

September 16, 2014

Beverly Mackereth, Secretary
Department of Public Welfare
Harrisburg PA 17120

Re: Transition Plan for Compliance with New Federal HCBS Rules

Secretary Mackereth,

I am writing on behalf of the Person Driven Services and Supports (PDSS) coalition which is made up of people with disabilities, family members and the following organizations. The following coalition members support these comments: Pennsylvania Developmental Disabilities Council, the Institute on Disabilities at Temple University; Pennsylvania Health Law Project; Pennsylvania Mental Health Consumers Association; Mental Health Association of Southeastern Pennsylvania; Values into Action-PA, Mental Health Association in PA, The Arc of PA, PA Statewide Independent Living Council, and Self-Advocates United as 1. The focus of our coalition's efforts is to expand and enhance person-driven services in Pennsylvania so that *all people with disabilities shall have the option to design, control and direct their own services and funding.*

First and foremost, thank you for the opportunity to provide input regarding the Transition Plan for the new federal Home and Community Based Services regulations. Our coalition's comments will focus specifically on improving options for person-driven service and supports. Enhancing and expanding person-driven services in the Commonwealth can play a critical role in compliance with the new federal rules. Self-directed services, by their very nature, ensure that services are provided in non-disability specific settings.

Our Recommendations:

Use the opportunity to transform and help rebalance system.

The new CMS Rule presents an unprecedented opportunity for Pennsylvania to revise its system of providing community-based services to people with disabilities. The plan that has been published for comment is quite modest and represents minimal compliance with the Federal requirements. Working toward the intended outcome of

the new federal rules (real and meaningful inclusion of people with disabilities in our communities) would also advance our goal around rebalancing our system away from institutional care. It is our hope that a revised, more ambitious plan will be submitted that is consistent with the spirit and intent of the new CMS rule.

Ensure involvement of people with disabilities and families in development and implementation of transition plan.

A core principle of person-driven services is that people who use the service systems are the ones making the decisions not only about their own services, but also about how the systems are designed and operated. Since the disbanding of the HCBS Stakeholder Planning Team in 2011, the mechanisms for systematic input from a broad cross-disability stakeholder group have diminished. The only avenue for input of which we are aware is the Long Term Care Subcommittee of the Medical Assistance Advisory Committee. That group is primarily comprised of providers, does not include broad consumer representation, has many unrelated items on its agenda (i.e. nursing home reimbursement) and thus limited time for these issues and does not generally share materials in advance with non-members. In short, it is an inadequate forum.

We ask for the opportunity to provide ongoing input to the Department of Public Welfare regarding any proposed changes in regulations, waiver service definition modifications and waiver amendments, and implementation of new policy and procedures. We also request outreach and education to individuals and their families who may be impacted by systems reform.

Further, people with disabilities and families should have direct input as to determinations on whether specific “settings have the effect of isolating individuals receiving HCBS”[441.301(c) (5) (v)]. CMS has provided guidance precisely on factors to consider in determining whether setting are isolating in effect. Applying these factors to specific settings will take more than an analysis of provider information (pg.3 #4). We urge DPW to include feedback from waiver participants and their families by using existing data collected from service recipients through IM4Q and the Money Follows the Person Quality of Life Survey and to expand the use of these survey tools to capture feedback from participants and their families about specific service settings. We support the Office of Long Term Living’s (OLTL) plan to conduct face-to-face quality monitoring visits with a sampling of participants in each waiver in order to determine whether settings comply with the federal regulations.

Plan should address new federal requirement on person-centered plans.

The fact that the plan is silent on section §441.725 *Person-Centered Service Plan* is concerning. If we want a service system that can actually deliver services in non-disability specific settings and involve people "to the same degree of access as individual not receiving Medicaid HCBS waiver" [441.301(c) (4)] then we need to revamp our approach to Individual Supports/Service Planning. Our Service/Supports Coordination needs better training, more time and support and incentive to facilitate person-centered planning. Specific activities that should be included in the transition plan are:

1. The transition plan include a plan to comply with the section §441.725 Person-centered service plan.
2. We urge the Department to take an inventory of the capacity of Supports and Service Coordinating Organizations to facilitate person centered planning and to take steps to expand that capacity, if necessary, based on that inventory.
3. The plan should include provisions for Supports/Service Coordinators to be provided extensive and mandatory training in the person-centered planning approach and how it should fundamentally change their approaches to plan development. Moving from service driven plans to plans driven by person-centered planning begins with the Service/Supports Coordinator's approach and skills to facilitate plans. The following steps should be taken to improve the capacity of Supports Coordination to effectively facilitate person-centered planning and assist people to live and work in non-disability specific settings:
 - a. Comprehensive training in planning for individually identified outcomes not just the services available.
 - b. Comprehensive training in non-traditional models (participant-direction, lifesharing, Services My Way, reverse lifesharing, customized employment, etc). There is little to no training currently available to SCs on these topics.
 - c. Training in housing resources and how to access them.
 - d. Incentivize planning. DPW should examine SC rate structures or other mechanisms that could incentivize or provide for good person-centered planning, with monitoring by Office of Developmental Programs (ODP) and the Office of Long Term Living (OLTL) of these plans' results.
 - e. A mechanism for SCs and waiver participants to get quality technical assistance when they are working with people who want non-traditional models of service.

4. An example of where person-centered planning could be invaluable in complying with the new rules is in relation to p.1, #12 of the plan. Where individuals are receiving services “on the grounds of or immediately adjacent to public institutions,” if providers are unable or unwilling to come into compliance with the new rules, then people in those programs will need to be transitioned to other sites or programs. We urge the Department to be more specific in its plan to assist those individuals in making those transitions beyond “work with case management entities.” For each person served in these non-compliant settings, DPW should ensure that Supports Coordinators are notified and begin formal, comprehensive person-centered planning processes. Through these processes the following should be identified: each person’s needs that were being met by the non-compliant program, any other relevant needs each individual has and an alternative means of meeting each person’s needs in non-segregated settings. Each person-centered plan should result in an action plan for ensuring that the individual’s needs are met once the person transitions out of the non-compliant setting.

Needed policy changes and waiver amendments.

In relation to the new rules requiring that a person must have options of non-disability specific settings, a private unit in a residential setting, and the ability to receive services in the community to the same extent as a people not receiving MA HCBS [441.301(c) (4) and 441.301(c) (5) (v)], we have a number recommendations for policies that should be specifically added to the plan and/or changed immediately to promote these ends (In response to Transition Plan Page 5 #3 analyze current services, policies, regulations).

1. Person-driven options should be available in all HCBS Waivers.

An immediate amendment should be submitted to CMS for the AIDS and Autism Waivers to include person-driven options. All people with disabilities who qualify for services should have the same opportunities to have the maximum choice and control over their settings, services and supports. People with diagnosis of AIDS or autism should have the same options for self-direction as people with the diagnosis of cerebral palsy or a physical disability. Frankly, it seems discriminatory that they do not have these options.

2. Service Definitions that allow for better self-direction.

Services My Way (Cash and Counseling) option should be added to all waivers as a way to allow for purchase of generic goods and services that can promote more integrated lives in community settings. The Services My Way option allows for waiver participants to more creatively meet their disability-related needs without being bound to strict menus of specialized services otherwise available through the waivers. This option is already in two of PA’s HCBS waivers. We believe that it should be offered in all

waivers to help waiver participants and to help PA meet the intent of the new federal rules.

3. In ODP, examine impact of ISP Checklist.

Though ODP's current Intellectual Disability Waivers rules and regulations may largely meet the requirement for choice of settings on paper, we believe that ODP also has conflicting rules and procedures that create extensive barriers to waiver participants exercising these choices. The ISP Checklist and subsequent additional scrutiny regarding use of 1:1 staffing creates significant barriers for individuals who choose to live in non-congregate settings and to engage in non-licensed/non-group daytime activities. The use and impact of the ISP Checklist must be examined thoroughly.

4. Technology.

ODP should add a service definition to the waivers for Smart Home Technology, Telecare and PERS that could have cost saving potential for people who do choose to live independently and may be able to use technology instead of staffing to manage aspects of their daily lives and/or maintain health and safety. OLTL should add Assistive Technology to the Attendant Care and AIDS waivers. Assistive Technology can play a vital role in people living and working independently in their communities.

5. Expand Use of the Supports Broker.

Supports Brokering service should be added to all HCBS waivers. People directing their own services often need some assistance to do so. For many people who need services, they have never managed "staff" before, never written ads to recruit support workers, never interviewed prospective employees, never submitted payroll. For many people who want to use person-driven services, they also need some assistance blending the paid and the unpaid service and supports they have in their lives. This service is currently only offered to people in the Intellectual Disability Waivers and is not actually available in most parts of the state.

6. Change Supports Broker Limitations.

Currently in the Intellectual Disability Waivers, Supports Brokering is limited to people who live in private homes. There is no option for people who want to transition from Residential Habilitation (group homes or institutional) settings to self-directing services in a private home. This creates a phenomenal barrier for people who want to make this change. For a person to transition from a residential setting, they would typically need staff in place in their new home. Without a Supports Broker, the waiver participant may have no one who can assist with recruiting and hiring the new Support Service Workers. We recommend that ODP amend the waiver to allow for people transitioning from residential settings to private homes the option to use a Supports Broker during that

transition. Likewise, OLTL should consider Supports Brokering an invaluable service for people transitioning from Nursing Homes to person-driven models.

7. Housing Subsidies.

The plan should address issues related to people finding affordable, integrated, and accessible housing. A major barrier to people choosing non-residential service/institutional settings is a lack of accessible, affordable housing. We recommend the following approaches to addressing the issue:

- a. Build capacity and availability of housing specialists and resources. In PA, we do have some excellent organizations for assisting people to find housing. These organizations, however, are under-funded and cannot fill the need. Our Service/Supports Coordination often lacks the expertise and/or availability to assist people in the time-consuming process of budgeting for housing and locating suitable housing.
- b. Develop a plan to prioritize the housing needs of people with disabilities. A key component of this plan should be to reinvigorate the Local Housing Options Teams (LHOTs) and require that there is representation by the disability community on all LHOTs.
- c. Improve access to home modifications. All waivers should include coverage for needed home modifications. Other resources like the Department of Economic and Community Development should be adequately funded to support the needs for home modifications. Additionally, the process for payment of contractors who provide home modifications needs to be examined. The process is cumbersome and results in delays of construction which may mean that people have unnecessarily prolonged stays in institutional settings while waiting for their homes to be modified. We would recommend that the Departments consider working with PHFA to make lines of credit available to enrolled contractors, using Financial Management Services to process payment and consider any other solution that may assist in the timely modification of homes.
- d. Subsidies – HCBS participants who choose residential settings essentially receive subsidized housing (the ineligible billing codes). This same subsidy/assistance should be available to people who choose non-residential settings and do not have access to other federal subsidy programs like Section 8.

Thank you so much for the opportunity to provide input as you develop the transition plan for the HCBS waivers. We would be happy to answer any questions or provide

additional information. Please contact me at the above number or at kahrens@temple.edu.

Sincerely,

A handwritten signature in black ink, appearing to read 'Kristin Ahrens', with a long horizontal flourish extending to the right.

Kristin Ahrens
Policy Director

- c. Bonnie Rose
- Stephen Suroviec
- Ralph Lollar
- Leesa Allen
- PDSS Coalition Members