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Re: Public Comment on Proposed Heightened Scrutiny Information for Residential Services Locations

To Whom It May Concern:

Thank you for the opportunity to comment on the Proposed Heightened Scrutiny Information for Residential Service Locations. This comment is submitted by the Pennsylvania members of Together for Choice. Together for Choice is a national advocacy organization with a mission to protect and advance the rights of individuals with intellectual and developmental disabilities (I/DD). TFC's position is that individuals and their families should have the right to choose from a broad array of residential and vocational service settings, the settings that best meet their needs and preferences.

TFC Pennsylvania's primary concern with respect to ODP's Proposed Heightened Scrutiny Information for Residential Service Locations is that it automatically presumes that all farmsteads, gated communities and campus settings are isolating and therefore subject to heightened scrutiny. This presumption is not consistent with CMS's Settings Rule and its most recent guidance under the Rule issued on March 22, 2019. In fact, ODP's position on farmsteads, gated communities and campus settings is based on CMS's old guidance which CMS specifically revoked when it issued its new guidance this past March. CMS explicitly stated that its new guidance replaced "in totality prior guidance published on the criteria of an isolating settings under 42 CFR 441.301(c)(5)(v); 441.530(a)(2)(v); and 441.710(a)(2)(v)".^{1,2}

¹ *Guidance on Settings that have the effect of isolating individuals receiving HCBS from the Broader Community*

² <https://www.medicaid.gov/sites/default/files/Federal-Policy-Guidance/Downloads/smd19001.pdf>

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Under its new guidance, CMS makes clear that a setting should not be presumed isolating based on its size, locations or type. Instead, CMS identified three characteristics of a setting to determine if the setting should be subject to heightened scrutiny. Those characteristics are: (1) whether a setting limits the individual's opportunities for interaction in or with the broader community, (2) whether the setting restricts individual choice to engage in activities or receive services outside the setting, and (3) whether the setting fails to facilitate access to the broader community consistent with the individual's person-centered plan. Whether a setting has these characteristics cannot be determined based merely on whether it is a farmstead, gated community, or campus setting. Instead, an individualized review of the settings is required to determine whether the individuals served by the setting are receiving the community engagement they desire as set forth in their person-centered plans. In explaining its new guidance, CMS has made it clear that if a setting is providing the community engagement desired by the individuals it serves, it is compliant with the Settings Rule and is not subject to heightened scrutiny.

The new guidance also addressed HCBS Settings in rural communities:

Settings located in rural areas are not automatically presumed to have qualities of an institution, and more specifically, are not considered by CMS as automatically isolating to HCBS beneficiaries. States should only submit a specific setting to CMS for a heightened scrutiny review if the setting has been identified as presumed to have qualities of an institution, and if the state believes that the setting has overcome the presumption. With respect to determining whether a rural setting may be isolating to HCBS beneficiaries, states should compare the access that individuals living in the same geographical area (but who are not receiving Medicaid HCBS) have to engage in the community. See question 2 for the elements of an isolating setting, which states should use to apply to all settings where individuals are receiving Medicaid-funded HCBS, **irrespective of geographic location.** (Answer to Question 3)

The purpose of CMS's revised guidance was to broaden the scope of those settings that comply with the Settings Rule and therefore qualify for Medicaid waiver funding. The revised guidance eliminates the bias against disability-specific settings and focuses instead on outcomes based on choice and person-centered planning "reflected in both individuals' person-centered service plans and the policies and

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practices of the setting.”³ Pennsylvania’s Heightened Scrutiny Information for Residential Locations should do the same.

Eliminating the presumption against farmsteads, gated communities and campus settings is not only consistent with CMS’s latest guidance, it is also good policy. We have met with families whose children had thrived in farmstead settings, but had to transition to small adult group homes once they aged out of the school system because of Pennsylvania’s restrictive policy against farmsteads. One family with two sons with significant behavioral and cognitive challenges shared that in the farmstead setting, their children were safe, confident, and happy being immersed in nature and farming. They lived and worked with peers and coworkers growing organic food, caring for animals, learning trades and living an authentic purposeful life. There was no feeling of isolation and fear. They had access to nearby urban communities and enjoyed outings and shopping. Since moving into a group home four years ago, their sons have experienced increased anxiety, aggression, self-injurious behaviors, weight gain, depression, rages, increased medication use and overall poor health. They have encountered multiple police calls with several ambulance rides to the ER for evaluations following escalated house crisis. They have endured living in a neighborhood cul-de-sac with neighbors who resent their presence.

Their current residential group home has no structured day program. Endless hours and days are spent in their bedrooms lying in bed due to the lack of jobs or planned events. Daily outings may consist of walks, trips to coffee shops, malls and countless hours of van rides to fill their day. Futile attempts have been made at volunteer jobs without direction or success. These young men have become “isolated” in their home, they have no community, peers or life opportunities. They are living a life without purpose or choice and it is causing them needless anxiety and depression.

The above is just one example among hundreds of Pennsylvania citizens who are needlessly harmed by Pennsylvania’s restrictive policy on which settings qualify for Medicaid waiver funding. Pennsylvania must recognize that the diversity of needs and preferences among those with disabilities requires a wide array of settings so that individuals and their families can choose the type of setting that best meets their needs. There is no one size or type of setting that fits all. The true intention of the Settings Rule is to preserve options for individuals receiving Medicaid waiver funding. Those who prefer small homes in neighborhoods should have that option. Similarly, those who prefer a farmstead, campus or gated community should be permitted to make that choice. Pennsylvania’s restrictive policy against

³ *Ibid*

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farmsteads, gated communities and campus settings will only eliminate viable options for the rapidly growing number of individuals with intellectual and developmental disabilities. Let Pennsylvania's individuals with disabilities have the same freedom to choose where to live and work as those who are not disabled.

Please see our additional comments (using "track changes") on Attachments 2 and 3.

Thank you.

Best,

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Together for Choice, Pennsylvania

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