AUTISM SOCIETY
Improving the Lives of All Affected by Autism
San Francisco Bay Area

Myths v. Facts: California's Adults with Autism/DD and the New Medicaid HCBS Rules

The federal Medicaid Home and Community Based Services ("HCBS") program helps to fund much of our residential and nonresidential regional center services for adults with autism and other developmental disabilities ("DDs"). This program is very important because it helps California's Department of Developmental Services ("DDS") fund services in the home and community to those who would otherwise require services at an institutional level of care.

The federal Center for Medicaid and Medicare Services ("CMS") recently updated the HCBS rules, emphasizing positive, person-centered outcomes for individuals with developmental disabilities, free from coercion or loss of access to the greater community. They are focused on quality of life and the primacy of choice, dignity, and respect for the HCBS recipients, and are intended to expand choices and opportunities for people with developmental disabilities. The regulations can be found at 42 CFR Part 430 et seq. States have until March 17, 2019 to implement the requirements for home and community-based settings in accordance with CMS-approved plans.

Unfortunately, there has been misunderstanding and misinformation about the rules, with most of the confusion focused on whether HCBS can fund services in settings characterized as "congregate," "clustered," or "disability-specific." Here, we separate myth from fact.

MYTH	FACT
1. HCBS "mandates inclusion," "requires full inclusion," and "requires regional centers to fund <u>only</u> services in settings that provide real inclusion in the general community and do not segregate consumers."	The new rules clearly require that inclusion and community access must be among the options offered to regional center clients as part of the person-centered planning process. However, the rules do not "mandate" or "require" full inclusion for all consumers. The precise contents of the person-centered plan ("PCP") depend on the preferences and needs of the DD individual. As a consequence, the regional centers must respond with a fuller range of service and program options. Specifically, CMS has stated that an individual must have the option to select a setting that is not limited to people with the same or similar types of disabilities. "Clients may receive services with other people who have either the same or similar disabilities, but must have the <u>option</u> to be served in a setting that is not exclusive to people with the same or similar disabilities." HCBS Final Regulations 42 CFR Part 441 Q&A (emphasis added). The language and intent reflect the Supreme Court's <u>Olmstead</u> decision which held that under the Americans with Disabilities Act, individuals with mental disabilities have the right to live in the community, if appropriate and desired, rather than confined by government into institutions.

MYTH	FACT
2. The rules do not allow for services provided in congegate residential or nonresidential settings, such as a day program specializing in the needs of adults with autism and similar DDs.	CMS has stated: "It is not our intention to exclude a state from receiving [HCBS funds] for a setting solely based on the fact that it is a congregate setting. Our intention is to specify qualities necessary for a setting to be considered a HCB setting. Congregate settings may be included." HCBS Final Regulations 42 CFR Part 441 Q&A. Congregate settings, if desired, should be specified and justified in the individual's PCP (in California, the Individualized Program Plan, or IPP). The rules do not require full inclusion for all clients at all times, but rather that programming must "support full access to the greater community." 42 CFR §441.530(a)(1) (emphasis added). The rules do not allow HCBS funding for services in settings that are institutional, but they also do not require that a DD adult visit the mall, library, bowling alley, supermarket, theater, restaurant, coffee shop, art museum, barbershop, or anywhere else in the broader community, or that the adult live in a generic apartment or home with majority nondisabled neighbors or housemates, unless desired by the individual. If an individual chooses to spend time living and/or working in conjunction with others with disabilities, rather than in a generic community setting, that congregate setting must support full access to the community to the extent desired and the PCP/IPP must reflect and facilitate that.
3. A client can be denied HCBS funded services based on location, geography or physical characteristics of his chosen setting.	Eligibility for services does not hinge on location, geography, or physical characteristics of a setting: "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 setting's location, geography, or physical characteristics." CMS Fact Sheet, CMS 2249-F/2296-F, January 10, 2014, p 1. HCBS rules require a higher scrutiny for settings presumed to have institutional characteristics, including a "setting that has the effect of isolating individuals receiving the HCBS waiver from the broader community...." 42 CFR §441.530(a)(2)(5). A CMS subregulatory guidance states that settings that may be considered presumptively isolating include farmsteads or communities that offer all-inclusive housing, day programming, medical, therapeutic, social and recreational activities, with "limited, if any, interaction with the broader community." CMS Guidance On Settings That Have The Effect Of Isolating Individuals Receiving HCBS From The Broader Community. *So long as opportunity for interaction with the broader community is not restricted, these settings should not be presumed isolating under the terms of the new regulations.* And in the event they are presumed isolating, that presumption is rebuttable via evidence submitted by stakeholders and community members during a heightened scrutiny process initiated by the state. In support of this position, California's DDS has already stated it would not shut down settings based solely on their location. "Federal guidance states that the location alone does not make the setting or the type of service unallowable." DDS HCBS Frequently Asked Questions, p. 3.

MYTH	FACT
4. Disability-specific programs and housing will lose funding or not be funded.	CMS has stated that "the goal of this regulation is not to take services from individuals, or make individuals move from a location where they have always lived, but to describe the qualities of settings in which services intended to provide an alternative to institutional care may be delivered. The goal of this regulation is to widen the door of opportunity for individuals receiving Medicaid HCBS to support the same choices to participate in community activities as are available to individuals not receiving Medicaid HCBS; to have a choice in how, when, and where they receive services; and to remove unnecessary barriers and controls." HCBS Final Regulations 42 CFR Part 441 Q&A. In other words, the goal of HCBS is to increase options, not to narrow them: the recipient is empowered to select which options fulfill his or her goals and needs, and a regional center will need to bolster its roster of services to encompass full inclusion. A state does have the authority to assert a setting as non-HCBS compliant if it does not meet the standards set forth in the federal regulations, but the mere fact it may be disability-specific is not among the reasons why it could be ineligible for funding.
5. HCBS won't fund services for individuals with autism or DD who reside on farms, residential developments with agricultural features, or rural setting.	The CMS subregulatory guidance offers a certain form of disability-specific farm community as an example of residential setting that may "have the effect of isolating people receiving HCBS from the broader community." The farmsteads contemplated by CMS in this document are described as large, self-contained, and remote, without supporting access to the broader community. They are characterized as being located in rural areas, on large parcels of land, offering little ability to access the broader community outside the farm. This example offered by CMS hinges on the question of access to the broader community. As with Myth/Fact #3, such a setting may create a rebuttable presumption of isolation, however so long as opportunity for interaction with the broader community is unrestricted and driven by the individualized terms of the PCP/IPP, these settings should not be presumed isolating (and therefore to not have the qualities of an institution) under the express terms of the new regulations. In the event they are presumed isolating for some reason, that presumption is rebuttable via evidence submitted by stakeholders and community members. Additionally, a rural setting is compliant with HCBS so long as it does not discourage an individual's integration with the broader community. According to CMS, "the determination would not be based on whether the setting was in a rural, urban, or suburban community, but on whether it has the qualities of home and community-based settings as specified in this rule." HCBS Final Regulations 42 CFR Part 441 Q&A. California DDS has already stated that rural settings are not automatically presumed to be isolating. The question is whether "individuals with disabilities who receive services in a rural area have the same opportunity for community integration as people without disabilities in that community." DDS HCBS FAQ p4.

MYTH	FACT
6. Autism- and DD-serving residences can't have gates.	Nothing in the regulations prohibit the installation of gates at disability-serving residential or nonresidential settings. Rather, the subregulatory guidance offers a "gated/secured community" for people with disabilities as an example of a residential setting that may be subject to heightened scrutiny. These gated communities are characterized as large developments providing residential, behavioral health, day services, social and recreational activities, and long term services and supports all within the gated community. Simply by featuring a gate, fence or a perimeter landscape element—like those featured at countless urban, suburban, and rural residences of people without developmental disabilities—the home does not, by any definition, amount to a "gated community." While gates (or doors, windows, landscaping, or property rules) cannot be used to forcibly isolate a client from the community, gates may be used for privacy, aesthetics, and/or safety purposes. If a gate or natural barrier is needed as a support to keep a person with a mental disability from wandering away, walking into traffic, or otherwise endangering himself or herself, this should be noted in the PCP/IPP along with the goal of learning community safety behaviors.
7. HCBS mandates that autistic/DD clients must be allowed to leave the premises at any time.	DDS has already acknowledged that where HCBS requirements put someone at risk (specifically, the requirements that consumers have access to food any time they want, or the freedom to leave the home or to have visitors any time) the federal rules allow for some of the requirements to be modified if: • There is an assessed need for the modification. • The modification is documented and included in the PCP/IPP. • The modification is reviewed regularly and that review period is consistent and documented. DDS HCBS FAQ p. 2-3.
8. There's a cap on the number of disabled adults who can live together.	CMS has stated that that HCBS does not focus on the number of people being served, but instead on the experience of the individual. Accordingly, DDS has stated that the HCBS setting requirements do not address the number of individuals living in a residential home or other community-based setting. DDS HCBS FAQ p.4. "While size may impact the setting's ability to meet, or likelihood of meeting, the home and community-based setting requirements, the rules do not specify size restrictions." Id. Many people believe, for example, that no more than 25% of the units in an apartment can be set aside for people with DD. This is only applicable to certain properties that have received federal funding through HUD Section 811. Also, there's a myth that HCBS won't fund services for autistic or DD adults who reside in a building in which 100% of the units are designated/ set aside for people with developmental disabilities. There is no authority for this in California.

MYTH	FACT
9. Only the individual with a developmental disability, and not a conservator, can determine the content of his or her person-centered plan.	To the extent possible, the PCP meeting should be led by the individual with a disability, and all efforts should be made to ascertain the individual's thoughts and intents. For those who have been deemed by the courts to need conservatorship, the conservators, who are legally authorized to make decisions on the disabled person's behalf and in his or her best interests, are the leaders of that person's PCP/IPP. §441.725(a). In the HCBS rules, all references to individuals include the role of the individual's representative. Id. The conservator, as the legal representative, is bound under California law to act in the best interest of the individual. Exercise of such a duty would include ascertainment of the individual's preferences and goals not only as an ongoing matter, but also as part of the PCP process.
10. There's plenty of money in the DDS system to achieve the HCBS vision.	The DDS autism population has skyrocketed from 3,000 cases in the early 1980s to about 83,000 today. As the numbers swell, and young ASD adults age out of school in unprecedented numbers, enormous stress is being placed on a regional center system already under great pressure. There is near-universal concern that our state DDS budget, even as enhanced by federal HCBS funding, cannot support the person-centered HCBS vision, which will require 1:1 or 1:2 staff per autism or DD client in a great many cases. Many adults with autism, particularly those with aggression and/or self-injurious behaviors, in fact require even higher levels or care per client as an alternative to institutionalization. HCBS requires that the PCP/IPP provide individually determined appropriate services that support access to the greater community "especially for an individual with limited social skills," (See HCBS Final Reguations 42 CFR Part 441, Q&A re HCBS Settings, p 4) but until adequate funding and ratios are a reality, the noble HCBS vision represents an unfunded mandate that cannot realistically be achieved.

In summary

HCBS-funded services are a lifeblood for many adults with autism and other developmental disabilities. If implemented in accordance with the language and intent of the regulations, the person-centered power of the new rules should positively affect all programs and living arrangements for the enormously complex and diverse variety of regional center clients. Misinformation, hyperbole, and scare tactics that falsely characterize the rules could hamper development of the diverse array of vital programs and projects needed to serve the lifespan needs of the growing autism/DD population.

We invite you to read the CMS HCBS documents: https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html

This Myth v Fact document will be supplemented with more extensive information in the coming months, including a planned Public Forum on Autism/DD and the HCBS Rules, in the SF Bay Area.

Please submit your questions for the upcoming Forum, and sign up to receive news about the event, at info@sfautismsociety.org.

website: sfautismsociety.org