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

Autism Society San Francisco Bay Area
PO Box 249
San Mateo, CA 94401
info@sfautismsociety.org
(650) 637-7772

Ralph F. Lollar, Director
Division of Long Term Services and Supports
Centers for Medicare & Medicaid Services
Disabled & Elderly Health Programs Group
7500 Security Boulevard, Mail Stop S2-14-26
Baltimore, Maryland 21244-1850

February 10, 2016

Re: Request to correct errors contained in Lollar letter to Cantwell, dated November 16, 2015

Dear Mr. Lollar,

This letter is in regards to a letter signed by you and dated November 16, 2015. The letter was addressed to Mari Cantwell, Chief Deputy Director, Health Care Programs, State of California Department of Health Care Services (herinafter, "The Letter").

In The Letter, the Centers for Medicare & Medicaid Services (CMS) ask the State of California for additional detail regarding various contents of its State Transition Plan, including its provisions for "heightened scrutiny." You ask our state to "clearly lay out its process for identifying settings that are presumed to have the qualities of an institution" and for assessing whether these presumed institutional settings have qualities that are home and community-based in nature, and therefore eligibility for HCBS participation.

In its explication of the settings "presumed institutional," The Letter specifies, per the HCBS regulations:

- Settings located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment;
- Settings in a building on the grounds of, or immediately adjacent to, a public institution;

> • Any other setting that has the effect of isolating individuals receiving Medicaid home and community-based services from the broader community of individuals not receiving Medicaid home and community-based services.

The Letter then goes on to say:

> If the state is operating with a presumption that an individual's private home or private family home is meeting this requirement, the state needs to confirm that none of these settings were purchased or established in a manner that isolates the individual from the community of individuals not receiving Medicaid funded home and community- based services, including recently piloted communities such as Sweetheart Spectrum and Golden Heart Ranch. Information available in the Toolkit on settings that isolate may be helpful in this regard.

We find this particular paragraph incongruous with the regulations of 42 CFR §441.530 and riddled with erroneous assumptions that, if left standing, could eviscerate attempts to create appropriately individualized autism-friendly housing and programs in our state. We therefore ask that CMS promptly issue a statement retracting this paragraph from The Letter.

Before we explain, let us say emphatically that we share the same goals as CMS. We are all looking for a variety of housing solutions for the massive number of individuals with autism who are aging into adulthood: in California, the number of adults with substantially disabling forms of autism (served by our DDS) will triple to more than 45,000 in ten years. Within 20 years, we will have more than 85,000 adults with substantially disabling autism. All of these significantly disabled adults, who exhibit a very wide variety of functional levels and needs, should be able to choose where to live, with whom to live, and how to spend their days. Your goals and ours are the same.

With that in mind, we explain the errors in the paragraph:

(1) "Purchased or established in a manner that isolates." The Letter states that any residential property that is "purchased" in a manner that isolates the individual from the community is presumed institutional. We cannot comprehend what this could mean. Does it mean that when people signed close-of-escrow papers that they, as private property purchasers, had the intent to isolate any and all future disabled renters from the community? How would CMS or the State of California possibly ascertain a property owner's "intent" to isolate for any home or residential property when "purchased" in years or decades past?

Similarly, The Letter states that any residential property that is "established" in a manner to isolate individuals is also presumed institutional. So, does that mean that a care home, established in 1970 with some programmatic aspects that restricted community access for developmentally disabled adults, but now in 2015 is operating based on person-centered directives of desired levels of inclusion and participation, would be presumed institutional?

What does CMS mean by purchased? What does it mean by established? These questions and principles about a residential property's history appear in The Letter but nowhere in the regulations. Further, the mental state of the purchaser or establisher of any given property is not only irrelevant as a matter of law, it is impossible to ascertain. The new standard requires a setting to "support access" based on ascertainment of present outcomes—a setting's past history is irrelevant.

The relevant question as outlined in the new HCBS rules relates to how a setting is actually operating. Per CMS's own language, the rules are outcome-oriented, and based in the actual experiences of the clients being served. The CMS rules clearly hinge on the reality of operations, and not on minor attributes of any particular setting or some guess about past history of the mental state of a property investor, landlord or purchaser.

(2) Called-out properties. More disturbingly, The Letter implies that two California undertakings, "Sweetheart Spectrum" (sic) and "Golden Heart Ranch," could possess the qualities of institutions and therefore must be subjected to higher scrutiny. This assertion is clearly based on erroneous information fed to CMS and not on any site visits or discussions initiated by CMS with the owners or residents.

With respect to Sweetwater Spectrum ("SS") (erroneously called Sweetheart Spectrum in The Letter), this is a small cluster of just four consumer-controlled (not provider-controlled) homes located in a center-of-town location just a few blocks from a lively and famous town square. SS receives no funding from the State of California or HCBS waivers. The residents are there of their own volition, with their own leases with the owner. Their daily schedules are driven not by SS, which is just a property owner and lessor, but instead by various independent supported living agencies following the contents of each of the Individualized Program Plans (IPP) of the residents. Some residents attend secondary education programs, some are engaged in supported employment, some have day programs as led by their own supported living agencies. Some of these IPP-authorized individualized services are funded via the HCBS waiver. Personally, when I visited SS one day last year, it was empty. I asked the site director where everyone was. She said, "I don't know. They're off doing their own thing. That's up to them and their supported living agencies, we have no control over their schedules."

With respect to Golden Heart Ranch ("GHR"), this residential opportunity does not even exist yet—there can be no "outcomes" to examine. A quick phone call to the leaders of this small-scale project would have easily revealed that. Furthermore, nothing in the future plans for GHR is institutional in nature. It would provide only those supports and contracts consistent with an adult's individualized, person-driven IPP. Nothing would be controlling, coercive, or segregating. The extent of community engagement would rest in the IPP-specified desires of future residents.

(3) Violation of CMS's own regulations on institutional settings. Third, The Letter's characterization of these "presumed isolating" settings is not consistent with the HCBS regulations or CMS's own subregulatory guidance on settings that are presumed isolating ("Guidance"). In that Guidance document, CMS offers the concept that settings presumed to have the effect of isolating include farmsteads or gated communities that offer all-inclusive housing, day programming, medical, therapeutic, social and recreational activities, with "limited, if any, interaction with the broader community." See CMS Guidance On Settings That Have The Effect Of Isolating Individuals Receiving HCBS From The Broader Community.

The large-scale all-inclusive operations as described in the subregulatory guidance bear no resemblance to the small, integrated SS or the nonexistent GHR. Neither of these places have anything like the suite of complex, extensive on-site amenities mentioned in the guidance. Nothing remotely like removal from the broader community is practiced at SS or contemplated at GHR. In The Letter, CMS is irresponsibly and wantonly stretching the notion of "farmstead" or "gated community" far beyond the bounds of common sense, the terms of the Guidance itself, or, of couse, the black and white terms of the regulation itself. CMS does not have the authority to *de facto* amend the regulations with a narrow reading and draconian enforcement never contemplated in the regulations themselves or the authorizing legislation.

(4) CMS has overstepped its jurisdiction. By asking for scrutiny of SS and GHR, CMS has overstepped its jurisdiction and undermined the authority CMS has given the California state Medicaid authority to identify and assess settings for compliance. The state has the authority to draw its own conclusion as to whether a setting can become compliant with modifications, whether it must undergo heightened scrutiny, or whether it is not and can not become compliant as if deemed institutional in nature. If the state had applied the regulations and Guidance published by CMS, it clearly would <u>not</u> have come to the conclusion that SS and GHR resemble institutions, as per the terms of the regulation and the illustrative examples cited in the guidance. CMS has inappropriately singled out these two among the thousands of homes providing residences for developmentally disabled adults in California.

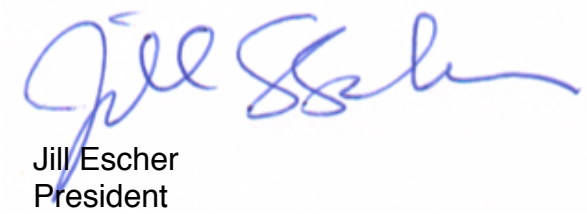
(5) The serious consequences of spurious assumptions. Finally, if consumer-controlled, community-based housing endeavors like SS and GHR are presumed "institutional" by CMS, this portends a most catastrophic future for enriched environments that serve the desires and needs of adults with autism and developmental disabilities, particularly those with more intensive needs. If housing environments that have autism or DD-friendly supportive elements are presumptively subject to "higher scrutiny," it could mean years of delay, ropes of red tape, and vastly higher costs in terms of attorney fees and associated expenses. The costs are already prohibitive to create new autism housing opportunities in California. By assuming enriched environments—even if consumer controlled and subject to person-centered planning including full access to the community as per the desires of the clients—are "isolating," <u>CMS is unjustifiably and without legal authority imposing an even tighter stranglehold on the creation of appropriate housing options.</u>

Not only are these community options such as SS driven by consumer choice, they allow flexibility for the consumers to change service providers, and provide a stable housing stock separate from a fluctating rental market and the whims of landlords who might (and legally) evict DD tenants due to disruptive or dangerous behaviors. That they were singled out for unequal treatment by CMS based on inaccurate assumptions and a framework for evaluation never contemplated in the regulations should send a shudder of fear through every autism family in our state.

California already has a staggering 83,000 residents with severe autism served by its Department of Developmental Services (up from about 3,000 25 years ago). At this time, only a tiny fraction of these 83,000 very disabled individuals live outside of the family home, owing to the paucity of funded and appropriately supportive and safe options. CMS must not be allowed to misapply regulations to squelch appropriate, robust, community-focused, choice-driven residential options. Settings such as SS (which is not even an HCBS service provider) will be the clear least restrictive environment for thousands upon thousands of adults with autism, many of whom have challenging behaviors and low functional abilities, and who would otherwise need to be institutionalized or placed in the "next empty bed" of a more restrictive provider-owned or controlled setting.

We therefore ask for the aforementioned paragraph to be officially struck from The Letter. Letters from your office are taken seriously, and we would be delighted to help you fact-check before you issue future letters pertaining to autism-serving programs in our region. In the meantime, we look forward to your response to the concerns expressed in this letter. In addition, sending a letter of correction striking the paragraph to those who received your initial letter would be entirely appropriate.

Very truly yours,



Jill Escher
President

cc via email: Henrietta Sam-Louie, ARA
Mari Cantwell, California DHCS
Rebecca Schupp, California DHCS
Jim Knight, California DDS
Robert Hamilton, North Bay Regional Center
Eileen Richie, Association of Regional Center Agencies
Beth Burt, Autism Society of California
Scott Badesch, Autism Society of America
Lisa Goring, Autism Speaks
Alison Singer, member, IACC
Andy Slavitt, acting director, CMS