ARMS BARRIERS WORK GROUP REPORT

On August 8, 2008 the following individuals met in Frankfort to discuss barriers that cause Kentuckians to not be able to adequately access services and supports through Medicaid and other state-funded or administered programs. The method used to develop the findings and recommendations contained in this report was to discuss an actual individual that one of our participants was aware of who had not received adequate supports from one or more existing programs. We attempted to determine whether the reason the individual failed to be adequately supported was due to a Kentucky-developed and implemented regulation, or to a policy of a state agency, or to a custom or long-held usage that was and is not mandated by a federal regulation or statute. We avoided discussion of any issue that was driven by a federal regulation or statute, focusing instead on barriers that have developed in Kentucky.

It is important to note that ARMS has an overarching belief that Kentucky has a Medicaid system that is some 40 years old, and during that time a program has evolved that at times contradicts its own purposes and creates internal confusion about the most effective and efficient methods to provide critically needed supports for some of our most vulnerable citizens. We believe that the Cabinet will be well-served by initiating a full review of its regulations and policies for program that support vulnerable individuals in their own homes and communities, with the goal of having individual-centered services. In addition, state-funded services for elders and persons with disabilities have not been substantively reviewed since the 1980s, and also need to have a comprehensive assessment performed.

ARMS and its member organizations and individuals offers to work with the Cabinet in this comprehensive systemic review of our programs and funding, which we believe is much needed during the present time of inadequate funding through both the state and federal budgets. All of us agree that Kentucky can maximize its available funds far better if we undertake an in-depth, critical evaluation of all our programs and funding supports with the goal of best-use on behalf of individuals, rather than continuing to be so program-silo oriented.

Those who participated in the Barriers Work Group are:

- Mary Alford — Parent of an adult child with disabilities
- David Allgood — Center for Accessible Living
- Darla Bailey — Kaleidoscope Services, Inc.
- Jan E. Day — Center for Accessible Living
- Barbara Gordon — KIPDA Area Agency on Aging
- Mary Hass — Brain Injury Association of Kentucky

- Karen P. Hinkle — Kentucky Home Health Association
- Marsha Hockensmith — Protection & Advocacy
- Jim Kimbrough — ARMS
- Meghan McGee — ARMS
- Cathy Allgood Murphy — AARP
- Lacey McNary — Kentucky Youth Advocates
- Rich Seckel — Kentucky Access to Justice
- Sheila Schuster — Advocacy Action Network

Rich Seckel was the facilitator for the Barriers Work Group.

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Barrier: Under HCBS, an individual must be assessed in their home environment. When someone is in a facility, and desiring to leave, the HCBS assessment is now not being paid by Medicaid.

Example: An individual placed in a nursing home due to MD, who desires to live in a home environment, but has spent all assets while in the facility. The person cannot obtain a paid HCBS assessment to set up services.

Remedy: Policy change in HCBS regulation that eliminates "in their home environment" as a choke-point for obtaining certification. Also, a message from the highest levels of the Cabinet to streamline assessment and other provider requirements in order to expedite transition.

Barrier: State agencies assumption that "one program is enough" for individuals.

Example: An individual with Down's syndrome, significant physical disabilities, and apparent early on-set Alzheimer's cannot receive an array of services from multiple waivers and state funded programs, although CMS allows that to happen. That affects virtually all individuals who have multiple conditions, and are eligible under multiple waivers and state programs.

Remedy: Amend state policy manual to specify that individuals will receive appropriate services from all waivers and state fund programs for which they are eligible, provided that they do not receive the same service from more than one waiver. Provide guidance to appropriate state staff, assessors, case managers, and service providers that makes clear that Kentucky services are client-orientated, not limited based on program silos.

Barrier: Families who actively seek community-based settings for a member who is either in a facility and wants to leave it, or who is at risk of being placed in a facility are frequently exhausted by a bewildering labyrinth of regulations and program options. Consequently, families often throw up their hands and default to facility placement because it is understandable, although usually not desirable to the family or individual.

Example: An individual with a brain injury as well as other physical conditions such as diabetes, and who has judgment deficiencies. Because the ABI waiver does not allow for nursing services (even when the brain injury co-occurs with other medical conditions), and because traditional Medicaid Home Health has very limited services available for someone with self-maintenance needs, this lack of fully providing supports leads to institutionalization because of a lack of coordination between two separate Medicaid programs.

Remedy: Amend the ABI waiver to permit needed skilled nursing services to be provided to a participant in order to allow the participant to continue living outside in a home/community living arrangement.

Barrier: SCL providers will not provide respite services at the rate of $10.50 per hour, so many participants are not being appropriately served.

Example: An individual with developmental disabilities who lives with an aging caregiver. The caregiver is in need of respite, but under the rigidly fixed payment rate of $10.50 per hour for an SCL provider per 907 KAR 1:155, very few SCL providers will provide the respite. However, the same regulation allows for more hours of respite service than many caregivers require.

Remedy: Amend 907 KAR 1:155 to allow for the total budget that the client has to be the primary driver of services delivery, instead of continuing to fragment the client's budget into service silos. Allow the individual's needs to be the determinant of how the budget is utilized, and allow flexibility in the hours/units/services provided within the participants plan and budget.

Barrier: SCL participants at times need services that cannot be provided by certified SCL providers, but are available from providers who are certified for traditional Medicaid or other waivers.

Example: An individual in the HCBS waiver may need behavioral supports, which is not an identified service for HCBS. However, there are behavioral supports providers in the community who are certified for other waivers, such as ABI.

Remedy: Allow existing SCL providers to subcontract, including subcontracting with non-SCL providers, in order to, within the client's budget, receive needed services and supports that are already provided under one or more Kentucky Medicaid programs.

Barrier: Assessors are inadequately trained or unavailable on a timely basis, leading to slow transition of participants to waivers or new programs, in some cases from facilities.

Example: An individual with multiple physical disabilities who desires to live in his own home and leave a nursing home cannot be assessed in a timely matter due to the lack of home health providers in the area who provide assessments.

Remedy: Enlarge the pool of assessors for programs by training and utilizing staff from the regional Centers for Independent Living.

Barrier: There are no mechanisms in place to start services immediately when the individual is assessed and certified for HCBS waiver.

Example: An individual may be assessed and found to be eligible, but services cannot begin until at least two services are in place. A provider cannot be reimbursed for a service unless the individual is receiving at least one other service.

Remedy: Adjust policy to allow services to begin as soon as possible to encourage transition. Also, policy to allow case management to be in place and billable at the time of discharge and transition.

Barrier: Confusion surrounds who the client or family or guardian needs to ask to perform assessment for waiver certification.

Example: Individual in a nursing home asks to leave to return to home or community, but no one in the facility acknowledges that they know how home and community based services can be set up and transition can occur.

Remedy: At time of admission to facility, the individual, family member, guardian should be given a written (in simple language) single page description of how to leave, which includes telephone numbers of agencies approved for assessments for home services. Also, long-term care ombudsmen should be more intensively trained in assessment and transition planning as part of their mandatory in-service education.

Barrier: Cabinet staff interpretation of waiver protocols and regulations are not consistent with language or intent of the waiver.

Example: Young person receiving EPSDT services due to a brain injury. He aged out of the EPSDT program and was accepted into ABI waiver. The EPSDT provider meets all requirements for ABI service provider, and desires to continue providing services, which participant also desires. However, the BI Branch staff denied services based on its policy interpretation that someone cannot transition from EPSDT services to ABI services with the same provider.

Remedy: Cabinet corrects interpretation to reflect the language and intent of ABI waiver, and remove the bias against client continuation with EPSDT provider.

Barrier: There are few EPSDT providers

Example: Individuals under the age of 21

Remedy: Increase rates for EPSDT services, which have not been adjusted since 1998.

Barrier: EPSDT process is not client friendly, with little assistance for families needing the specialized services that at times only can be provided through EPSDT.

Example: Family of young person with complex needs is told that it needs medical services for the individual without any assistance in finding EPSDT certified providers.

Remedy: The Cabinet develops information on EPSDT services and ways to access those services, written in simple language, and make available to families through distribution at pediatricians offices, public health departments, and Family Resource Centers.

Barrier: Homemaking services are capped at 2 hours per week under HCBS regulation.

Example: Older person who has left a nursing facility to live in their own apartment, and is not strong enough to do very much self-cleaning.

Remedy: Cabinet changes the regulation to allow flexible number of hours based on an individual's needs.

Barrier: There is an overall lack of community-based providers for personal care assistance services.

Example: Individuals often must call multiple providers to determine which agencies participate in waiver programs and whether they have capacity to provide services to new clients.

Remedy: Cabinet support the new version of SB 240 in 2009 legislative session, creating personal services levels.

Barrier: Drug and Alcohol treatment can only be provided by a licensed facility

Example: Many ABI and SCL clients have chemical addictions co-occurring with their condition. There are lengthy waiting lists for admission to treatment facilities, with additional barriers when the abuser also has cognitive or behavior defects.

Remedy: Amend 907 KAR 1:370 to replace "facility" with "entity", therefore increasing the potential for service providers that focus on ABI and SCL participants to also provide substance abuse treatment.