



To: CMS Innovation Center via CMMI_NewDirection@cms.hhs.gov

From: Coalition for Community Choice

Date: November 20, 2017

Re: Feedback on a new direction to promote patient-centered care and test market-driven reforms that empower beneficiaries as consumers, provide price transparency, increase choices and competition to drive quality, reduce costs, and improve outcomes

The Coalition for Community Choice (CCC) is an alliance of organizations, businesses, and housing professionals that strive to meet the housing and employment demand for an array of life options for citizens with Intellectual/Developmental Disabilities (I/DD).¹ The CCC applauds the leadership of the CMS Innovation Center for requesting information from stakeholders on the future direction of its mission. Our expertise spans across the country and includes site visits to over 100 residential opportunities and social enterprises. We would like to submit the following public comments:

1. Local communities across the country are responding to the national housing and long-term support services crisis by developing innovative, supportive housing communities.² Advocates know that without affordable, accessible housing, citizens with autism and I/DD will either become homeless or be forced to access long-term support services in the “next empty bed” of provider-controlled settings such as licensed group homes, nursing facilities, ICF-ID, etc. Although these settings may be appropriate and preferred by some advocates, for those who desire to remain in their communities, a lack of affordable, accessible housing is devastating to neurodiverse citizens and expensive for the taxpayer. Forced placement in “the next empty bed” may remove individuals with I/DD from their communities and negate investment of time and money into developing meaningful routines, employment options, and natural support systems.

¹ Coalition for Community Choice website: <http://coalitionforcommunitychoice.org/>

² Housing Directory of the Autism Housing Network which includes projects that exist, are emerging, and in development: <http://www.autismhousingnetwork.org/housing/>

In response, local communities have developed consumer-controlled, supportive housing solutions that provide non-Medicaid funded amenities and additional support services built into rent e.g., smart home technology, a community engagement specialist, employment navigators, coordination of planned activities on-site and transportation for planned activities off-site, a nurse to assist in health planning, on-call overnight assistance, etc. Residents benefit from the built-in support system and access additional residential supports of their preference. Being consumer-controlled, residents may choose any residential service provider for their individualized direct support needs through a Medicaid HCBS waiver or train and hire their staff through consumer-directed support system.

The investment of supportive housing for citizens with I/DD may 1. significantly decrease traumatic and expensive crisis intervention due to hurting oneself or others, 2. lessen dependence on in-person direct support staff, 3. increase community engagement and integration, 4. increase quality of life, and 5. prevent regression and enhance independent living skills of young adults who graduate from school “into the couch.”

Citizens with I/DD who live in these settings have more control over their home, more engagement with their local community, are rarely lonely, and have exceeded expectations in learning independent living skills. Additionally, the built-in support and amenities of these settings have allowed the opportunity for individuals with low support needs to live independently without an HCBS waiver.

Current federally-funded research, i.e., National Core Indicators³, State of the States in Developmental Disabilities⁴ and the Residential Information System Project⁵, does not include this model of consumer-controlled, supportive housing partnerships. These models are the next phase in the evolution of housing and long-term support service delivery. Quantifying the financial savings and impact of these models on quality of life of neurodiverse citizens is essential.

2. Official CMS guidance for implementation of HCBS Final Rule has created significant barriers to the expansion of local supportive housing solutions and limits the housing choices of citizens who rely on Medicaid.

We applaud the advancement of person-centered thinking of the HCBS Final Rule and its outcome-oriented ethos as described in the CMS HCBS Fact Sheet:⁶

³ Website for National Core Indicators, Human Services Research Institute (HSRI) and The National Association of State Directors of Developmental Disabilities Services (NASDDDS): <https://www.nationalcoreindicators.org/>

⁴ Website for State of the States in Developmental Disabilities, University of Colorado: <http://www.stateofthestates.org/>

⁵ Website for Residential Information System Project, University of Minnesota: <https://risp.umn.edu/>

⁶ CMS Fact Sheet: <https://www.medicaid.gov/medicaid/hcbs/downloads/final-rule-fact-sheet.pdf>

“In this Final Rule, CMS is moving away from defining home and community settings by “what they are not” and toward defining them by the nature and quality of individuals experiences. The home and community-based setting provisions in this final rule establish a more outcome-oriented definition of home and community-based settings, rather than one based solely on a settings location, geography, or physical characteristics.”

CMS guidance in the Settings Requirements Compliance Toolkit⁷, however, has at times reverted to non-outcome based direction such as indicated in the following guidance documents:

- ‘Additional technical guidance on regulatory language regarding settings that isolate’⁸ stigmatizes settings designed for people with disabilities, explicitly listing the following physical setting types without consideration of service delivery options nor consumer preference: farmstead or disability-specific farm community, gated/secured “community” for people with disabilities, residential schools, multiple settings co-located and operationally related, and intentional communities.⁹
- ‘Frequently Asked Questions on Planned Construction and Person-Centered Planning Requirements’¹⁰ describes a strong bias against “presumably institutional” settings without regard for the service delivery model, consumer preference of housing models, outcomes of residents, nor other evidence that a setting is institutional, *“It was CMS’ expectation that after the publication of the final regulation, stakeholders would not invest in the construction of settings that are presumed to have institutional qualities ...CMS strongly encourages states to limit the growth of these settings.”* State Medicaid authorities cite this guidance to dissuade local development of supportive housing opportunities without consideration that consumer-controlled, supportive housing has an entirely different service delivery system and, most importantly, that citizens with I/DD are demanding these intentional community¹¹ options.

Limiting an individual's choice to live in a preferred setting by withholding a person’s essential life supports is against the intent of the HCBS Final Rule that underscores person-centeredness and the CMS ethos of “putting patients first.” Attached is a legal memo describing the legal vulnerabilities of CMS “settings rule” and subsequent guidance.¹²

⁷ HCBS Settings Requirements Compliance Toolkit: <https://www.medicaid.gov/medicaid/hcbs/guidance/index.html>

⁸ CMS Guidance On Settings That Have The Effect Of Isolating Individuals Receiving HCBS From The Broader Community: <https://www.medicaid.gov/medicaid/hcbs/downloads/settings-that-isolate.pdf>

⁹ “Intentional communities” stated in person by Ralph Lollar and in text at the National HCBS Conference:

¹⁰ CMS Guidance on Planned Construction of Presumed Institutional Settings: <https://www.medicaid.gov/medicaid/hcbs/downloads/faq-planned-construction.pdf>

¹¹ Fellowship for Intentional Community website offers definition of intentional community: <https://www.ic.org/>

¹² Legal memo can be accessed on the Coalition for Community Choice website: <http://www.coalitionforcommunitychoice.org/legal-vulnerabilities-of-cms-regulation-of-home-and-community-based-settings/>

We request that CMS revisit the guidance documents cited above and provide additional guidance on consumer-controlled, supportive housing settings.

3. Promote and provide incentives for an investment of homeownership to decrease dependence on the rental market and increase the use of consumer-directed support services instead of forced placement in provider controlled settings.

With the inability to earn a living wage due to impairment or limitations on earned income that would disqualify a person from Medicaid, market rate rent is well out of reach and subsidized housing is extremely limited. As described above, it is this lack of affordable or accessible housing that forces neurodiverse citizens into more expensive provider-controlled or institutional settings.

The Autism Housing Network powered by Madison House Autism Foundation guides families and encourages saving money early for the lifespan needs of their loved ones with autism or other I/DD.¹³ When informed of options, families have an increased interest in investing in the future housing stability of their loved one. Medicaid should continue to work with HUD and other agencies to raise awareness and incentivize investment in ownership models including neurodiverse cohousing communities¹⁴, accessory dwelling units on family property¹⁵, tiny homes¹⁶, independent apartment communities¹⁷, and sharing in the investment of purchasing property or a single-family home.

The Coalition for Community Choice looks forward to continuing to support the important work of the CMS Innovation Center.

Respectfully submitted,
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¹³ Autism Housing Network: <http://www.autismhousingnetwork.org/>

¹⁴ Article 'Neurodiverse Cohousing: What is it, and why does it matter?':
<http://www.autismhousingnetwork.org/neurodiverse-cohousing-matter/>

¹⁵ Article, 'Putting Accessory Dwelling Units in Reach for Families':
<http://www.autismhousingnetwork.org/mhaf-guest-author-catherine-boyle-putting-accessory-units-reach-families/>

¹⁶ Article, '5 Reasons Why Autistic Adults Should Consider Tiny Homes':
<http://www.autismhousingnetwork.org/5-reasons-autistic-adults-consider-tiny-homes/>

¹⁷ Article, 'Independent Apartment Communities: What Are They, and Why Do They Matter?':
<http://www.autismhousingnetwork.org/independent-apartment-communities-what-are-they-and-why-do-they-matter/>