

**Response to the Advanced Notice of Proposed Rule Making for
CMS-2296-P, Medicaid Program Home and Community-Based Services
(HCBS) Waivers**

**Submitted by
A Four-State Alliance for ASDs Adult Community Housing and Living
and
The Autistic Global Initiative (AGI)**

We applaud CMS and HHS Secretary Sebelius for striving to make positive changes to HCBS regulations. This correspondence responds to **the ANPRM, detailed in CMS-2296-P. While in some instances the proposed rule change is supportive of the populations we represent, there are several instances where a sweeping rule change negatively impacts individuals with autism spectrum disorders (ASDs) and related disorders, and does not afford the nuanced diversity of needs and supports that the terms “person-centered” and “community-based” imply.**

Description of the Four-State Alliance and Autistic Global Initiative

Participants in this comment letter have come together for a specific purpose: to offer a collaborative statement that combines multiple perspectives from the autism community. In doing so, we offer commentary that includes self-advocates with ASDs, parents of individuals with autism, service providers, and professionals working in the autism and developmental disability fields. Although we hold a variety of opinions and beliefs, we find the process of understanding one another to be our strength, the result of which is this letter. We share the fundamental values that housing options for our citizens with ASDs and other developmental disabilities must support individuals’ safety and security, enable them to enjoy meaningful, productive lives, recognize their value within the broader community and promote choices for them and their families.

A Four-State Alliance for ASDs Adult Community Housing and Living

The members of a recently formed Four-State Alliance are all parents of aging teens and young adults diagnosed with ASDs. Their children include both those with some of the most challenging symptoms on the spectrum, and those who are viewed as higher functioning, but still need significant supports to live and work in the community. Each member has founded a well-respected organization that provides training to parents and service providers. Members include: Karen Kaye-Beall (Maryland), Cyndy Hayes (New Jersey), Denise D. Resnik (Arizona), Catherine Boyle (Massachusetts). Refer to the appendix for biographies.

The purpose of the alliance is to pull together the relevant federal and state agencies, nonprofits and private interests committed to creating a new paradigm that fills the services void for those aging with autism through comprehensive family training and

technical assistance for self-managed programs and through social innovation involving housing, employment and community support.

The Autistic Global Initiative

The Autistic Global Initiative (AGI), a program of the Autism Research Institute (ARI), is comprised of a committee of adults diagnosed with autism spectrum conditions. AGI members hail from all regions of the United States, representing the broad life span of autistic experience and expression. AGI members are active as professionals and consultants in many fields within the autism community, including education, social work, medicine, employment, fitness/wellness, rehabilitation counseling and the visual and graphic arts. Many members of AGI are also parents of individuals with ASDs and other developmental and intellectual disabilities. The group holds a centrist, no-nonsense view within the disability community. Key objectives are to:

- Build capacity in the adult services sectors through the development and implementation of promising and evidence-based curricula and trainings for autistic people, for their families, and for the adult service providers who support them;
- Engage in national level advocacy work with other groups and organizations to raise awareness and effect policy improvements/change with regard to the quality of life and citizenship of adults with ASDs; and
- Serve as a self-advocacy consulting group, bringing experiences as self-advocates on the spectrum and as practicing professionals in the fields to others who wish to create or improve upon person-centered practice, self-determination and universal design in their organizations, places of employment, housing environments, communities and more.

Members of the AGI Executive and Special Projects Committees include: Valerie Paradiz, PhD (California), Judy Endow, MSW (Wisconsin), Janine Collins, MSW, MTS (Maine), Ruth Elaine Hane (Minnesota), Zosia Zaks, CRC (Maryland), Paul Nussbaum (California), Charles Joiner, MD, PhD (Ohio), Sondra Williams (Ohio), and Robyn Heffelfinger (Arizona). Biographies are provided in the appendix.

Introduction to Comments on CMS-2296-P

CMS' ANPRM covers three main topics:

- removal of regulatory barriers to serve more than one target group in a single waiver,
- definition of home and community characteristics, and
- underpinning each of the above areas, requirements for person-centered planning.

In the next pages, we submit comments on each of these topics. First, we provide excerpts from the ANPRM, accompanied by a summary of our issues, then we offer exposition of critical issues.

In addition to our efforts to include an array of individuals from as many states as possible in our collaborative comment, we also suggest state agencies facilitate public input processes specifically for the proposed HCBS changes. News of the proposed changes must be more widely publicized to consumers and their families than has occurred, to date.

Our Comments on CMS-2296-P

1. Combining Targeted Groups within One Waiver

ANPRM	Critical Points
<p><i>A Federal regulatory change that permits combining targeted groups within one waiver would remove a barrier for States that wish to design a waiver that meets the needs of more than one target population.</i></p>	<p>a. The change should not result in a diminution of current services and supports.</p>
	<p>b. Those affected must have information and tools to negotiate the change in service provision.</p>

Exposition:

- a. The change should not result in a diminution of current services and supports:

There is a danger that a waiver serving multiple target groups will result in providers who have expertise with only one group, yet attempt to be all things to all people. Safeguards must exist to ensure that appropriate supports remain in place in settings where multiple groups are supported, and that hours are not reduced.

- b. Those affected must have information and tools to negotiate the change:

Families and individuals must have the information and tools they need to navigate the reorganization of service provision. For example, stakeholders have reported a number of gaps within state developmental disabilities systems and conclude that existing services do not “fit” adults with autism spectrum disorders (ASDs). Transitioning youth and adults with ASDs generally receive services through programs designed for persons with mental illness or other intellectual or physical disabilities that are much less focused on the unique needs of the ASD target group. Indeed, there is an overall perception by family members that, with the exception of a relatively small handful of exceptional vendors, service providers are not meeting the needs of adults with autism.¹ Thus, while housing does not necessarily need to be designed around a diagnosis, this does not mean that the characteristics of the disability can be ignored.

One explicit example of this phenomenon is the case of a young man who transitioned from a residential school for students with autism into an adult residential program. Staff in the new setting provided him with no schedules, no visual supports and no choices, all of which are standard, evidence-based tools used with individuals with autism to support them in everyday environments. These simple supports, which had proven invaluable to him while in school, caused his challenging behaviors to recede. However, within six months in the new setting, the young man put his head through a closed window.

This incident illustrates a failure to implement best practices for adults with autism, in spite of the fact they have been widely adopted for children on the spectrum.

Additionally, further research is a pre-requisite to widespread adoption of evidence-based practices for adults with autism. According to “Autism Spectrum Disorders (ASDs) Services: Final Report on Environmental Scan,” which was submitted to CMS in 2010, few models that address the needs of adults with autism have been studied to date, and only one-third are considered to be evidence-based. This point is underscored in the January 2011 Interagency Autism Coordinating Committee (IACC) Strategic Plan for Autism Spectrum Disorder Research:

Although considerable research has focused on the earliest phase of ASD, including early screening, improved diagnostics, and early intervention, far less effort has addressed the adolescent, adult, and older adult phases of life. Minimal guidance exists for people with ASD across the spectrum and their families about the trajectories of ASD across the lifespan. Although the general assumption is that children who possess expressive and receptive language skills and coping strategies and who do not demonstrate significant challenging behaviors can sometimes excel as adults, while children who do not currently possess typical expressive language skills and who engage in significant challenging behavior will grow up to need long-term, 24/7 supports and services, the evidence base for these ideas is lacking. Scientists have not yet identified key prognostic factors or detailed information about how adults across the spectrum with ASD function, where they are, and how they are best supported. More research is needed to tailor treatments, interventions, and services and supports to the evolving needs of adolescents transitioning to adulthood, and adults across the spectrum with ASD.²

In view of this situation, it is also worth noting that the two areas of the IACC’s Strategic Plan that have received the least amount of funding are: services research (1%) and research on lifespan issues, including transition into adulthood (5%).³

The Centers for Medicare & Medicaid Services (CMS) ASD Services Project’s “Report on State Services to Individuals with Autism Spectrum Disorders (ASDs)” identifies a number of elements instrumental to implementation of evidence-based practices:

Training clinicians, educators, and program staff about ASD standards, evidence, and methods is fundamental to provider readiness and the capacity of systems to deliver sound and effective services. In most states, university partnerships are instrumental in meeting training and technical assistance objectives.

Manualized standards and training programs are needed to promote quality and assure consistency in the application of evidence-based/promising practice methods. Careful data collection and analysis is essential to care planning, quality improvement, program evaluation, and research directed at producing the next generation of evidence-based practices.⁴

Aside from states providing CMS the standard assurances regarding necessary safeguards taken to protect the health safety and welfare of persons receiving HCBS waivers, including service provider standards and facilities compliance with state standards, states

should also provide safeguards concerning use of restraints and other restrictive interventions; medication management and administration; quality improvement measures and staff training regarding abuse, neglect and exploitation; verification of staff criminal background checks; and reportable events.

Given the astonishing rise in the rate of autism diagnoses in the past 15 years, and the more than 500,000 children entering adulthood in the next decade alone,⁵ the infrastructure for housing, employment and community supports must significantly expand.

Yet, after more than 40 years of funding increases to Medicaid, budgets are now being dramatically cut. In order to ensure that those with the greatest need receive the scarce resources that remain a “New Service Paradigm” (NSP) is being implemented.⁶ Under this new paradigm, 24/7 support resources will shift to those who are most in need; whose support requirements reflect that they are either a danger to themselves or to others; or who are at immediate risk of becoming homeless.

For those whose needs are not as severe, they will be asked to stay at home much longer with their parents, their siblings or other extended family. This group will be offered a menu of service packages and options to assist their families in long-term care, either within the family home or in the community. The result: families will be operating as case managers and service providers. Proper training by support brokers/coordinators in self-determination and self-direction models will become indispensable. In order for the New Service Paradigm to even function, people with disabilities, their families and other support providers at home must be informed, empowered and prepared to understand and determine the level of supports and housing costs they will have to shoulder.⁷

For those who receive 24/7 supports, training of individuals, their families and support providers are equally important. In many cases, models that separate control of the housing from services offer greater stability for the individual and greater flexibility. Should an individual’s needs change or should there be a desire to change service providers, then the individual does not have to relocate. Individuals and families will need training as they move from the role of service recipient to service manager.

2. Defining HBSC Settings

ANPRM	Critical Points
<i>HCBS settings [...] must not be a housing complex designed expressly around an individual's diagnosis or disability [...]</i>	a. Settings created must nevertheless recognize the characteristics of individuals with autism and provide appropriate evidence-based supports.
<i>[T]he settings must not have qualities of an institution [...] Such qualities may include regimented meal and sleep times, limitations on visitors, lack of privacy and other attributes that limit an individual's ability to engage freely in the community.</i>	b. One size cannot fit all. The most important principle of self-directed housing is that it encourages community integration and affords choice in daily life.
<i>[C]ertain settings are not home and community-based because they are not integrated in the community. A setting that is integrated in the community is a setting that enables individuals with disabilities to interact with individuals without disabilities to the fullest extent possible. Further [...]</i>	c. The current fiscal environment is not a time to discourage innovation in either design or service delivery.
<i>such settings do not preclude individuals' ability to access community activities at times, frequencies and with persons of their choosing. Such settings are not segregated based on disability, either physically or because of setting characteristics, from the larger community [...]</i>	d. Many individuals already use waivers for intentional or agricultural communities.
<i>such settings will afford individuals choice in their daily life activities, such as eating, bathing, sleeping, visiting and other typical daily activities.</i>	e. The purpose of HCBS waivers is to promote choices for individuals.

Exposition:

- a. Settings created must nevertheless recognize the characteristics of individuals with autism:

They must also provide appropriate evidence-based supports; this has implications for training of families and staff, that support a variety of modalities for effective daily life skills training and behavioral therapies which advance the goals of the individual and promote quality of life.

- b. One size cannot fit all:

Our position is simple. One size does not, must not and cannot fit all. A policy that rules out entire housing models cannot be described as person-centered. The most important principle of self-directed housing is that it encourages community integration and affords choice in daily life. Provided this is safeguarded, individuals should not be precluded by regulation from *choosing* an intentional, clustered or congregate setting. For some, these settings provide the greatest autonomy combined with appropriate supports and because they address specific aspects of autistic experience and challenge (sensory, behavioral, social), they naturally attract individuals with similar diagnoses and traits.

It's imperative to underscore that living with a group of people does not automatically replicate institutional conditions. The factors that decrease isolation and increase community integration are neither due to the number of occupants in a residence, nor to the specific location of a residence. Rather, community integration is directly related to the degree of self-direction the individual has over his or her daily living, as well as policies and supports that foster successful community participation.

Consider that people without disabilities make choices to live in groups for various social, economic or ideological reasons. As citizens, people with disabilities should not be disqualified or prevented from the same freedoms. For example, living in a group situation can provide both social and financial benefits. Such settings can also offer greater safety, access to shared resources, and new integration opportunities through mutual support, encouragement and planning.

While not eschewing entirely options for single-occupancy or "family style" residences of just a few people, CMS funds should also support housing models that include agricultural and other types of intentional communities in urban, rural and suburban environments, maximizing choice and opportunities to be close to where other family members or friends live. Intentional communities can simultaneously address several societal needs at once. For example, disabled and non-disabled people can live together intentionally, reducing isolation for all, while meeting the needs of each person through mutual support and cooperative commercial and non-commercial endeavors. The Camphill communities of Upstate New York, Lambs Farm just north of Chicago and other locations in the U.S. illustrate this successful model.

Aside from questions of choice, for certain individuals an intentional or congregate community results in greater autonomy than in a small group home.

Consider the case of a young man with a history of severe aggression, who is able to participate in activities at a school serving individuals with autism with one teacher faded to 20 feet away. For the same young man, community excursions require close supervision by a team of three teachers assigned exclusively to him. Clearly, he experiences greater freedom in the congregate setting, where fading of supervision is possible because adequate staff is present on the premises and the young man is more relaxed in a predictable setting. In fact, he actually self-limits the amount of time he chooses to spend in the community to self-regulate.

Parents of young adults with autism who elope or become aggressive tend to flock in large numbers toward the rural, agricultural model. This has a lot to do with families' wish to avoid the potential encounters and misunderstanding with police in areas where law enforcement have not yet been adequately trained interpreting or identifying common autistic behaviors.

Unfortunately, as a result of forced and horrendous institutionalization, and decades if not centuries of a custodial attitude that infantilized disabled people, many self-advocates propose a policy of absolutely no restrictions on the activities and events of an ordinary

life. The idea that an individual should be allowed to determine what he does, when and under what conditions is fundamental to our society's understanding of individual liberty. As long as a person is not in violation of anyone else's rights, Americans pride themselves on being the nation that has legalized the right to "pursue happiness."

Tension arises when society confronts the reality of disability as expressed in some individuals. What if a person cannot keep himself or herself safe? What if a person cannot or will not complete basic tasks of daily life such as eating, bathing, going to the bathroom, dressing or sleeping? What if a person is severely restricted in his or her ability to communicate preferences? What if a person does not understand the consequences of an action or choice? Should people be left to do as they please anyway, because society does not want to risk affronting personal freedom?

In some instances, supports, programs and training that enable participation in a community may necessarily include restrictions that ultimately facilitate the creation of a meaningful life. For example, some individuals with disabilities do require visitation guidelines so the individual remains safe and free to enjoy life. The person should never be barred from visiting and spending time with loving family, friends, neighbors and intimate companions of the person's own choosing. But a policy that bars an integrated community living program from instituting any rules around visitation is actually neglectful toward citizens who cannot adjudicate nuances such as who is a safe visitor or at what times visiting is appropriate. Rather than adopting a policy at the extremes of either the totally restrictive and isolative life of an institution or the absolute freedom to do as one pleases, housing options must take a multidimensional approach, providing the person with reasonable visitation guidelines that do not violate his or her volition. Additional training in other skills and opportunities are also essential for some people with autism and related disabilities, such as social skills training to increase the individual's ability to make appropriate social choices, opportunities to participate in ever-widening social activities that take into account the person's needs and preferences, and the right to socialize in non-normative ways, such as remaining quiet at a party but still being present.

Similarly, some individuals with disabilities do require eating and sleeping guidelines so the individual may remain healthy and regulated. One would not say that a diabetic has lost his or her personal freedom just because now diet and eating times must be carefully scheduled. People with a variety of disabilities who require regular eating times, restricted diets, restricted access to food, or regular sleep and wake cycles can be accommodated without violating the person's right to express preferences, access various areas of his or her home, or decide what he or she wants to do that day.

Technology is poised to play a unique role in achieving this balance. For example, if someone has a disability that predisposes the person to eating uncontrolled amounts of food, a refrigerator or pantry can be installed in the kitchen that requires a code to open. Then, the person can still go into the kitchen any time he or she wants to, without being in danger. Additionally, a basket or small personal fridge filled with a few allowed items can be placed in the kitchen so the person can retrieve a snack whenever he or she wants

to, without staff assistance or interference, and without the risk of uncontrolled eating. In sum, regular meal times, regular sleep times, regulated diets, and installed safety protocols do not simultaneously have to violate a person's liberty or choices.

The role of technology underscores another reason for the attraction of congregate settings. Rarely does the wider/larger community build conventional, commercial housing that supports the needs of those most impacted by autism and other sensory integrative dysfunctions. Discussions with service providers and contractors indicate that extensive retrofitting of features—such as sound-proofing, abuse-resistant drywall, bathroom floor drains and “smart-home” technology—are frequently more expensive than new construction. Families may choose to gravitate toward a home that includes such specially adapted features and, by choosing to do so, create a small but congregate setting that serves individuals with similar diagnoses and traits. This is not simply a question of cost savings, but of safety.

c. The current fiscal environment is not a time to discourage innovation in either design or service delivery:

The reality of the fiscal environment is that fixating on a certain number of residents results in fewer people being served and more on waiting lists. One resident in a four-person setting can be the “odd man out,” while an eight-person house may lead to more fluid social groupings. Similarly, in a four-person house, when a single staff person calls in sick, the presence of a substitute causes more disruption to the routine than it does in a larger home supported by additional staff.

In contemplating an eight-person house, consider that not everyone is required to engage in the same activities at the same time – that is not autonomy. But in a haste to prevent the errors of the past, let us not forego the opportunity to explore creative design possibilities. One example might be single room occupancy (SRO) housing in which individuals have their own large rooms with half-baths, refrigerators and microwaves, yet also share common rooms, allowing for both socialization and solitude as desired. The use of technology could allow for adequate staff support, while remaining unobtrusive. A duplex with four SROs in each half, plus an accessory apartment for live-in staff, would maximize the value of Sec. 8 vouchers (as two four-bedroom vouchers are worth more than one eight-bedroom voucher), maximize autonomy and privacy, and still have some economy of scale.

While economies of scale are usually seen as limiting the autonomy of individuals, there are instances where the opposite is true. In the presence of a strong staff support and training program, staff members have the confidence to support individuals in activities in which they might otherwise restrict participation.

An example of this is the young man with maladaptive behaviors who went swimming regularly while attending school, but is no longer taken swimming since moving into a residence “in the community.”

Another example of a new and innovative model is the construction of homes built on the edge of properties, controlled by places of worship, and where congregation members provide volunteers to serve as extended circles of support.

The key criteria of any housing model being considered a community placement should not be numbers or design, but adherence to the key principles that individuals have the right to choices in their daily lives, to interact with those without disabilities and to access the community. In that regard, it may be an additional useful requirement for all models to provide DD officials with a written plan for (1) integrating residents into the activities of the closest town and (2) developing social circles of support that include members of the broader community as an extra safeguard against too much isolation.

d. Many individuals already use waivers for intentional or agricultural communities:

In addition to those who already use waivers for intentional or agricultural communities, others participate in such communities while on the waiting list for waivers. Neither group should be forced to choose between their home and accepting a waiver. We are concerned about the impact this proposed rule could have on family-driven communities, including agricultural communities. As the *Opening Doors* report on autism and housing produced by the Southwest Autism Research & Resource Center states:

Many [agricultural] communities start with families coming together to create a model. Waiting lists at all of the communities studied are long and openings are rare ... [locations] “near to town” (many within walking distance) ... enhance integration into the larger community through many available activities, including innovative community supported agriculture (CSA) programs, greenmarket and food bank initiatives, and partnerships with other community-based nonprofits and faith-based groups.⁸

The report goes on to say that waiver funds comprise part of the funding streams of agricultural communities in some instances. The proposed rule could be interpreted as removing this option for individuals using HCBS waivers. Furthermore, it could mean that individuals currently using waivers for this purpose would no longer be able to do so, and thus might be forced to leave their residences.

It is important not to lose sight of the fact that the wait for a HCBS waiver can take years, if not decades. In the interim, families will, of necessity, engage in the creation of innovative housing models, including intentional communities that provide both a supportive environment and economies of scale. By the time a waiver becomes available, an individual may be thoroughly ensconced in such a community. If the proposed rule prohibits the use of a waiver in an intentional community, the family is now faced with the prospect of uprooting their family member in order to accept the waiver. Such a prospect should rightfully be considered intolerable.

e. The purpose of HCBS waivers is to promote choices for individuals:

Choice should rest with the waiver recipient and not be dictated by policy. In keeping within the ideals of a person-centered approach, a broad menu of options must be available, similar to the processes that took place under “Money Follows the Person.” Some people may wish to live with those who have the same diagnosis; some may not. This should be their decision, in consultation with their families and/or closest allies.

3. HBSC and Assisted Living Models

ANPRM	Critical Points
<p><i>The comments noted that persons who are older with and without disabilities may choose to live together in assisted living facilities and urged CMS to allow them to exercise this preference and receive waiver services. Similarly, some persons who are older may desire to live in retirement communities, such as continuing care retirement communities. As a result, in accordance with a person-centered plan, we will allow such settings to be permissible under the section 1915(c) HCBS program for older persons under certain circumstances, which are noted below.</i></p>	<p>a. Assisted living models should not be arbitrary, by becoming limited to those of a certain age.</p>

Exposition:

- a. Assisted living models should not be arbitrary, by becoming limited to those of a certain age:

Assisted living options should be available to those who choose them and for whom they are appropriate, regardless of age. For some, assisted living may in fact be a viable model of inclusive living.

4. Person-Centered Planning

ANPRM	Critical Points
<p><i>Underpinning all aspects of successful HCBS is the importance of a complete and inclusive person-centered planning process that addresses health and long-term services and support needs in a manner that reflects individual preferences. To fully meet individual needs and ensure meaningful access to their surrounding community, systems that deliver HCBS must be based upon a strong foundation of person-centered planning and approaches to service delivery.</i></p>	<p>a. Successfully transforming a person-centered plan to a self-directed life requires weaving existing programs and funding streams with natural supports into new patterns.</p>

Exposition:

- a. Successfully transforming a person-centered plan to a self-directed life requires weaving existing programs and funding streams with natural supports into new patterns:

The move to person-centered planning gives individuals, their allies and families unprecedented ability to direct their futures. However, outcomes are likely to be poor unless training is provided to the relevant stakeholders. To coordinate these elements, all affected require training about what is both positive and possible. A commitment to person-centered planning must encompass a commitment to providing and funding such training.

Preliminary survey results in Maryland,⁹ as well as conversations with family members in other states, reveal that many families with adult children on the autism spectrum do not even know what a Sec. 8 voucher is. This is indicative of the scope of the challenge.

Additionally, it is unclear that families can look to case managers to guide them. A study in Texas found families reporting that state case managers had little to no specialized training in how to work with people on the autism spectrum. Furthermore,

a surprising number of parents reported that they abandoned their careers to, effectively, become their child's case manager. For most families, this is not a feasible option. Even for those that are currently filling this role, in addition to the personal sacrifices that are required, they expressed concerns about how their children will fare when the parents are no longer able to care for them.¹⁰

A common point raised in the deliberations of autism commissions in Maryland, New Jersey, Massachusetts, Arizona, New York and California is the need to provide individuals and their families with a single point of entry to the system, which could in turn refer them to appropriate resources. Conceptually, such single points of entry might be similar to ADRC's One-Stop Centers or the Centers for Independent Living, but would specialize in autism. While this might imply duplication or overlap with the above-named centers, it is relevant to cite the findings of the "Report on State Services to Individuals with Autism Spectrum Disorders (ASDs)."

All states interviewed indicated that, although adults with ASDs need a range of rehabilitative, employment, housing, supportive and therapeutic services that are similar to those delivered in developmental disabilities and behavioral health systems, the optimal approach to serve them should be tailored to their specific needs.¹¹

Massachusetts has, in fact, done something similar in establishing seven autism support centers around the state, although they only serve children. The ASCs are independent non-profits that receive funding through the Massachusetts Department of Developmental Services.

“Autism One-Stops” could also fill a niche by acting as a focal point for training of service providers. Appropriate curriculum topics would include sensory integration, positive behavioral supports, visual supports, executive functioning, social skills training, supporting the emerging self-advocate, staffing ratios and crisis training. In so doing, Autism One-Stops would answer the call of Advancing Futures for Adults with Autism (AFAA), representing a collaboration of 14 organizations, and the AFAA *National Public Policy Agenda*, which prioritizes the training of direct care workers to provide vocational and residential assistance to adults living with autism.”¹²

Obviously, the primary stakeholder community is comprised of self-advocates. In addition to providing self-advocates with the same services provided to family members, “Autism One-Stops” would also be a logical focal point for training of self-advocates, and training in the use of Augmentative and Alternative Communication (AAC).

Considering that HCBS costs 50%-75% less than institutional care,¹³ it is certainly worth the expense of providing stakeholder training to ensure that person-centered approaches live up to their promise. Further, it costs 41% less to provide permanent supported housing than it does to serve someone in a state of homelessness.¹⁴

4. Issues Regarding State Compliance

ANPRM	Critical Points
<p><i>[W]e identify serious quality issues, such as potential harm to individual health and welfare or significant financial concerns, and States fail to take appropriate remedial action, the only enforcement options addressed in the regulations are for CMS to refuse to renew the waiver or terminate the waiver [...] We are interested in specifying a broader array of approaches CMS may take to achieve and maintain full State compliance with the requirements specified in or under section 1915(c) of the Act in addition to waiver termination.</i></p>	<p>a. The standard audit process is the best way to achieve compliance.</p>
	<p>b. Providers need to have a way to cover the cost of staff and family trainings if compliance is to improve.</p>
	<p>c. CMS must avoid cutting hours and reimbursement rates if health and safety are to be maintained and experienced providers are to remain in the field.</p>

Exposition:

- a. The standard audit process is the best way to achieve compliance:

Medicaid aspires to achieve high compliance without having to terminate non-compliant waivers. The standard audit process is the best way to achieve compliance, allowing CMS to recover questionable billings and requiring individual service providers to pay these recoveries back if they do not comply.

Moreover, in terms of financial accountability, states should assure financial accountability for funds expended for home- and community-based services, and maintain and make available to the Department of Health and Human Services (including the Office of the Inspector General) and the Comptroller General, or other designees) appropriate financial records.

The State Medicaid Agency (SMA) should routinely initiate a recovery of funds paid to a provider for services provided in excess or not in accordance with, the participant's approved plan of care. The primary general method for problem correction in this area is provider group training by the OSA and SMA on Medicaid waiver billing. Additionally, the SMA distributes Billing Instruction Guidelines to all providers and updates them as necessary to reflect changes in the waiver impacting billing.¹⁵

b. Providers need to have a way to cover the cost of staff and family trainings for groups of parents if compliance is to improve:

Operating on razor-thin margins leads to poor performance. Outcomes will improve if providers can bill for the cost of trainings.

c. CMS must avoid cutting hours and reimbursement rates if health and safety are to be maintained and experienced providers are to remain in the field.

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Biographies of the Four-State Alliance

MARYLAND - Karen Kaye-Beall is the Executive Director of the Foundation for Autism Support and Training (FAST). She is also Executive Director of the Center for Autism Support and Training (CAST) a Medicaid service provider and contractor (with 45 employees) with the State of Maryland Department of Health and Mental Hygiene/Maryland State Department of Education, on Maryland's HCBS for individuals with autism spectrum disorder (ASD). FAST's community housing and living initiative for adults with autism is ARCHway to Independence (www.myarchway.org) ARCHway has chapters in Maryland and Massachusetts, and provides training and advocacy to parents of loved ones with autism and those who are self advocates with ASD. ARCHway has gathered together an alliance of national leaders who have unique expertise on finding solutions to help solve the huge crisis of lifelong care and support needs. She participates on the Adult Services and Housing Subcommittees for the Maryland Autism Commission and she is the parent of two transition-aged teens with autism.

NEW JERSEY - Cyndy Hayes, DBA, is the Founder and Executive Director of Aging with Autism, and has been a strong advocate for individuals with autism since her son Brandon's diagnosis in 1992. In 2007, Dr. Hayes founded Advancing Futures for Adults with Autism in collaboration with Autism Speaks and the NY Center for Autism, and serves on its steering committee. She also founded Reaching Potentials, a 501(c) 3 organization, which provides early intervention training and services. In 2001, she founded Global Communities of Support, which focuses on creating residential, vocational and recreational support for teens and adults with autism.

ARIZONA - Denise D. Resnik, mother of a 20-year-old son with autism, is co-founder of the Southwest Autism Research & Resource Center (www.autismcenter.org), serves on the steering committee for Advancing Futures for Adults with Autism (AFAA) and is a member of the Autism Speaks Family Services and Housing Committees. She is the author of the Opening Doors Report: A Discussion of Residential Options for Adults Living with Autism and Related Disorders, a collaborative study by the Urban Land Institute (ULI) Arizona, Southwest Autism Research & Resource Center (SARRC), the Arizona State University (ASU) Stardust Center for Affordable Homes and the Family and the ASU Herberger Institute School of Architecture and Landscape Architecture.

MASSACHUSETTS - Catherine Boyle is the founder and President of Autism Housing Pathways, which participates in the ARCHway Chapter network. AHP is an information clearinghouse on self-directed housing for Mass. families. She sits on the Adult Subcommittee of the Mass. Autism Commission, and is a commissioner of the Winchester Housing Authority. She is also the publisher of the St. Mary's Curriculum for Students with Autism and Other Developmental Disabilities. She is the parent of a transition-aged son with autism.

Biographies of the Autistic Global Initiative

This list includes AGI's Executive and Special Projects Committee Members.

CALIFORNIA - Valerie Paradiz, PhD, is the Director of the Autistic Global Initiative (AGI), a program of the Autism Research Institute, where she also serves as the Editor-in-Chief of the *ARI Adults with ASD eBulletin*. Valerie's specific areas of focus include content and program development and curriculum design for children and adults with autism spectrum and related conditions, including such venues as NYU Asperger Institute, where she served as Director of Education, New York City Board of Education, where she is a regular vendor, and the Autism Society of America, where Valerie served on the National Board of Directors and as director of the Panel of People on the Spectrum of Autism (PSA). Dr. Paradiz is the developer of *Integrated Self Advocacy ISA™*, an evidence-based curriculum and certification training series for families and support providers who wish to foster individuals with ASD and other disabilities in achieving greater self-determination and ability in self-advocacy. Her memoir, *Elijah's Cup* (Simon & Schuster, 2003), is the story of her experiences raising her autistic son, their involvement together in the self-advocacy community, and her own ultimate diagnosis with Asperger syndrome. Dr. Paradiz serves on several national and university boards related to disability. Her work has been featured in the *New York Times*, *Redbook Magazine*, *The Guardian* and on National Public Radio. For more information visit www.autismselfadvocacy.com.

WISCONSIN – Judy Endow, MSW, maintains a private practice in Madison, Wisconsin, providing consultation for families, school districts and other agencies. Besides having autism herself, she is the parent of a grown son with ASD. Judy presents internationally, is part of the Wisconsin DPI Statewide Autism Training Team and a board member of both the Autism Society of America, Wisconsin Chapter and the Autism National Committee. *Paper Words, Discovering and Living with My Autism* (AAPC Publishing, 2009) was 2010 International Book Award Finalist in Autobiographies/Memoirs. Judy has also received the 2010 Autism Society Media Excellence Award for her DVD, *The Power of Words: How we talk about people with autism spectrum disorders matters!* (AAPC Publishing, 2009). *Practical Solutions for Stabilizing Students With Classic Autism to Be Ready to Learn: Getting to Go* (AAPC Publishing, 2011) is Judy's most recent book. To see Judy's other works please visit AAPC Publishing at www.aapcpublishing.net

MAINE – Janine Collins, MTS, MSW, is a Research Associate at the University of Maine's Center for Community Inclusion and Disability Studies and works on special projects for the Autism Research Institute (ARI). She holds an undergraduate degree in Special/Elementary Education and Psychology and graduate degrees in Theology and Social Work. Prior to work in the area of research, her experience was in direct service, first as a special educator and then as a case manager in adult social services. She is co-author of *Quality Employment Practices for Supporting Individuals with Autism Spectrum Disorders*. She is Managing Editor for the *ARI Adults with ASD eBulletin*,

served on a statewide workgroup reviewing evidence-based practice for the education of individuals with ASD, serves as Board Vice President/Legislative Chair of the Autism Society of Maine, and lends a consumer perspective as a member of Maine's State Rehab Council.

MINNESOTA - Ruth Elaine Joyner Hane with classic autism, who was nonverbal until nearly 5 years old, believed she was a cat. A neighbor insisted she was a child and taught her functional speech. Defying a prediction of mental retardation in grade school, she graduated Phi Beta Kappa, magna cum laude with a BS in Human Ecology. She overcame face blindness inventing the Hane Face Window©, based on research and structured visual integration. Ruth Elaine was recently the Midwest Director for the Autism Society, serving on the national board. She has written numerous articles about autism and co-authored *Ask and Tell*, and *Sharing Our Wisdom*. She also served as guest co-editor of the Autism Society's *Advocate* and featured on *Adults on the Autism Spectrum Today*. Ruth Elaine serves on the Executive Committee of the Autistic Global Initiative, and the Advisory board for Fraser Child and Family Center. She continues research with the Hane Face Window.

MARYLAND - Zosia Zaks, M.Ed., CRC, director of Zaks Autism Consulting, counsels adults with disabilities and teaches courses on adult autism issues at Towson University. He is the author of *Life and Love: Positive Strategies for Autistic Adults* (AAPC) and numerous articles. Zosia also serves on the Maryland Commission on Autism and on the board of Itineris, a Baltimore-based, DDA-approved agency exclusively serving autistic adults. In an advisory capacity, he serves on the Autism Society of America's Panel of People on the Spectrum of Autism (PSA). Zosia has two daughters, both of whom are diagnosed on the autism spectrum.

CALIFORNIA - Paul Nussbaum was diagnosed with Asperger's syndrome/high functioning autism at age 40 after decades of struggle with social, employment and developmental issues. Managing to complete a BA degree, Paul then went on to serve a three and a half year term in the Air Force, with much determination and struggle. Today, he is active in advocacy work for ASDs issues, serving as founding and board member of AASCEND (Autism and Asperger's Syndrome Coalition for Education, Networking and Development), as well as on the ASDs guidelines committee for the State of California in 2007-2008. Paul has facilitated trainings and consulting for STEPS (Structured Teaching Environments Promoting Success) as well as for the Department of Vocational Rehabilitation for the State of California, parent advocacy groups, schools and other disability non-profits. In 2008, he completed a Trans-Sierra Ski Expedition as a fundraising to initiate a summer camp for children with autism, later publishing an article about his trek in *Autism Digest* magazine. Currently, Paul is designing a large-scale awareness-raising and fundraising expedition to the icecap of Greenland to call attention to ASDs globally.

OHIO - Charles Joiner, MD, PhD, is a licensed physician trained in Emergency Medicine. After receiving his PhD in Mathematics at the University of California, Santa Barbara, he joined the faculty at Case Western Reserve University. He left this position to

go to Medical School at CWRU, following which he did a residency in Emergency Medicine. Dr. Joiner is an active member of ARI's Autistic Global Initiative, a new program self-run by people with autism spectrum conditions, that offers advisory and consulting services to ARI and other organizations nationwide.

OHIO - Sondra Williams is a parent of four children with the diagnosis of Asperger's syndrome. She is a poet, author and speaker/presenter. As an advocate, Sondra's focus is on developmental disabilities. In October 2011, Sondra was chosen to meet with President Obama to celebrate National Disability Awareness Month. She was appointed by the governor of Ohio to serve on the Ohio Autism Task Force, and has also served as a board member of the Autism Society of Ohio and Ohio Center for Autism and Low Incidence (OCALI). Sondra was a parent advocate trainee under LEND, Ohio State University. Significantly impacted by autism as a child, Sondra lived in institutional settings where she was overly medicated and often restrained or locked in isolation. Through her experiences, she has gained enough skills to now be considered a higher functioning person with autism. She lives independently at home with her family as a mom and grandmother of children with a variety of developmental and cognitive differences.

ARIZONA – Robyn Heffelfinger, who was only recently diagnosed with Asperger's syndrome/autism, volunteers at a local animal shelter where she lives in Tombstone, AZ. Having experienced significant anxiety and auditory sensitivity for many years, she began to discover more sides to her condition while attending retreats for adults with autism. There she became aware of the Asperger community and felt most resonance with those on the spectrum who had difficulty with communication (i.e. eye contact). At a peer support group for autistic adults in Tempe, AZ Robyn began her journey, and with her new diagnosis she continues on a path of self-discovery.

¹ “Study on the Costs and Benefits of Initiating a Pilot Project to Provide Services to Adults with Autism Spectrum Disorders and Related Disabilities,” State of Texas, Department of Aging and Disabilities Services, Burns & Associates, Inc. (2010), pp. 41-46.

² “Autism Spectrum Disorders (ASDs) Services Final Report on Environmental Scan,” Young J, Corea C, Kimani J, and Mandell D (2010), <http://www.impaqint.com/files/4-content/1-6-publications/1-6-2-project-reports/finalasdreport.pdf> .

³ “2008 ASD Research Funding by Topic Area,” Interagency Autism Coordinating Committee IACC (2009), <http://iacc.hhs.gov/portfolio-analysis/2008/index.shtml#figure2> .

⁴ “Report on State Services to Individuals with Autism Spectrum Disorders (ASD),” Centers for Medicare & Medicaid Services (CMS) ASD Services Project (2011) <http://www.cms.gov/apps/files/9-State-Report.pdf> .

- ⁵ “Autism’s First Child,” in *The Atlantic*, J Donovan and C Zucker (October 2010), <http://www.theatlantic.com/magazine/archive/2010/10/autism-8217-s-first-child/8227/> .
- ⁶ “Constructing the New Service Paradigm: Responding to Today’s Challenges,” Nancy Thaler, National Association of State Directors of Developmental Disabilities Services NASDDDS (2009), www.ncpic.net/download/15/ and “Where We Are Today and Where We Want to Be in 10 Years,” Presentation by N Thaler to IACC, NASDDDS (November 2010), http://iacc.hhs.gov/events/2010/slides_nancy_thaler_110810.pdf .
- ⁷ “These ‘New’ Self-Determination and Self-Direction Models: Are They Fiscally Conservative?” Presentation by M Head and JW Conroy to IACC
- ⁸ “Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders,” Urban Land Institute of Arizona and Southwest Autism Research and Resource Center (2009), www.autismcenter.org/openingdoors.aspx .
- ⁹ “Housing Features and Adaptations that Support the Needs of Adults with Autism, OCD and Sensory Integrative Dysfunction,” ARCHway for Independence (2011)
<http://myarchway.ning.com/forum/topics/housing-features-and>
<http://autism-blog.com/housing-features-and-adaptations-support-needs-adults-autism-ocd-and-sensory-integrative-dysfunction>.
- ¹⁰ “Study on the Costs and Benefits of Initiating a Pilot Project to Provide Services to Adults with Autism Spectrum Disorders and Related Disabilities,” State of Texas, Department of Aging and Disabilities Services, Burns & Associates, Inc. (2010), p. 46.
- ¹¹ “Report on State Services to Individuals with Autism Spectrum Disorders (ASD),” Centers for Medicare & Medicaid Services (CMS) ASD Services Project (2011)
<http://www.cms.gov/apps/files/9-State-Report.pdf> .
- ¹² Advancing Futures for Adults with Autism (AFAA), www.afa-us.org .
- ¹³ “Cost of Homelessness: Benefit of Shelter Plus Care,” Office of Adult Mental Health Services Greater Portland (2008) <http://www.maine.gov/dhhs/mh/Housing/cost-homelessness-spc.pdf> .
- ¹⁴ Ibid.
- ¹⁵ “Application for a §1915(c) Home and Community-Based Services Waiver,” State of Maryland Department of Health and Mental Hygiene (2009),
http://www.dhmm.state.md.us/mma/waiverprograms/pdf/2010/Autism_Waiver_Application_070109.pdf .