction has been proven to be an effective strategy in controlling overall service costs at the same time consumer quality of life and satisfaction are increased. In addition, a secondary benefit of consumer direction is to overcome the shortage of direct service workers that has become a strategy many states have employed to address the projected shortage of direct service workers.

By building Ohio's long term care service and support system on a foundation of consumer direction, Ohio is emphasizing its commitment to consumer participation, empowerment, and advancement of consumer rights, responsibilities and accountability with regard to personal control over service delivery. Informed consumers and their representatives will be in control of making choices about how best to meet their specific needs. Consumers will have the freedom not only to define the life they seek, but to be supported by the State of Ohio in their desire to take risks and direct their own care and services in pursuit of that life.

Appendix A
Uniform Long Term Care Budget Committee
ULTCBC Consumer Direction Workgroup Membership

Kathleen Anderson Ohio Council for Home Care	Steve Mould Ohio Health Care Association
Joanne Arndt Paramount	Diane Phillips Area Agency on Aging 9
Cathy Ash Area Agency on Aging 8	Diane Ramey Area Agency on Aging 5
John Bleau Area Agency on Aging 4	Lisa Rankin State Street Consultants (Ohio Nurses' Association)
Alan Cochrun Access Center for Independent Living	Tiffany Ray Ohio Department of Aging
Kathy Foley Linking Employment, Abilities & Potential (LEAP)	Larke Recchie Ohio Association of Area Agencies on Aging
Victoria Gresh Ohio Academy of Nursing Homes	Bethany Rausch Ohio Council for Home Care
Debbie Gulley Area Agency on Aging 7	Carol Shkolnik Ohio Department of Aging
Deb Hathaway American Nursing/Ohio Council for Home Care	Hilary Stai Ohio Long Term Care Ombudsman / Ohio Department of Aging
Connie Hawthorne Area Agency on Aging 9	Bev Tatro Area Agency on Aging 5
Mary Ann Hemmert Catholic Social Services	Gwen Toney Ohio Hospice and Palliative Care Organization / Ohio Home Care Organization
Rebecca Holland Wellcare	Sharon Travis Erie County Board of Mental Retardation and Developmental Disabilities
Peg Ising Ohio Department of Insurance	Bruce Tuxhorn Hannah's House
Billie Johnson Area Agency on Aging 4	Ryan Weaver Area Agency on Aging 3
Diana Kubovcik Area Agency on Aging 6	
Jacque Martens Area Agency on Aging 1	Roger Fouts, Facilitator Ohio Department of Job and Family Services
Christina Miller Ohio Department of Mental Retardation and Developmental Disabilities	Sue Fredman, Assistant Ohio Department of Job and Family Services

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Appendix B
Uniform Long Term Care Budget Committee
ULTCBC Consumer Direction Workgroup
Resources
(Available upon request)

Enabling Personal Preference: The Implementation of the Cash and Counseling Demonstration in New Jersey, *Final Report*, March 2003, Phillips and Schneider (Mathematica Policy Research, Inc.)

Individual Providers: a Guide to Employing Individual Providers Under Participant Direction, March 2006, Human Services Research Institute and the MEDSTAT Group, Inc.

Medicaid Options for Model LIFE Account Programs, September 2006, Bezanson and Crisp, Boston College Graduate School of Social Work and the MEDSTAT Group, Inc.

Organized Health Care Delivery System, *Fiscal Brief*, August 2005, NYS Conference of Local Mental Hygiene Directors, Inc.

The Strangers in Our Parents' Homes: Inside the Unregulated Industry of Home Health-Care Aides, November 2007, Reno, Newsweek.