Partnering to Build Communities that Work for Everyone

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Ohio Department of Medicaid ATTN: HCBS Transition Plan P.O. Box 182709, 5th Floor Columbus, Ohio 4321 HCBSfeedback@medicaid.ohio.gov

January 23, 2015

Re: Ohio's Draft Plan to Comply with the New Federal Home and Community Based Services Requirements, 42 CFR 441.301(c)(4)-(6)

Dear Department of Medicaid,

The Ability Center of Greater Toledo is a Center for Independent Living that serves people with disabilities in Defiance, Fulton, Henry, Lucas, Ottawa, and Wood Counties in northwest Ohio. We have a commitment to changing systems, public policies and attitudes that prevent people with disabilities from living, working, and socializing in their communities.

As a Center for Independent Living, we employ and provide services, advice, and advocacy for people with disabilities that assist them to live and socialize in the community, and thus, we have daily exposure to the barriers faced by people with disabilities who wish to live and work in the community. Since October, 2013, 778 consumers with disabilities have received assistance through our center. We also have advocates who experience barriers to community living at a policy and state level, such as through the Ohio Olmstead Task Force. We appreciate the opportunity to submit comments on Ohio's Draft Plan to Comply with New Federal Home and Community Based Services Requirements. (hereinafter Draft Plan)

After reviewing Ohio's Draft Plan, we are concerned that: 1) the Draft Plan could blur the line between home and community based settings and institutional settings and make waiver funding available for institutional settings; 2) the Draft Plan has few goals for bringing Ohio's person-center planning process into compliance with the CMS definition of person-centered planning, which focuses on consumer choice and control.

1. Waiver funding should only be used in non-congregate, inclusive, home settings.

Historically, Ohio's system for care of people with disabilities has been entrenched in an institutional model of care. An institutional model of care denies people with disabilities the right to live independently in a setting under their control. Instead, in Ohio's system of care, people with disabilities have lived in segregated, congregate settings where providers control their choices and daily activities with no recourse for those with disabilities. Systems based on those principals violate the Americans with Disabilities Act and the U.S. Supreme Court decision of *Olmstead v. L.C.*. The state of Ohio has taken steps to counter this system and mindset by implementing the Medicaid waiver system, where money from Medicaid can be used to provide services that will allow a person to live independently in their own home.

Institutional care is still the prevailing model in Ohio, especially in funding, with only 31.4% of Medicaid funding going towards home and community based services in Ohio in comparison to 65.4% in top states.¹ We are concerned that, with Ohio's compliance plan, waiver funds may be used in congregate care settings as well. As those funds are limited, they should be reserved for providing home and community base services in inclusive, home settings only such as those identified in the Draft Plan as already in compliance with the new CMS rule (Draft Plan at 7).

While the new CMS rule gives specific characteristics of home and community based settings, which are referenced in the Draft Plan, it repeatedly uses the phrase "to the same degree of access as individuals not receiving Medicaid HCBS." 42 CFR 441.301(c)(4)-(5). Many of the suggested changes in the Draft Plan, referencing those settings that must come into compliance, fail to reach that level of inclusion and independence for people with disabilities.

A. While implementing the characteristics of HCB settings under the new CMS rule will create positive changes in the current DODD system, it is not enough to create a system where individuals are independent, have control over their choices and activities, and live and work in the community.

The new CMS rule re-defines "community-based setting" for the purposes of spending dollars dedicated to HCBS. 42 CFR 441.301(c)(4)-(5). The specific characteristics of home and community settings created many good changes to the current settings identified within the Draft Plan. For example, the Draft Plan includes creating new service definitions, etc. to

¹ Susan C. Reinhard; Enid Kassner; Ari Houser; Kathleen Ujvari; Robert Mollica; Leslie Hendrickson, *Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* (2014) available at http://www.aarp.org/content/dam/aarp/research/public policy institute/ltc/2014/raising-expectations-2014-AARP-ppi-ltc.pdf (accessed January 19 2015).

promote community supports and integrated employment services and the phase out of the Transitions DD waiver (Appendix 1, p 2). Additionally, it includes developing a new rule addressing personal funds of individuals that will give them control of financial affairs and creating a lease agreement where individuals reside in provider-owned or controlled settings (Appendix 1, p. 3). It requires provider-owned settings to place locks on doors and limit staff access to rooms (Appendix 1, p. 5); it requires that people with disabilities get a choice in their roommates (Appendix 1, p 6); it allows people to furnish their rooms, control their schedules and activities, and have access to food (Appendix 1, p. 7); it provides for a rule for people with disabilities to be able to have visitors at any time (Appendix 1, p. 8); and it provides for a rule that the housing be accessible and that homes not be located next to ICFs/ NF/ or psychiatric hospitals (Appendix 1, p 9 and 10). Enforcing these characteristics would bring about good reforms to current settings that have characteristics of an institution such as group homes with greater than four individuals, disability specific farms, cul-de-sacs of group homes, and campus settings, but where the settings do not provide access to the community to the same degree as individuals not receiving Medicaid HCBS, they should not be funded with waiver funds.

Additionally, we are in support of the Draft Plan's provision for removing waiver funding from residential settings that are located inside, on the grounds of, or adjacent to a public institution or inside a private institution (Appendix 2, p 6).

The Draft Plan focuses on bringing already-existing settings into compliance with the new CMS rule rather than re-designing the system to allow individuals with developmental disabilities to live in their own homes with waiver services. Even without the new CMS rule, it is clear that people with developmental disabilities are not residing in settings that meet the mandate of *Olmstead* when they live in place where they cannot have locks on their doors; choose their roommates; control their daily activities; control their finances; choose their own providers; that are accessible; and that are segregated on campuses for those with disabilities.

While the new CMS rule creates certain characteristics for home and community based settings, simply evaluating whether current provider-owned, congregate living complies with those characteristics without looking at whether the setting provides the same access to the community as those not receiving HCBS does not implement the *Olmstead* mandate of providing services in the most integrated setting appropriate. These characteristics in themselves do not create an inclusive, community setting. Where the plan relies on providers to promote integration in and access to the community (Appendix 1, p. 1, p.2); relies on county boards to implement "person-centered planning" (Appendix 1, p.1); and still allows provider-owned housing as long as people can choose their roommates and have locked doors, etc. (Appendix 1, p 7) it relies too much on a provider control, rather than a consumer- controlled system. Integration of people with developmental disabilities should not rely on provider's efforts to create a plan to make them more integrated, they should be placed in the

community with sufficient supports to succeed there. As long as one provider has too much control over people's lives, a system promoting integration and consumer choice will not be possible.

According to the Draft Plan, the only settings that could not meet those requirements under the Draft Plan were ones that housed over 43 individuals (Draft Plan p8). Yet, where a person lives in a group home with more than four individuals; a disability specific farm; a cul-de-sac of group homes; or a campus setting, even if the new HCB setting characteristics are implemented and there is a plan to move the person into a more integrated setting during the day, the person still lives in an institutional setting and waiver funds should not be used to fund that residential placement (Appendix 2, p. 3). Also, if the settings identified by Ohio as non-compliant with the rule simply re-locate their residence to one that is a congregate setting but not located inside or on the grounds of a public or private institution, that is an institutional setting that should not receive waiver services (Appendix 2, pg. 6).

In short, we are concerned that the Draft Plan creates a plan to use waiver funding to provide services in residential settings that are too large and segregated from the community to come into compliance with the rule simply because they implement the characteristics listed in the rule. We are concerned that if a new Ohio rule is implemented that codifies that attitude, it will be very difficult for individuals with developmental disabilities to choose to live independently and receive services truly in the community.

B. We are encouraged by Ohio's re-design of its adult day waiver settings, and look forward to commenting further once it produces its new Adult Waiver Service package.

Ohio has also planned to make good changes to its adult day waiver settings. We are excited by its decision to create and implement a new Adult Day Waiver Service package that maximizes opportunities for integrated employment and integrated wrap-around supports. (Appendix 1, p. 2). We also support the closing of day settings located inside or on the grounds of a public institution or inside a private institution. (Appendix 2, p. 6). With little detail in the plan about what other "compliance" will look like for providers and the changes that will be made, we will comment on this more as Ohio creates its new package.

C. Likewise, implementing the characteristics identified in the new CMS rule for home and community based settings will make positive changes in the NF-LOC system, waiver funds should not be used in congregated care settings, even with those characteristics.

In the Draft Plan, Ohio has completed a similar review of current settings for individuals who have been historically confined to nursing facilities. However, again, simply implementing these characteristics does not make congregate care settings into community settings that should be funded by waivers. In short, people who meet a nursing home level of care should not be placed in provider-owned settings at all with waiver funds but should be placed in their own home. Again, it will be a positive change that people in provider-owned settings will have a lease (Appendix 3, p. 6); will have privacy, including locked doors that most staff cannot enter (Appendix 3, p. 6); will get to choose their roommates (Appendix 3, p. 6); will be able to furnish or decorate their living units (Appendix 3, p. 7); can control their own

schedules and activities and have access to food at any time (Appendix 2, p.7); and can have visitors at any time (Appendix 3, p. 8). These are positive changes to institutional settings.

However, institutional settings are not home and community based settings, and they should not receive waiver funding. In Appendix 3, p. 9, the plan states that locations within a building that is also publically or privately operated providing inpatient institutional treatment in a building on the grounds of a public institution can be considered a home and community based setting if it complies with a new Ohio rule regarding characteristics required for provider controlled settings. However, a residential setting in a building that provides inpatient institutional treatment or on the grounds of a public institution should not be considered a home and community based setting and should not receive waiver funding, even if it implements characteristics that give residents more privacy, dignity, and respect. In those settings, people with disabilities will not have access to the community to the same extent as someone who does not receive Medicaid HCBS services.

Likewise, Appendix 4, p. 4, states that residential care facilities located on the campus of a continuing care retirement community can receive waiver funding if they implement characteristics of home and community based settings. However, congregate care facilities located on a continuing care campus also cannot constitute a community placement, even if they implement HCB setting characteristics and should not receive Medicaid waiver funds. Additionally residential care facilities located in the same building as a nursing facility do not constitute community settings regardless of additional characteristics and should not receive Medicaid waiver funds. Congregate care facilities are not home and community based placements and should not receive waiver funding.

The Draft Plan regarding NF-LOC has "TBD" marked in the category of residential settings that cannot come into compliance with the CMS rule. It is not logical to think that all of Ohio's waiver settings can currently meet the definition of HCB settings if they simply adopt certain new characteristics.

D. We support a more integrated model of Adult Day Health waiver services.

In its Draft Plan, Ohio has set goals of modifying adult day health service specification rule to incorporate community integration/ access characteristics. We are in support of more community integrated adult day services and look forward to commenting more on Ohio's plan when it creates more details about what those services .

However, we are again concerned that, simply because certain settings will be required to implement characteristics giving participants more choice, dignity, and independence, Medicaid waiver funds will be used for segregated settings where people do not have access to the community to the same extent as those not receiving Medicaid HCBS. For example, in Appendix 4, p. 6, Ohio plans to allow adult day health settings in the same building as a nursing facility furnishing the adult day health waiver services to receive Medicaid waiver funds if they change certain characteristics. By definition, adults who spend their days in nursing facilities are not in a community-based setting that should receive waiver funds.

2. Consumers must drive the process for receiving HCBS, including being able to make their own decisions on where to live, what providers to use, and what services they need to receive.

Additionally, while the federal rule defines a new person-centered planning process, the Draft Plan does not name specific steps that will bring the state into compliance and should call the process the consumer control and choice process. The traditional person-centered planning model in Ohio is driven by providers and simply urges providers to make decisions about consumers options based on their best interests rather than the interests of the provider. While that is a step in the right direction, the new rule clearly puts person centered planning in control of the consumer, as the process must be initiated and controlled by the consumer, involve individuals of the consumer's choosing, make sure the consumer is fully informed of his or her options, not be drafted by the provider, and reflects the consumer's choice of providers and services. 42 CFR 441.301(c)(1).

In the current plan, the state of Ohio has not identified what changes it plans to make to the person-centered planning process to come into compliance with the rule aside from staff training. However, the new CMS rule requires the provider to be absent in the decision making process. This is very different from Ohio's current model of "person-centered planning." The Draft Plan should mention specific steps to come into compliance with that rule, and for the purpose of Ohio, should identify it as the consumer choice and control process.

3. The planning process should include the input of consumers and families.

The Draft Plan, in part, simply creates the planning process for rules that will bring Ohio in compliance with the new CMS rules. While we would assume that Ohio will seek the input of consumers, family members, and advocates in the various workgroups and meetings set out in the draft plan, it is not written in the plan, and we would like to offer comment that consumers, family members, and advocates should be included in the process of creating such new rules.

The Ability Center is encouraged by some of the changes that will be made under the new CMS rule and Ohio's Draft Plan. The home and community based setting characteristics cited in the CMS rule will offer more dignity and independence to people who are living in provider-owned settings and could bring Ohio closer to a fully inclusive community. However, bringing more dignity and independence to people living in congregate care settings does not make those settings home and community based settings that should receive portions of the limited pot of waiver funds in Ohio.

Olmstead requires that the state of Ohio provide services to consumers in the most integrated setting appropriate. This means that if individuals wish to live in the community, in consumerowned residences, they should have the choice to do so, and that consumers must have their choice of provider. It means that consumers must be assisted by the state to spend their days, too, in a community setting. The current system of care in Ohio raises many barriers to those goals, and waiver funds should be used to further Olmstead implementation rather than to maintain institutional settings with some characteristics of home and community based settings.

We are concerned that the draft plan will allow waiver funds to be used in congregate, rather than community settings, even if those settings are reformed. Because of this, as noted above, we object to the use of waiver funds in the settings noted above, and we object to the implementation of a new Ohio Home and Community Based Services Administration rule that allows services provided in provider-owned congregate care facilities to receive waiver funds.

We appreciate the chance to offer our comments on these issues and look forward to discussing them further.

Sincerely,

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Shelley Papenfuse

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