

The Coalition for Community Choice (CCC) is a unified voice for increasing options and decreasing barriers to housing choices.

# HOME IS WHERE THE HEART IS

BY DESIREE KAMEKA AND TAMIE HOPP

## DID YOU KNOW...

- *In the next decade, over 800,000 adults with autism will transition to adulthood.*
- *5 million people have autism or other intellectual and developmental disabilities (I/DDs), but residential placements are only available for 613,000 and barely increasing to meet the current need.*
- *Almost one million individuals with intellectual and/or developmental disabilities are still living with caregivers over the age of 60.*
- *Current data shows that there are still more than 200,000 individuals younger than 65 in nursing homes—almost 16 percent of the total nursing home population.*

In response to these staggering statistics, there is an awesome movement of families and local organizations working together as the new Coalition for Community Choice to create local solutions to this national housing and support service crisis. They are organized and sharing information at conferences, on blogs, and on the recently released Autism Housing Network ([autismhousingnetwork.org](http://autismhousingnetwork.org)). This collective energy and collaboration is in direct response to efforts by some government officials and even advocacy organizations to limit and eliminate certain options based solely on residence or workplace size and location, without assessing the smiles, laughter, sustainability, job security and true empowering sense of community and belonging that is alive and well in these residential and vocational opportunities.

## WHAT DOES POLICY HAVE TO DO WITH HOUSING, EMPLOYMENT AND SERVICE CHOICES?

Federal policy and laws are largely responsible for how long term support services (LTSS) are regulated and funded.

In one recent, significant example, the Affordable Care Act of 2010 required that the Centers for Medicare & Medicaid Services (CMS) modify their regulations (“rules”). This process began several years ago when CMS released their first proposed rule change that defined what settings people with disabilities could use for their Home & Community-Based Services (HCBS), a LTSS funding resource that offers people the chance for greater choice of their

desired home setting and service providers.

Ultimately, after three rounds of comments, CMS officials were charged with reconciling thousands of comments from individual and family advocates, states, providers, and organizations representing both older adults and people with disabilities relating to “home” and “community” perspectives.

On January 10, 2014, CMS released the long-awaited final version of the rule [CMS 2249-F and CMS 2296-F; 79 Federal Register 2948 et seq. (January 16, 2014)]. The rule itself and CMS-developed fact sheets can be found at [www.medicaid.gov/hcbs](http://www.medicaid.gov/hcbs). The new rule defines what CMS considers to be characteristics of community living and vocational opportunities for people with intellectual and developmental disabilities (I/DD) and person-centered plan-



## AUTISM HOUSING NETWORK

The Autism Housing Network exists as a platform for creating and sharing great housing options and resources for autistic adults and others with intellectual / developmental disabilities (I/DD).

where they call home and receive services may be at risk of losing funding. According to the new rule, HCBS-funded supports may not be received in a setting that does not meet the new HCBS “community” criteria. Some existing and emerging innovative housing, vocational and day program options, such as agricultural and planned/intentional residential communities for people with I/DD and autism, may be in jeopardy simply due to their size and/or location, without any regard for the quality of person-centered programming or an individual’s desire to live and/or work in that setting.

Upon implementation, if a State and/or CMS upon application by a State, decides to implement a rigid interpretation of “community”, individuals receiving HCBS-funded supports may find themselves losing funding in settings no longer considered “community enough,” regardless of the individual’s choice. Housing and vocational settings must meet certain “outcome-oriented” HCBS criteria:

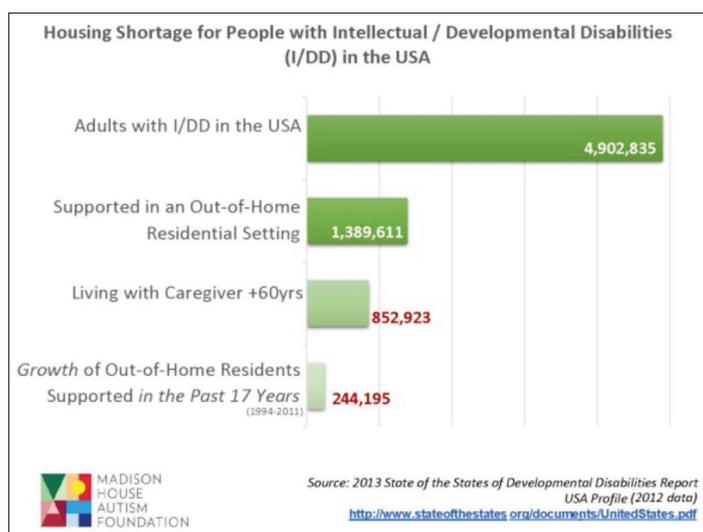
ning requirements, for the purpose of receiving funding via Medicaid’s 1915(c) HCBS Waiver program, 1915(i) HCBS State Plan Option, and 1915(k) Community First Choice.

For some individuals with I/DD and autism,

- Is selected by the individual from among setting options;
- Ensures individual rights of privacy, dignity and respect, and freedom from coercion and restraint;
- Optimizes autonomy and independence in making life choices; and
- Facilitates choice regarding services and who provides them.

## COLLECTIVE ADVOCACY AND ITS IMPACT ON HOUSING AND VOCATIONAL OPTIONS FOR PEOPLE WITH I/DD AND AUTISM

Realizing our voices were disconnected, the newly formed Coalition for Community Choice (CCC) is bringing together organizations that believe people with disabilities have the right to choose from a full array of housing, lifestyle and support service options. Respect for individual choice is at the core of CCC's current objectives, and the impetus for its formation.



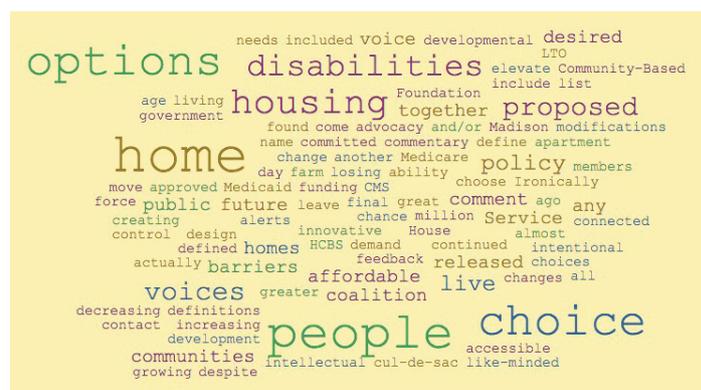
The new federal rule includes some positive changes due to our unified advocacy, as well as continued opportunities for stakeholder input. This is a bittersweet victory for choice advocates, including CCC. Despite our gains, serious challenges to choice remain. Although CMS left the door open, many individuals with I/DD and autism, their families and advocates must convince states to defend their homes and workplaces as community integrated and not institutional, consistent with the new rule, or face being displaced.

As a national grassroots collaboration of persons with disabilities, their families and friends, disability rights advocates, professionals, educators, and housing and services providers, the Coalition for Community Choice wants to send the message that community can be experienced in all residential or vocational settings and the choices of people with disabilities, as outlined in their person-centered plan, must be honored!

## ADVOCACY CHALLENGES & OPPORTUNITIES AHEAD

In one year, states must demonstrate to CMS with public input that current HCBS waivers are funding eligible "community" settings, or describe what changes will be made to ensure compliance.

As the rule requires ongoing stakeholder input at the state and federal levels, our voices will be heard! Housing and service choice advocates are compelled to remain involved and provide input at every opportunity. Although CMS supports "meaningful choice" among all available residential options, the bias against congregate settings that offer friendships and benefits from living together and accessing services and amenities in intentionally planned communities remains. The final rule presumes that any form of congregate care to be institutional and not community, so we must prove that this stigma is not always true. It will be up to choice advocates to (1) urge states to seek HCBS funding for such settings, and (2) urge federal reviewers to approve such applications. Check out our policy brief and action steps on the Autism Housing Network.



## CONCLUSION

The Coalition for Community Choice (CCC) will remain a unified voice for advancing solutions for increasing options and decreasing barriers to housing and employment, and providing true communities for adults with I/DD and autism. The need, now and in the future, is significant.

In light of the staggering figures above, CCC will remain united in support of strategies to ensure that people with I/DD and autism, not government officials, define their own home and community. People, who have found their sense of belonging and purpose in intentional communities, who live and work in farm communities, who are planning to move into an apartment building with "smart home" technology and design strategies for their unique needs, or who choose to live in neighboring homes with their peers on the same cul-de-sac, have the right to live in that home and community of their choice. Join us in increasing options and decreasing barriers to home and community choices!

If you would like to be involved in the Coalition for Community Choice, please visit [autismhousingnetwork.org](http://autismhousingnetwork.org) to learn more, or contact [thopp@vor.net](mailto:thopp@vor.net) or [DKameka@MadisonHouseAutism.org](mailto:DKameka@MadisonHouseAutism.org).

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