

Home and Community-Based Settings Transition Plan

Summary of Public Comments

Who Submitted Comments	
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Advocate	11
Provider	14
Total Commenters	69

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General Comments

Comments on Draft STP	Organization/ Relationship to the HCBS Program
<p>1. Thanks to all who have contributed to the important work of formulating the draft STP.</p> <p>I notice in the Final Rule of the CMS, it says: 'we have revised the rule to remove the term "disability-specific housing complex" and replace it with the following language: "any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS..." '</p> <p>The STP, however, seems to contradict the final rule, stating: 'Settings that may have the effect of isolating HCBS members are settings specifically designed for people with disabilities, often for people with a certain type of disability, and on-site staff provides many of the services available.'</p> <p>I think it's important that the STP reflect the final rule, rather than contradict it, particularly on a topic where the authors of the rule went to the trouble of explicitly making a change. They chose to remove the term "disability-specific housing complex", but the STP has simply reinstated it with the phrase "settings specifically designed for people with disabilities."</p> <p>My experience, as the step-dad of an adult woman with DD, is that she is thriving in an arrangement where she has chosen to live with other people with DD. She is intensely active in the broader community, singing in the community chorale, and playing flute in the local hometown band. She calls these her "mandatory activities", meaning that other conflicting demands on her time must not interrupt her participation in these pursuits. She also has been a student at the local community college, attends synagogue services from time-to-time with her family, wanders the local farmers' market on her own regularly, works in local businesses, and shops in local stores for food and clothes. She grew up in the town she lives in, and knows — and is known — by hundreds of people, many of whom greet her as she walks down the street. She's a model of community involvement for people with DD, despite her living in a "setting specifically designed for people with disabilities." In fact, I believe that setting is critical to her success in calmly, safely, confidently, and actively participating in the local community. I use her as just one example, and I could cite others; but clearly the rule authors got it right in recognizing that we do not want to disallow "disability-specific housing complexes" from the range of possible HCBS settings.</p>	<p>Parent of a young adult woman with developmental disabilities (DD)</p>
<p>2. Thank you for furthering the effort for our son to live a purposeful, engaged life and respecting his rights to appropriate choices. We are told that CMS intends to place a priority on the individuals "experience" in their home and work settings.</p> <p>As each person with DD is truly unique, please allow for different options for our son – what works for him may not work for others. His needs are specific and we try daily to meet each one. We hope that DHSC will not get caught up on "labels" and truly look at each person and their needs individually – which is the true intent of the new HCBS settings rules.</p>	<p>Parent & conservator of an adult child with developmental disabilities</p>

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	Housing in CA is already tremendously difficult to find for persons with DD. Over 80% of DD individuals between ages 18-31 still reside with their parents. Creative options (that still meet the intent of the HCBS settings rules) should be encouraged.	
3.	<p>Thank you for your efforts to engage developmentally disabled adults in the greater community. Since our daughter was diagnosed with autism at the age of two, we have taken it upon ourselves to include her in all activities – travel, restaurants, family gatherings, etc. This was partly for her benefit, and partly for the benefit of all who have come to know her. She brings out the best in them all. She is incapable of advocating for herself given her very limited language. My husband and I are her conservators.</p> <p>We have traveled the country looking at residential options that could meet her needs. It is very clear to us that an array of options should be developed and supported so that each individual has the choice of what works best for him/her. Some like urban, some rural, some (like our daughter) like a small town – not too busy, but lots of good restaurants. We looked at single apartments/homes as well as intentional communities. The former is not appropriate for our daughter because of isolation (the only friend is a paid caregiver), and safety concerns (neglect or abuse would go unobserved). We have chosen an intentional community where she chooses to live with her friends (who happen to be other individuals who share her diagnosis), but has access to the entire town in which she lives. She is happier there than she has been in any of her previous twenty-two years.</p> <p>The bottom line is that everyone – disabled or not – has the right to choice and self-determination. No one should be forced to live in a setting deemed “appropriate” by a governmental agency that is not appropriate to their needs.</p>	Parent & conservator of a member who has developmental disabilities
4.	<ol style="list-style-type: none"> 1. The plan does not address some of the unique aspect of members with developmental disabilities served by the Department of Developmental Services through the regional center system except very generally. Many regional center clients have multiple services from different providers. Specifically in the assessment tool and the plan, I'd like to see the Person Centered Plan acknowledged as a plan that works across agencies and settings. A client in our day program might make some clear choices that their parent (who they live with) will not honor, and we cannot implement those choices. Each agency or organization that serves a member will not have a person centered plan, rather the client has the plan, and the agencies will coordinate and integrate their services. And often it is the parent or conservator--for the clients in our program--who ultimately will have the final say. 2. Regarding the issue of parents and conservators who may say "no" to a member's choice--the transition plan needs more information about educating providers, families and members regarding choice and the HCBS settings rule. 3. With the focus on competitive, integrated employment, the difficulty of providing community activities for people with a high level of care needs and/or who are medically fragile is not addressed. When someone does not have 	Executive Director of Marin Ventures, a Regional Center funded Community Integration Training Program

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<p>employment, either because of choice or the inability to acquire employment skills sufficient to gain employment, they usually do not have the monetary resources to access community activities and experiences. In our program, we fund community activities using monies we get from donations. Community resources are not always easy to access for reasons other than money as well. Trying to support ONE PERSON to register at a community college for aadaptive yoga class took about ten staff hours.</p> <p>4. I will quote a colleague when I say it's difficult to ask staff to support choices (self determination) when they don't earn enough to be self-determined themselves. Our employees bear the burden of our underfunded system. Thirty years ago, working in direct service was paid above what you could earn in a restaurant or other low-skilled work. A young person with a college degree could earn a decent enough wage, learn the skills, and move up in the field. To implement the HCBS settings rule through the direct service workers--who are the real implementers of the rule--we need skilled workers who understand nuances in communication, can learn to document appropriately, and be sophisticated critical thinkers as they support people with developmental disabilities. We need teachers. Currently, most direct service employees are care givers with a very different set of skills than we need to become compliant with the rule. To train and develop this workforce takes greater than "adequate" funding.</p>	
<p>5. Thank you, in advance, for your commitment to providing meaningful lives with choices for our adult children with DD. The public message from CMS states the commitment to and the priority of the consumer's "experience" in the HCBS setting – hopefully, this will be put into practice in the real world. Too often, the realistic needs and desires of persons with DD are sacrificed in the interest of pursuing idealistic visions that have little chance of success. A pragmatic balance of realism and idealism has a much greater chance of creating fulfilling lives for the individuals served. I also hope that the DHCS and DDS pay particular attention to the true intent and language of the new CMS guidelines - rather than arbitrary guidance that has been issued after the fact by CMS staff or third-party advocates who do not truly represent the entire spectrum of the DD population. CMS issued a subsequent Informational Bulletin entitled "Guidance on Settings That Have the Effect of Isolating Individuals Receiving HCBS from the Broader Community" which conflicts with the original intent of CMS which was derived from years of public comment. The Bulletin was intended to provide information and further guidance to state and stakeholders about new regulations promulgated under CMS 2249-F and 2296-F that were finalized on January 16, 2014 under 79 FR 2947. However, it raises many concerns to many organizations and the rights guaranteed citizens under the US Constitution, Americans with Disabilities Act, Administrative Procedures Act and as interpreted in the Olmstead decision, and other laws for all persons to be supported and accommodated where they live, work, socialize, recreate, learn, love, and worship in the settings and manner they choose for themselves, and with the support and guidance of their parents, families, friends and caregivers.</p> <p>DD consumers need a spectrum of services and one size does not fill all. No two IPP's or ISP's are alike. Also, attaching labels and or stigmas to types of settings often results in the individual needs of a consumer being ignored. The term</p>	<p>Parent & conservator of a consumer accessing the HCBS Waiver for Persons with Developmental Disabilities (DD Waiver)</p>

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	"appropriate to their needs" should be kept in the forefront of all decisions. This is a fundamental principle established by the Olmstead Decisions that often gets lost in the mix. The Court held that public entities must provide community-based services to persons with disabilities when: (1) such services are appropriate and (2) the affected persons do not oppose community-based treatment. Consumers deserve choice and services to fit their needs.	
6.	<p>Our son has limited expressive language, has cognitive impairment and sensory integration challenges. He currently lives with his aging parents partially due to the lack of living options that will address his needs. In considering housing, daytime activity and recreational options consideration needs to be directed toward the needs and interests of the individuals being served.</p> <p>Our son is very successful at outdoor physical activity. He is accomplished in such activities as swimming, ice skating, skiing, bike riding, sailing, kayaking, hiking albeit with supervision. These activities and others address his need for sensory input and organization. Our son also is very social in a non-verbal way and craves being around peers. He is very visual, very aware of his environment and very anxious to help and be engaged in meaningful activity.</p> <p>We have involved our son in outdoor physical work such as participating in work on the farms of Sunflower Hill in Livermore and Big Wave Project near Half Moon Bay and he has thrived both with the physical activity and benefits of working with others.</p> <p>We urge you to consider the needs of individuals like our son who do not do anything that involves sitting, does not watch TV or use the computer and for whom the group home model is not workable to meet his needs. Communities with a focus on outdoor physical work are not institutions and serve the needs of many individuals like our son.</p>	I am the mother of son who is on the autism spectrum.
7.	CONGRATULATIONS! You have won the car of your dreams with all the accessories that you personally need with two tiny exceptions: 1) Your destinations have been limited to those chosen by us and, 2) Your passengers are restricted to those we feel are suitable.	1) Parent. Child is a client of the Regional Center of Orange County, diagnosed with Rett syndrome, lives at home, 2) Advocate on behalf of infants, children and adults with developmental disabilities and their families during the past 44 years, 3) Representative of California's CHOICE Coalition

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8	<p>We all know that a wave of individuals with developmental disabilities who are aging out of schools and family homes is coming. Where will these individuals live and how will they be cared for when their parents are gone? We need LOTS of options and creative solutions including public and/or private options and partnerships. Guidelines and rules should be kept as OPEN-ended as possible with the KEY to all options being Consumer CHOICE and cost containment. Although we want to limit ‘institutionalizations’, options should be phrased to emphasize goals – access to community, access to friends and family, opportunities for choice versus trying to specify exclusions. One person’s view of limits may be exactly what another chooses and/or needs for safety and/or health reasons. To that point – Adult Residential Facilities (licensed facilities) should be recognized as a housing option of choice by those otherwise qualifying for an HCBS waiver. The presence of a license insures a safe, monitored living environment while still allowing for optimal community access, access to friends and work and personal choices – e.g. a person’s choice to live in such a facility. Under 1915(k) Community First Choice (CFC) State Plan Program, CFC members select their residential setting. If this choice is one that includes living with others who share the same disability, so be it as it is the member’s choice. If such a living environment is one that includes supported living services, so be it as it is the member’s choice. We agree that the final rule should outcome oriented and guided by the member’s choice.</p>	Aging Parent of a current HCBS Waiver Participant
9.	<p>We believe strongly in the potential of the federal HCBS regulations, and are always available to work with you and your colleagues for proper implementation. Please feel free to contact me with any questions or suggestions, or to arrange for any collaboration on the implementation process.</p>	Disability Rights California, the Disability Rights Education and Defense Fund, Justice in Aging, and the National Health Law Program. We represent both persons with disabilities, and older individuals, and have significant experience with Medicaid home and community-based services (HCBS).

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10.	I am the parent of a child with special needs. I want to be assured he will have a stable and sustainable home for his lifetime. Many of our children in the disabled community need stable, predictable settings to allow them to flourish. My solution to this is to band together with friends who also have children with special needs and buy land, build a couple of homes, and give our children a rural environment for them to flourish. But from my reading of the STP, this option is not mentioned, so there is a question about whether such a community would qualify for federal and/or state funding. We know such communities exist—our group is not the first to come up with this model. Am I correct in interpreting the STP as excluding my child from supported or independent living services if he lived in a rural environment? Is the definition of “community” limited to urban areas only? Please help us set up a reliable and stable future for our children who will need support for the rest of their lives.	HCBS Advocate
11.	Thank you for recognizing the need of individuals with disabilities to live in an environment that is both safe and allows them the opportunity to integrate with the community whenever and wherever possible. Because achieving this goal is complicated and requires attention to multifaceted needs of the disabled, I appreciate your inclusion of the following statement into the the STP: "DHCS believes community is not the mere physical presence of other buildings and people. It includes a safe and purposeful environment where individuals have needed support and safety, and the greatest freedom to live production, connected lives according to their own desires."	Parent of HCBS Waiver participant
12.	<p>The goal of integration to community and personal development is of the utmost importance for all members of the disabled community but for individuals with developmental disabilities which are severe in nature and require dedicated resources in order to be safe both at home and in the community, the HCBS plans are lacking. In summary, integration, access to community resources and employment depend upon third party resources such as the regional center, a qualified behaviorist, transportation (public, private or paratransit), the Dept. of Rehab funding and what is available within a community itself.</p> <p>The emphasis on an physical setting being responsible for these things is unrealistic. A person can live in a rural community where there are few jobs for a person with developmental disabilities, where there are few vendors to provide behavioral services, where there is no public transit and few amenities within the community for recreation. A person could wish to live in a city where there are many options for recreation but housing is expensive and years long wait lists for subsidized units.</p> <p>In addition, in an effort to integrate there seems to be a bias against those with disabilities when "community" is defined in such a way as to EXCLUDE communities of the disabled. It is necessary for the disabled to live with "other people" so long as they are not disabled peers. Yet, in our society and institutions that serve the non-disabled we encourage the creation of community within our peer group and those who share our interests and goals. Colleges and universities receive public funds yet "isolate" students by assigning them to dorms or other forms of student housing, separating</p>	Attorney representing individuals with developmental disabilities

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	graduate student housing from undergraduate, have fraternities and sororities and interest houses for socializing and communal meals based upon ethnicities, interests, religion, race etc. Yet the disabled individuals are devalued as a community and are punished with the loss of services if housing and community is built to accommodate them.	
13.	The STP must take into account the great and increasing need for for housing and services for adult California residents with developmental disabilities, including those who limit decision-making ability. Policies and regulations that cater to "higher-functioning" people with DD risk preventing other people from living and receiving services in settings that are best for them. Furthermore, when a conserved person with DD does not have full ability to express preferences, the STP must acknowledge the power of a conservator "to fix the residence or specific dwelling of the limited conservatee."	Parent of HCBS Waiver participant
14.	Thank you for taking comments.	Parent of HCBS Waiver participant.
15.	Thank you for your commitment and efforts to provide support and choices for our adult children with DD. Those with developmental disabilities need a range of services. One size does not fill all. The term "appropriate to their individual needs" should be the basis of all decisions. Our comments herein address the issues.	Parents of a member who has developmental disabilities
16.	<p>Hello and thank you for the opportunity to provide feedback.</p> <p>Health Net has a concern surrounding non-residential settings and the concept of CBAS and "secure perimeter technology" on page 17 of 30 of the Revised Draft CBAS HCB Settings Transition Plan. There has been much discussion about "delayed egress" as an essential safety mechanism for specified CBAS members at specified facilities. Given today's increasing notice of public safety risks, can the Settings and Transition Plan include comments or requirements about "entrance door safety mechanisms" for community based non-residential CBAS facilities?</p> <p>According to 42 CFR 441.301(c)(4)(vi)(B)(1) "entrance doors lockability" is a documented regulation for controlled residential settings, but there does not appear to be a similar regulation for community based non-residential facilities. Furthermore, we support the comments note on page 30 of 32 in Appendix III (Analysis of Laws, Regulations, Waiver, Policies, and Other Requirements) "program requirements do not prohibit visitors" and the resulting addition of a question on the Provider Assessment Tool to validate visitor access. Safety is need for both entrance and exit security.</p>	Government Programs Policy and Strategic Initiatives, Health Net, Inc.
17.	One change or clarification I would like to see when the changes are implemented is that consumers of regional center be allowed to exercise their personal rights to engage in extracurricular social activities when they are in "In Home Respite Care", according to 17 CCR Section 50510 (a) Sections (6) (7). I have attached a copy of 17 CCR Section 50510 (a) Sections (6) (7) denial of their right to participate in activities because they are in In Home Respite Care appears to be a violation of their rights.	Foster Parent Outreach Coordinator

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<p>Currently the family members are told that a consumers cannot participate in any activity "outside" of the consumers own home when the family member is out of the home and care and supervision is being provided by a respite care worker. Example, the caregiver was away from the home and the consumers were being cared for and supervised by the respite care worker. It was fourth of July weekend. Up the street at a community park there is an annual fireworks display and the consumers wanted to go and after the fireworks show they wanted to go down the street to Sonic and get a hamburger, fries, and coke. The caregiver had left some of their P&I allotment with the respite worker in case they wanted to participate in an activity. The consumers were told no, that they could not go and enjoy the fireworks show because the staff employed by the Respite Care Agency had been informed that they are not allowed to transport the clients anywhere outside of their own home. The respite worker was informed that In Home Respite care means exactly that, "in the own home of the client."</p> <p>I contacted the consumers regional center service coordinator about this incident and she confirmed that the action taken by the substitute respite care worker was correct and she sent me WIC 4690.2 (a) "In-home respite services" means intermittent or regularly scheduled temporary nonmedical care and supervision provided in the client's own home.</p> <p>(a) The Director of Developmental Services shall develop program standards and establish, maintain, and revise, as necessary, an equitable process for setting rates of state payment, based upon those standards, for in-home respite services purchased by regional centers from agencies vendored to provide these services. The Director of Developmental Services may promulgate regulations establishing these standards and the process to be used for setting rates. "In-home respite services" means intermittent or regularly scheduled temporary nonmedical care and supervision provided in the client's own home, for a regional center client who resides with a family member. These services are designed to do all of the following:</p> <ol style="list-style-type: none"> (1) Assist family members in maintaining the client at home. (2) Provide appropriate care and supervision to ensure the client's safety in the absence of family members. (3) Relieve family members from the constantly demanding responsibility of caring for the client. (4) Attend to the client's basic self-help needs and other activities of daily living including interaction, socialization, and continuation of usual daily routines which would ordinarily be performed by the family members. <p>I understand what in the consumers own home mean, but no where in WIC 4690.2 (a) does it state the consumers are confined to the home and denied their "civil rights" to (6) social interaction and participation in community activities, and (7) a right to physical exercise and recreational activities while in respite. I would appreciate clarification of this statue. Does being placed in "In Home Respite Care mean the consumers is confined to their own home the entire time they are being cared for by a respite care worker in the absence of their "family member" and no longer have the same rights as</p>	

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	other non disabled people have? I have Power of Attorney for my two family members and I need clarification whether or not this action is appropriate, or in violation of their rights under laws and the Constitution of the United States.	
18.	<p>I would like to give some input in regards to the State Wide Transition Plan. I am a vendor in the Non-Residential Community Setting. On the self-survey there are a couple questions that I think need to be addressed. My company is a 1-3 ratio program design that uses the Self-Directed approach to helping insure that the clients that attend this program we assist to become self-sufficient with less reliance on supports as a goal. In the first 30 days a client is assessed to identify barriers towards self-sufficiency in which we then develop a program plan called a ISP-individual service plan that works in conjunction with the regional centers IPP plan to help individuals with their PCP plan. In other words we design the help necessary to assist them reach their life goals. ADP-Adult Day Programs were initially more about community integration, but they have truly evolved over the years. All programs are developed differently, because clients have different needs from supports we all offer.</p> <p>Now to the questions that I have from the Self-Survey for Non-Residential settings.</p> <p>*Section 4 question 4c. Does a setting allow participants to choose with whom they interact?-No After a client is assessed in the first 30 days of the program there is a meeting to go over barriers towards Self-Sufficiency. The IDT team works together with the client to develop a plan that the client would like to work on towards self-sufficiency. If a client wants to focus more on whom they want to interact with and not utilize the program to become more self-sufficient we will not improve an outcome of the clients we serve. Do we take in consideration who works well together and do our best to set up the daily 1-3 to be successful with clients that have common goals they are working on yes of course. In life we sometimes have to work right along some we don't like, but that's life we need to respect one another and figure out how to get along in a professional matter.</p> <p>*Section 4 question 4e. Does the setting provide participants the option to choose both individual and group activities? – No We are a 1-3 that is our rate structure we would have to hire an excessive amount of staff at the 1-1 ratio which is a much higher rate to allow clients to work with individuals rather than a group like setting we will truly increase the budget. Please keep in mind in school settings you get to bill when a student calls in sick. When a client calls in you are not allowed to bill, so it will be interesting to retain staff on a very variable type of financial setting to not know how many clients want 1-1 setting that day and the next day they want to be in the 1-3 setting. Staff don't appreciate being on-call status, because they have to pay their bills and need to have steady income.</p> <p>I know that you are working on the DC Task Force for rate reform and at the same time doing your best to have an approved State Transition Plan which is very difficult to do. The above two questions are two areas in which rate reform needs to be done prior to meeting compliancy on these two questions. The rate structure will need to do away with</p>	Director Community Vocational Services, LLC

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	<p>ratios unless you are dealing specifically in an area of safety and security. This will allow programs the freedom to have clients that can truly choose their setting of choice.</p> <p>I am looking forward to attending the State Wide Transition Meeting on Wed Oct 5 in your office. If I can help in any way with the changes that lie ahead please feel free to contact me.</p>	
19.	<ul style="list-style-type: none"> • There is a dire need to expand residential and nonresidential capacity to serve the burgeoning numbers of adults with autism and DD. • We must minimize bureaucratic hurdles and foster the creation of many different types of projects and programs to meet a wide variety of needs. • For housing, we must expand both provider-controlled and privately-controlled residential options. • For private residential options, CMS has no authority to conduct systemwide inspections of private residences or impose heightened scrutiny on those homes. • Any review of the quality of a beneficiary's plan, and any examination of undue restraints via HCBS services, must occur through the individual's person-centered plan, not at the level of an unauthorized private property review. • A beneficiary and landlord whose private residential property is deemed "noncompliant" in any way must be accorded the full protections of due process, and the procedures for due process and appeal must be spelled out in legally valid regulations following required notice and comment. 	Parent of HCBS Waiver participant, Advocate
20.	<p>I am the parent of a beautiful and sweet boy with moderate autism. While he can communicate basic needs and requests, he will never be able to live or work independently. He will require supervision his entire life – unless a miracle cure comes along. I am a single mom now and my son's dad recently passed away. Before I die it is critical I know that he will have a stable home after I am gone. I am currently involved with a group of other parents to special needs kids who want to buy land, build a couple homes, and give our children a nice community in an environment full of nature and gardens. My son also suffers from debilitating anxiety when in a loud and hectic environment. Because of this, a suburban or rural environment will be essential if he is to function well and be a contributing member to society. I reviewed the STP and did not see this option mentioned. Does this mean that if my son lived in such a community he would not qualify for federal and/or state funding? That would be preposterous – even inhumane. We know such communities exist—our group is not the first to come up with this model. Will the STP exclude my child from support and independent living services if he lived in a rural environment? Is the definition of “community” limited to urban areas only? Please help parents like me (and so many others) set up a reliable and stable future for our children in an environment that will work best for the individual who will need support for the rest of their lives. It is in everyone’s best interest to do so.</p>	Parent and volunteer with Living Unlimited

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<p>21. Thank you, in advance, for your commitment to providing meaningful lives with choices for our adult children with DD. We hope that the commitment and priority of the consumer's "experience" in the HCBS setting will be put into practice. I hope that the DHCS and DDS pay attention to the true intent and language of the new CMS guidelines - rather than arbitrary guidance that has been issued after the fact by CMS staff or third-party advocates who do not truly represent the entire spectrum of the DD population.</p> <p>CMS issued a subsequent Informational Bulletin entitled "Guidance on Settings That Have the Effect of Isolating Individuals Receiving HCBS from the Broader Community" which conflicts with the original intent of CMS which was derived from years of public comment. The Bulletin was intended to provide information and further guidance to state and stakeholders about new regulations promulgated under CMS 2249-F and 2296-F that were finalized on January 16, 2014 under 79 FR 2947. However, it raises many concerns to many organizations and the rights guaranteed citizens under the US Constitution, Americans with Disabilities Act, Administrative Procedures Act and as interpreted in the Olmstead decision, and other laws for all persons to be supported and accommodated where they live, work, socialize, recreate, learn, love, and worship in the settings and manner they choose for themselves, and with the support and guidance of their parents, families, friends and caregivers.</p> <p>DD consumers need a spectrum of services and one size does not fill all. Attaching labels and or stigmas to types of settings often results in the individual needs of a consumer not being met. The term "appropriate to their needs" should be kept in the forefront of all decisions. This is a fundamental principle established by the Olmstead Decisions that often gets lost or coopted. Consumers deserve choice and services to their needs. My son wants a farm based program, and I am very worried that the new regulations will be interpreted in such a way that will result in reducing the choices available to him ie: limiting his choice by precluding farm based programs. This would be harmful to him!</p>	<p>Parent of HCBS Waiver participant</p>
<p>22. I am the parent of a very cool boy with autism. While he can communicate basic needs and requests, he will never be able to live or work independently. He will require supervision his entire life. Before I pass, I want my son to live in a safe home in a healthy environment/community where he will have dignity and choices that any of us would expect in the normal course of a lifetime. I am currently involved with a group of parents of special needs kids who want to create a cooperative agricultural community in an environment full of gardens and opportunities. My son also suffers from anxiety when in a loud and hectic environment. Because of this, a quiet suburban or rural environment will be essential if he is to function well and be a contributing member of society. I reviewed the STP and did not see this option mentioned so I am very concerned. Are you saying that if my son lived in such a community he would not qualify for federal and/or state funding? Will the STP exclude my child from support and independent living services if he lived in a rural environment? Is the definition of "community" limited to urban areas only? Please enable parents (like me) set up a reliable and stable future for our children who need support for the rest of their lives. Please do not add more obstacles in what is already a monumental task for us families by limiting our options unnecessarily.</p>	<p>Parent of future HCBS Waiver participant</p>

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<p>23. I am the parent of two teenagers with autism and intellectual disabilities. As a mom, I am acutely aware that as California's population of adults with autism and developmental disabilities continues to soar, it is imperative that all housing and program options not only be preserved, but be radically expanded. California's STP should ensure that every person-centered plan is based on the needs and preferences of the individual and not on a one-size-fits all solution. Available solutions must include:</p> <ul style="list-style-type: none"> • Center-based programs addressing the often intensive needs adults with autism • Group homes of varying sizes and structures to address a broad spectrum of support needs • Private residences of all sizes and types, including homes, condos, apartments, shared living, and rural options such as farms. • Residential options that include intentionally autism-friendly and supportive elements, including safety and recreational and space amenities, must be made available, as may be required by individual needs. Just because a property has intentionally disability-friendly amenities does not render it "institutional." Prohibiting autism-friendly housing or subjecting it to "heightened scrutiny" is disability discrimination. <p>DHCS should also be mindful that it lacks legal authority to require private residential landlords who are not HCBS providers to submit information to DHCS or CMS regarding their tenants, their property or their business operations. All inquiries regarding qualities of one's private residence and whether his or her private home "supports access" to the community must be made at the level of the developmentally disabled individual's person-centered plan. DHCS has no jurisdiction to impose this inquiry a priori on private residences.</p>	<p>Parent of two teenagers with Autism.</p>
<p>24. First, thank you for presenting the Sept. 27th webinar and for taking public comment on the STP. I concur with what Marty Omoto and Judy Mark commented on during the webinar, and that is the absolute need for Person Centered Planning to be a key focus and consideration (the keystone) as we move forward. It is not only policy makers and influential advisers who understand how important the enactment of true person centered planning is. I understand that the changes afoot have a great potential to improve the lives of persons with disabilities, seniors, etc, but if real person centered planning is not implemented the changes will be superficial, and maybe even a step backwards. Again, thank you for your continued efforts to serve all the people of California.</p>	<p>Special Projects Coordinator CHOICES Person Centered Services I am an advocate, a person with disabilities, and an employee with CHOICES Person Centered Services in Sacramento, CA.</p>

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<p>25. First of all I would like to thank the staff from all the various agencies that have put this thoughtful transition plan together. It certainly has been a huge undertaking.</p> <p>I think everyone understands the enormous problem the state faces to house and employ individuals with disabilities so I won't belabor this point. This is why I believe it's critical to incentivize creative options to expand and maximize housing and employment resources by honoring individual's choice and autonomy, and not restricting the options of where, how or with whom individuals with developmental disabilities should live.</p> <p>Across the county alternative housing/employment models have been developed emphasising private/public collaborations which include work/live housing arrangements. This could be in the form of a ranch environment, a planned community or the conversion of an apartment complex into a unit dedicated to individuals specifically with disabilities. Others have focused on leveraging tax credits used for low income housing to tap into existing housing development processes to create homes for this disadvantaged population. My concern is that the new HCBS rules, if not interpreted correctly, will hinder or possibly halt these unique endeavors. DHCS believes community is not the mere physical presence of other buildings and people. It includes a safe and purposeful environment where individuals have needed support and safety, and the greatest freedom to live productive, connected lives according to their own desires. I think it is extremely important that the transition plan incorporate language to protect against such misinterpretations.</p> <p>Accordingly, I hope Regional Centers, DDS, DHCS and CMS do not hyperfocus on the concentration or numbers of individuals with disabilities living in close proximity and immediately classify a setting as "presumed to have institutional qualities" and forcing the organization into the additional bureaucratic "Heightened Scrutiny Process". Likewise I hope that the mere fact that a setting designed specifically for a disabled population does not trigger "Heightened Scrutiny" simply based on this fact alone.</p> <p>Instead of focusing on the physical nature of a housing development, I hope the transition plan prioritizes creativity and encourages settings that are looking to address other legislative mandates such as the Workforce Innovation and Opportunity Act or the SCDD Employment First Policy. Settings that promote competitive integrated employment, microenterprises and self employment within a residential setting should be highly encouraged. Language should be added to the transition plan to make this a clear priority. Assessment questions should be added to give the setting representative an opportunity to fully explain the unique features of their environment that promotes all of the above.</p>	<p>Parents of HCBS Waiver provider and residential care facility</p>

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26.	<p>I want to thank the state for working diligently on this process and for the opportunity to participate and comment. My son is nearly 21 years old now and has quadriplegic CP. My goal for him, which I think is consistent with the CMS guidelines, is to give him an opportunity to live where he wants to live, with whom he wants to live, and find meaningful employment or activities that help him to grow and develop throughout his lifetime. This is nothing novel among families who love and care for their family members with I/DD, but who know they had better plan for a future when parents are no longer living and supports are critically important to the I/DD population.</p> <p>I am a strong advocate for choice and my biggest fear is that well-intended, paid advocates and staff will be allowed to decide what is best for my son, perpetuating the paternalism we are all hopefully trying to avoid. Specifically, I am very concerned about comments made by our regional center director, in advance of the final rules, that indicate his strong preference for individual apartment living and his public statements that people with developmental disabilities who prefer to live with their friends and peers, who often also have I/DD, would be prohibited from doing so if they wanted to receive HCBS funded supports.</p> <p>I hope the state will find ways to help MANY different housing, program, and support services to flourish, acknowledging the diversity of needs, skills, and desires of people living with I/DD. It would be even better if our public institutions would welcome private efforts to increase options for housing stock, employment opportunities, intentional communities, efforts to retain support staff, etc. Seems HCBS presents a wonderful opportunity for public-private partnerships in housing development, a particularly big challenge in the high cost bay area.</p>	Parent of a future HCBS waiver participant.
27.	<p>There are many exciting things to like in support of choice and increased opportunities to be involved in community life. As a result the only real outcomes that truly matter are those achieved by the people. Thus, the real outcome oriented evaluation system is a Person Center Plan and demonstration of the HCBS characteristics being delivered. The focus seems to have moved far away from the consumer. The proposed solution is to strengthen the evaluation tools focused on outcomes aligned with the Person Center Plan.</p>	Advocates and providers
28.	<p>I am submitting my comments by email as follows:</p> <ol style="list-style-type: none"> 1. Baby boomers are aging and retiring soon. They should live close to their children or relatives or friends for emergent needs and for social activities, to prevent and limit medical expenses and IHSS. They can ask help from family, friends, or relatives instead of ambulance service when experience mild to moderate injuries from falling, dizziness, or other health problems that are not life-threatening. 2. Young adults with autism or other developmental disabilities and their aging parents are also with increasing needs for their daily living. 3. For facilitating to meet their increasing needs and supports due to aging, Tenant-Based (Section 8 Voucher) Program is the solution so that those seniors living in Project-Based Program can move close to their family/relatives or friends for increased medical needs in order to minimize government expenses. 	N/A

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	Therefore, Transition Plan should include from Project-Based to Tenant-Based Programs. (I did mention it to the LA Housing Authority during the July community meeting. Some of the government officers agreed it.)	
29.	<p>My beautiful autistic son is still in diapers, cannot speak, and needs assistance in all activities of daily living. He has occasional outbursts that involve hurting himself or lashing out at whomever is nearby. He cannot be unsupervised for any period of time, ever, because of his lack of judgment and tendencies to explore or destroy things. Right now he lives at home with me and his dad, ages 56 and 58. How much longer he can live with us, we don't know. What we DO know is that we worry ourselves sick every time we imagine him living somewhere else. What kind of options exist that provide 100% supervision, that give him recreation and community activities, that have humane and trained personnel, and that are affordable?</p> <p>We have found other parents in the same situation, and we have worked together to explore the intentional communities that others have worked very hard to form, and to learn the ins and outs of funding and regulations. It is a daunting prospect, to imagine finding property, figuring out the way to organize, getting the money together, and navigating the rules and regulations that may limit what services we can get from the government to help manage our children's lives, to name just a few of the steps involved.</p> <p>I implore you to consider carefully how you proceed with the STP. We need ALL options to be available. We need more help, not more restrictions. The situation is desperate. We are aging, and our kids will be never be independent.</p> <p>Right now the way I understand it, we may not be able to form a community and get funding for services or housing, because of rules that restrict institutionalization. While we wish for a non-restrictive environment for our kids, the rules go too far.</p> <p>Please imagine the futures of individuals who are disabled and dependent when their parents are no longer capable of caring for them, and base the STP on allowing every option that can meet this growing and dire need.</p>	Parent of HCBS Waiver participant

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30.	<p>I am very interested in how the proposed HCBS regulations will affect him when he leaves our home and moves to another setting. I wish to make the following comments about the State Transition Plan:</p> <ul style="list-style-type: none"> • People with disabilities vary greatly in their needs and preferences. There must not be a “one size fits all” approach to housing options. • HCBS regulations must not presume that living with non-disabled people is always preferable to living with other people with disabilities. This must be a matter of choice and of finding the optimal way to meet an individual’s needs. For example, there must not be an automatic assumption that living alone in a city is preferable to living communally on a farm or rural setting with others who have developmental or other disabilities. By the same token, those individuals who prefer to live in a neurotypical setting must be given the full support they need to do so successfully. • It is essential that we expand residential and non-residential capacity to serve the exploding numbers of adults with autism and DD. • We must minimize bureaucratic obstacles and foster the creation of many different types of residential and other programs to meet a wide variety of needs. • We must expand both provider-controlled and privately-controlled residential options. • Regarding private residential options, CMS has no authority to conduct systemwide inspections of private residences or impose heightened scrutiny on these homes. • Any review of the quality of a consumer’s plan and any examination of undue restraints via HCBS services, must occur thru the consumer’s person-centered plan, not thru an unauthorized private property review. • A consumer and landlord whose private residential property is deemed “non-compliant” in any way must be accorded the full protections of due process, and the procedures for due process and appeal must be spelled out in legally valid regulations following required notice and comment. <p>Thanks you for your consideration.</p>	Parent of a young adult with autism.
31.	<p>1. Please ensure that the regional centers are administering the roll-out of the STP for the transtion of the programs not currently in compliance in the same way so that there are not 21 different variations</p> <p>2. Please ensure that the regional centers have the flexibility needed, and are willing to use that flexibility in order to help providers make changes necessary for the transition of programs that are not in compliance with the new rule.</p>	HCBS Waiver Provider

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<p>32. We are responsible for creating a stable and forever home after we are gone. Our solution to this is to band together with friends who also have adult children with special needs. We will buy land, build a couple of homes and give our children a rural environment for them to flourish. The natural environment is preferable for more independent living than the busy life of city living.</p> <p>After reading the STP, we are concerned that this option is not mentioned. There is the big question then about whether or not such a community as we are planning would qualify for federal and/or state funding. Our group isn't the first to come up with this model. Is it true that our child with special needs will be excluded from supported or independent living services if he chooses to live in a rural environment?</p> <p>This is very scary for our family.</p> <p>Please help us set up a reliable and stable future for our children. Our children will be a valuable part of their community and deserve the benefits wherever they decide to make their home.</p>	<p>We are the parents of a child with special needs.</p>
<p>33. Appreciate the outreach by Department of Health Care Services, especially with the webinar/conference. The department took the time and made the effort to answer all questions asked during the webinar/conference call held on September 27, 2016, and in other forums.</p> <p>In the past I have urged the department to add a direct link to the Statewide Transition Plan and other Home and Community Based Services Final Rule information and documents on its department homepage - with the response that there was not enough hits on a previous link when it first was put there, to justify continuing the link on the homepage. However since that time, interest in the issue - with the deadline for the State to comply fast approaching - has grown. Certainly outreach to the communities impacted by the Final Rule not only from the State but advocacy groups needs to increase, especially in the larger effort to reduce cultural disparities. Toward that goal, it would be helpful to post the link to the Statewide Transition Plan on the department's homepage at least until the March 2019 compliance deadline. While I appreciate very much the good efforts the department and other agencies have made in outreach, I have talked with many people across the State who found it difficult to find documents, and this (along with other outreach ideas) would help.</p> <p>In addition to my comments made during the September 27th webinar/conference call, I am adding the following additional comments:</p> <p>PERSON CENTERED PLANNING PROCESS</p> <p>The person centered planning process is critical in all areas of providing services and supports that are compliant under the Final Rule, and especially so when allowing for any health and safety exceptions for an individual.</p>	<p>CDCAN (California Disability-Senior Community Action Network and the California Person Centered Advocacy Partnership)</p>

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	<p>Urge that the revised draft State Transition Plan put additional emphasis on the person centered planning process for the State and the various departments responsible for specific HCBS funded programs and services to provide services and supports to people in a person centered plan, as required by the Final Rule..</p> <p>Urge that the revised draft State Transition Pan (and the individual departments) include the need for training on person centered planning for state agencies, contracted entities responsible for eligibility (including regional centers), people who receive services and providers</p>	
34.	<p>1. Please ensure that the regional centers are administering the roll-out of the STP for the transtion of the programs not currently in compliance in the same way so that there are not 21 different variations.</p> <p>2. Please ensure that the regional centers have the flexibility needed, and are willing to use that flexibility in order to help providers make changes necessary for the transition of programs that are not in compliance with the new rule.</p>	HCBS Waiver Provider
35.	<p>The largest overall concerns are:</p> <p>First, the ever shortening time frame to start helping programs move towards compliance, which is hindered by historic practices and procedures that focus/require line of sight supervision of individuals with Intellectual and Developmental Disabilities. This is due to a heavy reliance on Community Care Licensing, which has been designed to regulate and supervise "facilities" rather than looking for alternative Quality Assurance/Improvement mechanisms for supporting folks in the community. The transition from that mindset is going to potentially take years to accomplish meaning settings are going to be viewed as out of compliance due to the pace that bureaucracy's change.</p> <p>Second, the implication is that the Federal "Funding" requirements are now more important than the Lanterman Acts - Human Rights and empowerment of individuals with Intellectual and Developmental Disabilities focus that has maintained services to all who qualify for Lanterman Act Services, not just those "funded" by the Home and Community Based Waiver and State-Plan Amendments. The Lanterman Act is based on the premise and support of the Individual Program Plan and so has to viewed thru that lens.</p> <p>Third, the plan identifies private residences in compliance, but does not positively assert other services are currently deemed to be in compliance with the setttings rule and therefore do not need to be assessed. Clarity on who is "deemed" compliant would be helpful.</p> <p>Finally, CMS has focused on evaluating "Settings" and the assessment forms are very bureaucratic and use very formal Federal language, which will be a barrier to encourage the community to help in this process.</p>	Futures Explored provides services to over 650 individuals every day in day and employment services, ranging from those with significant restricted health care conditions to those attending college and being employed in the community full-time.

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36.	<p>At a time when there are so many different documented disabilities ranging from mild to severe, there are so many different needs. There are no blanket solutions to address these needs. Every situation is unique and needs to be addressed as such.</p> <p>Please reconsider your STP rules to reflect the needs of all disabilities.</p> <p>I am a parent, advocate and Special Olympics assistant with an adult son with special needs. He will require supervision for the rest of his life. As a parent, I would like to see him reach his potential in a safe, healthy, rural and productive community where he can thrive as an individual for the rest of his life.</p> <p>Please help us set up a reliable and stable future for our children who will need support for the rest of their lives.</p>	Parent of future HCBS Waiver Participant
37.	<p>1. Please ensure that the regional centers are administering the roll-out of the STP for the transition of the programs not currently in compliance in the same way so that there are not 21 different variations</p> <p>2. Please ensure that the regional centers have the flexibility needed, and are willing to use that flexibility in order to help providers make changes necessary for the transition of programs that are not in compliance with the new rule.</p>	Director of Rehab Hesperia VIP, INC. HCBS Waiver Provider
38.	<p>As a parent, advocate and Special Olympics coach for over 20 years, I have learned a great deal about different disabilities. After reviewing the CMS rules and California's STP, I am very concerned. I have been working with other parents to establish a rural farm community. This would be the perfect affordable environment for my son to do the things he loves. When I read CMS's reply to the STP, it appears they are attacking communities like (Sweetheart) Sweetwater Spectrum and Golden Heart Ranch, which do not even remotely resemble an institution.</p> <p>Does this mean my son would lose his funding, and am I wasting my time and money?</p> <p>At a time when disability housing is in short supply, with long waiting lists and getting worse - why would CMS enforce tunnel vision rules that contradict the needs, wants and affordability of many adults with disabilities.</p> <p>Most of the low income housing options in my area are in neighborhoods known for problems with violence, drug and alcohol abuse.</p> <p>Is this the community-based setting my son is required to associate with? My son will need support the rest of his life and does not possess the abilities to safely go in public places without supervision. Requiring him this freedom would put his life in danger. As I am getting older, please allow me to set up a safe environment for my son before I die.</p>	Parent of future HCBS Waiver participant

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39.	<p>I am the parent of a child with special needs. I want to be assured he will have a stable and forever home after I am gone. My solution to this is to band together with friends who also have children with special needs and buy land, build a couple of homes, and give our children a rural environment for them to flourish. The natural environment seems more preferable for our children than the busy, aggravating life of city living. But from my reading of the STP, this option is not mentioned, so there is a question about whether such a community would qualify for federal and/or state funding. We know such communities exist—our group is not the first to come up with this model. Am I correct in interpreting the STP as excluding my child from supported or independent living services if he lived in a rural environment? Is the definition of “community” limited to urban areas only? Please help us set up a reliable and stable future for our children who will need support for the rest of their lives.</p>	Parent of HCBS Waiver participant
40.	<p>I have been working with people with developmental disabilities in one form or another for the past 32 years. I have seen numerous positive steps over the years in the areas of advocacy, client rights, health and wellness, safety, careers, recreation, and general quality of life.</p> <p>The residents that live in my care home invited me to a meeting to discuss the new Federal requirements affecting Community-Based Adult services (CBAS). They are worried that the place they are currently working will get shut down if it cannot comply with the new Federal Regulation about giving minimum wage to all that work at the facility. One of my residents has been happily working for this organization for over 40 years! He is completely happy seeing his friends, socializing at community events, and yes--going to work each day. He looks forward to going to work each day and gives his best effort. He will never be able to produce enough to make his time profitable for the company that employs him, which is why they cannot give him minimum wage. In fact, none of the residents that live in my care home have the qualities to compete with non-disabled individuals.</p> <p>So if the CBAS company that they are currently employed goes under because they need to pay minimum wage, where will all the people currently employed by these kinds of places go each day? What will their quality of life be like?</p> <p>They are worried that there will be nothing to replace their current reality and support system. Is this really the direction we want to go? It all sounds good on paper until you realize the true effect on the individual who will never be able to compete with others who do not have Intellectual and other developmental disabilities.</p> <p>Continue to look for ways to support competitive employment, but don't throw the baby out with the bath water!</p>	Owner of ARF care home
41.	<p>1. Please ensure that the regional centers are administering the roll-out of the STP for the transition of the programs not currently in compliance in the same way so that there are not 21 different variations</p> <p>2. Please ensure that the regional centers have the flexibility needed, and are willing to use that flexibility in order to help providers make changes necessary for the transition of programs that are not in compliance with the new rule.</p>	HCBS Waiver Provider

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42.	<p>There are Californians who live in large institutional settings or ICFIID's, which are considered to be institutional settings. These individuals often receive adult day services, which are considered to be HCBS services. California's draft state plan does not address this important group of individuals. They are entitled to HCB services during the day, but their home environment is exempt. California's state plan should identify a process to ensure that every individual who receives HCB services lives in a setting that is HCB compliant. Residential settings can be identified during the annual person centered planning process.</p>	HCBS Advocate
43.	<p>I am submitting this general comment that applies to all aspects and sub parts/ attachments of the draft statewide plan. I ran out of time to offer specific language revisions. (There is much more to say). My overarching comment for the plan, and ultimately the program it implements, is that the plan must address the urgent and critical need to provide adequate staff support for DD/ autistic adults with significant behavioral (aggression, self- injury,etc) challenges. Without adequate support in all settings (residential, day program, employment, transportation) the laudable goals and focus of the community based, person centered program(s) will not come anywhere near even minimal fulfillment.</p> <p>From my own experience with my son and my close familiarity with the experience of many other families in my local (SF Bay Area-RCEB clients) parent group, I can say with certainty that virtually all residential settings (home, licensed care, SLS) are not currently provided with adequate support for our children with challenging behavior. The residential situation is dire. Medication alone is in no way sufficient to manage behavior. (every single adult child in our group of families is on medication- it may be necessary but far from sufficient).</p> <p>There can be no meaningful choices available for these individuals in any setting if they are not helped with and through the ravages of behavioral episodes. And that requires sufficient numbers of trained staff available in all settings. When he is well supported my son can flourish and thrive in community and social settings - he loves the workability program at his wonderfully supported school. However, when he has been in residential situations without enough well trained staff to help him through agitated periods leading to aggression, he becomes dangerous and cannot safely be in the community (or anywhere). It is truly terrifying and, again this has been the case for all the families in our group.</p> <p>I implore the agencies administering this important program- please build in staff support for our behaviorally challenged adult DD children so that they can survive and enjoy the promise of HCBS.</p> <p>Please include me on mailing lists for this program. Thank you for the opportunity to comment.</p>	mother/ conservator of autistic son, current Regional Center client/ likely HCBS waiver participant

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44.	<p>It is encouraging to see the California Department of Health Care Services' recognition that each individual's goals, preferences, choices and needs take precedence:</p> <p>"DHCS believes community is not the mere physical presence of other buildings and people. It includes a safe and purposeful environment where individuals have needed support and safety, and the greatest freedom to live productive, connected lives according to their own desires."</p> <p>Consistent with this fundamental principle, assessment tools must be outcome oriented and reflect each resident's person-centered plan. It is critical that there are no one size fits all approach or assessment. Housing choices must be exponentially increased to address the surging population of individuals with autism and other developmental disabilities. I also applaud the presumption that "private residences" are HCBS compliant. However, the apparent exception for private residences that are "limited to or designed specifically for people with disabilities" and the implication that they do not share this presumption and must go through the heightened scrutiny process (which results in CMS determining compliance as opposed to the state of California) is discriminatory. Individuals with developmental disabilities should not have their housing options reduced by restrictions on where, how or with whom they should live.</p>	Parent of a consumer and volunteer Board Member of Sunflower Hill, a 501(c)3 nonprofit organization working to create a sustainable residential community for individuals with special needs.
45.	<p>California's long-term services and supports (LTSS) system is experiencing a number of changes in how services are delivered and funded. The new HCBS rules, and this associated draft plan for implementation, provide an important opportunity for the state to deliver services in accordance with consumers' needs, desires, and preferences. In addition to the HCBS STP, we also recommend that the department together with the Health and Human Services Agency take this opportunity to develop and publish a comprehensive, visible, and forward-thinking state strategy that is inclusive of this STP and ensures that Californians with daily living needs can access care and appropriate supports in the place they call home.</p>	N/A
46.	<p>I don't pay microsoft to use word docs, so I am not able to access your public comment template, but I am very concerned about the long term options for my twin sons who both are significantly affected by autism. My son's do not communicate verbally, have not yet learned to successfully advocate for themselves, are not generally able to effectively communicate their wants and needs to unfamiliar communication partners, and at this point, on the verge of adulthood, appear to have little chance of independence or employment. While I intend to care for sons as long as I can, inevitably they will likely outlive me, and be reliant on the state for their long term care. I am currently exploring possible options, and the most promising option may be to collaborate with other parents to purchase some land in an affordable rural setting, build or renovate appropriate housing for our adult sons and daughters and their caregivers, and put necessary services in place.</p> <p>I am very concerned that the current situation seems to make this kind of supported living arrangement unobtainable, even though for many young adults with autism and other developmental disabilities, this is a very appealing and desirable option, maximizing their comfort and opportunities for the greatest levels of independent living.</p>	N/A

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	Please be as open minded and inclusive as possible when legislating options for the tsunami of individuals with autism aging into adulthood in California.	
47.	<p>SFASA appreciates this opportunity to provide comments on the STP. The STP presents for the most part a reasonable and legally viable implementation of the CMS rules. We appreciate the state’s efforts in that regard. The STP does, however, contain some violations of law and/or reason that should be corrected prior to submission of the final document to CMS.</p> <p>As a preliminary matter, it goes without saying that given California’s immense size, population, diversity, explosive growth of autism, and our intensive and growing shortage in housing and program options, our state must actively work to maximize options to address the wide and growing variety of needs. To that end, and pursuant to the CMS regulations, our HCBS program should be:</p> <ul style="list-style-type: none"> • Person-centered, and driven by the individual needs of the waiver participant; and • Outcome-oriented, judged by the desires of and appropriateness for the participant. California has no legal obligation, however, to adhere to the cloudy blob of non-regulatory restrictive pseudo-rules that CMS has suggested outside of the official regulatory process. The pseudo-rules (which to a large extent still remain unclear) threaten to oppress innovation, choice, and individual legal rights in our state. Therefore we urge DHCS to reject the following: • Neither CMS nor DHCS nor any other entity administering HCBS funds has legal authority to conduct investigations of private residential properties to determine “compliance” with HCBS rules. There is no “settings rule” contained in the actual regulations that require or authorize systemwide investigations of private properties. Rather the “settings rule” only authorizes an inquiry during an individual PCP process as to whether the recipient has access to the community as appropriate and desired, and whether his chosen home/program “has the effect of isolating.” Though California is presuming all private residences are in compliance, it must go father, and dispense entirely with any requirement that private residences (ie, non provider-controlled) be investigated as an abstract propertybased quasi-licensing inquiry. • Likewise, CMS lacks legal authority to review the abstract “compliance” of private residence through a “heightened scrutiny” procedure. The state has no authority to refer a private residence to CMS for heightened scrutiny, as the state has no authority to conduct a preliminary investigation which might trigger such scrutiny in the first place. In addition, CMS regulations are silent as the nature of the heightened scrutiny process and are entirely devoid of any due process procedures to safeguard the rights of recipients and landlords who may be found “noncompliant.” This property-based “settings rule” is only a hint in the regulations, and not a true and valid and enforceable regulation. California must reject it outright. • Any attempt to limit the numbers of persons with developmental disabilities who may live or work together is arbitrary, capricious, and in violation of numerous anti discrimination laws. If an individual desires to live and work among those 	Advocacy organization for HCBS waiver participants and their families

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	<p>without disabilities, that is a personal choice per his or her PCP that should be honored if appropriate. However, if an individual chooses to live or work among others without disabilities, that as well should be honored.</p> <ul style="list-style-type: none"> Disability-specific settings are of immense and indispensable importance to a great many adults with autism and developmental disabilities. It is discriminatory and a violation of numerous state and federal laws to disallow settings with disability-friendly and supporting amenities and programmatic aspects. Likewise, it is a violation of the ADA for DHCS, DDS, regional centers, service providers or private landlords to use CMS rules to deny reasonable disability-specific accommodations to a person with a disability. 	
48.	<p>Our daughter receives supported living services (SLS) which are partially funded by HCBS waivers. Though she is entitled to SLS regardless of HCBS funding, this funding (by subsidizing SLS) does help her live a life with purpose. She is allowed to make choices in every aspect of her life – housing, housemates, friends, activities, services and the like. CMS has stated that the individuals "experience" in their home and work settings is of the utmost importance. For the most part, the proposed STP satisfies this goal and we appreciate the effort on behalf of DHCS to pursue this goal.</p> <p>Individual needs must be stressed as CA implements the STP through 2019. No new persons are alike and each setting must be examined through the lens of the individual's choices and needs. A setting that works for one person may not be appropriate for another. We hope that HCBS realizes that assigning a label or stigma to a certain type of setting ignores the potential benefits of that setting. "Community" means different things to different people.</p> <p>Housing in CA is outrageously expensive – especially for those with DD receiving SSI as their primary source of funds. We are thankful to have found a viable alternative for our daughter. The vast majority of DD individuals still reside with their parents and will do so until the parents become unable to care for them. CA needs more creative options (that still meet the intent of the HCBS settings rules) for housing and work. Presently, over 6,000 persons with autism are turning 18 each year – less than 10% are finding homes in the community.</p>	HCBS waivers provide funding for our daughter with autism
49.	<p>I am the parent of a child with special needs. I want to be assured he will have a stable and forever home after I am gone. My solution to this is to band together with friends who also have children with special needs and buy land, build a couple of homes, and give our children a rural environment for them to flourish. The natural environment seems more preferable for our children than the busy, aggravating life of city living. But from my reading of the STP, this option is not mentioned, so there is a question about whether such a community would qualify for federal and/or state funding. We know such communities exist—our group is not the first to come up with this model. Am I correct in interpreting the STP as excluding my child from supported or independent living services if he lived in a rural environment? Is the definition of "community" limited to urban areas only? Please help us set up a reliable and stable future for our children who will need support for the rest of their lives.</p>	Parent of HCBS Waiver Participant

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<p>50. I am looking at the probability that he will need a supported living environment as an adult, and I have become aware that there are alarmingly few options available for adults with autism and related developmental disabilities. I have learned that I have an opportunity to advocate for government attention to this very pressing issue. It is my opinion, based on my priorities as well as those of the Autism Society San Francisco Bay Area, that available solutions must include:</p> <ul style="list-style-type: none"> • Center-based programs addressing the often intensive needs of adults with autism • Group homes of varying sizes and structures to address a broad spectrum of support needs <p>*Private residences of all sizes and types, including homes, condos, apartments, shared living, and rural options such as farms. This is very important to our community of families facing the housing dilemma.</p> <ul style="list-style-type: none"> • Residential options that include intentionally autism-friendly and supportive elements, including safety and recreational and space amenities, must be made available, as may be required by individual needs. Just because a property has intentionally disability-friendly amenities does not render it "institutional." Prohibiting autism-friendly housing or subjecting it to "heightened scrutiny" is disability discrimination. <p>DHCS should also be mindful that it lacks legal authority to require private residential landlords who are not HCBS providers to submit information to DHCS or CMS regarding their tenants, their property or their business operations. All inquiries regarding qualities of one's private residence and whether his or her private home "supports access" to the community must be made at the level of the developmentally disabled individual's person-centered plan. DHCS has no jurisdiction to impose this inquiry a priori on private residences.</p>	<p>I am a grandparent-caregiver for a child with autism.</p>
<p>51. We are encouraged to see the Department of Healthcare Services' commitment to honoring individual's autonomy, independence, and choice with your statement below:</p> <p>"DHCS believes community is not the mere physical presence of other buildings and people. It includes a safe and purposeful environment where individuals have needed support and safety, and the greatest freedom to live productive, connected lives according to their own desires."</p> <p>We also appreciate California's assessment of the characteristics of "private residences".</p> <p>California has the 6th largest economy in the world and has one of the lowest residential vacancy rates in the country. Many Californians are scrambling to find safe and affordable housing in the midst of rising living cost. These days, safe and affordable combination is difficult to find. For example, the average wait time for affordable housing for people with developmental disabilities in San Diego is around 10 plus years.</p>	<p>Permanent Supportive Housing Developer</p>

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	<p>While the cost of living continues to go up, the rapidly growing number of adults with developmental and/or intellectual disabilities who are still living at home with aging parents and/or family caregivers cannot find affordable living and/or housing options.</p> <p>This is why we believe it's critical to incentivize creative options to expand and maximize housing resources by honoring individual's choice and autonomy, and not restricting the options of where, how or with whom individuals with developmental disabilities should live.</p> <p>While we appreciate the direction of California's statewide transition plan draft, we would like to comment on "private residences presumed to be in compliance".</p>	
52.	<p>My son, who has cerebral palsy and other DD, needs and wants to be part of a community that includes his friends, many of whom also have DD. His choices should not be restricted in order for him to have access to services that are essential for his survival. He and his friends want to live together and share a home base from which to explore the wider community. Please don't restrict his choices by forbidding community-building out of a fear of institutions.</p>	Parent of DD Consumer
53.	<p>We note that the Statewide Transition Plan does not mention Pediatric Day Health & Respite Care Facilities (PDHC) as a provider of HCBS. As you know, PDHCs provide skilled nursing care and day health services to children who are medically-fragile and/or technology-dependent.</p> <p>If PDHCs are also licensed to operate a Transitional Care Unit, the center can continue to provide skilled nursing care and services to participants who are 21 years of age or older, as well as sorely-needed respite care services.</p> <p>While much of the funding for PDHC care and services comes from EPSDT, there are clients whose care and services is paid for through the HCBS/DD waiver (and we hope through the NF/AH Waiver).</p> <p>If PDHCs are not mentioned in the STP, will PDHCs be able to continue to provide services to waiver participants?</p> <p>We would request that Pediatric Day Health and Respite Care facilities be added as a provider of HCBS in the Statewide Transition Plan so that there is no question about the role of PDHCs in providing essential services for waiver participants.</p>	HCBS Waiver Provider - Pediatric Day Health & Respite Care Facility with a Transitional Care Unit
54.	<p>CONCERN: BABY AND BATHWATER : That said, I DO see a trend that worries me in the growing regulations of our loved ones' living and working situations. I know that the intent is to assure our loved ones have choice in the work and living setting that is best for their own growth, integration, interaction, independence and emotional status. And, I agree with this premise. But what I see that worries me is the assumption that living in a manner other than with 1 or maybe 2 roommates is not "good" or "normal", and begins to approach "institutional", "segregating" and "isolating".</p> <p>I worry we are going to throw out the baby with the bathwater. RESIDENCES: In fact, for some people, co-living and working with many people of like-minds is the best way to help them integrate with others, to nurture their emotional well-being, their sense of connection and belonging. REAL LIFE STORY: I have seen my own sister be moved from</p>	Mother of child with Down Syndrome and Autism.

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<p>"institutional", where she was living with about 50 other women on a huge campus, (where she was free to roam to other living centers on campus, the activity room, the church, the play areas, to pet the dog, to the work site etc, so she felt connected, interacted, talked, played), to 2 different small group homes "integrated into the community" where she collapsed into depression and loneliness from lack of appropriate FOR HER interactions. She was no longer free to roam to friends' places, to go to an activity center and find others to hang out with; .. It was heartbreaking. She is now BACK to the large campus, and blooming again. (This is another State where such places are still allowed to exist. One of the only things that they do better than we do.) I am all in favor of people being able to choose more "isolated" living, living alone or with just one person etc , in the community. But I strongly oppose removing the ability of people to choose co-living as well. Think of all the "typical" people choosing such co-living options such as at Common (common.com), a multiple bedroom but common kitchen/living room/activity room living situation springing up all over the nation. Or, seniors choosing senior living centers. Or, graduate students choosing co-living homes with fellow similar graduate students on campus. Or how many of us are choosing cul-de-sac type "pocket neighborhoods" to return to some sense of community? There are many reasons, of course, for such choices, but the bottom line is our loved ones need to be able to make those choices also. My own son sparkles when with people of like mind, but self-isolates if not. Even at home with us, he will retreat into his earphones or TV, unless enticed out to interact by us. My big fear is that he will not be allowed to choose the living and working situations that help him sparkle. He needs to live with many others so that there is more likelihood that someone will draw him out into interactions, play basketball with him, enjoy a game of Mousetrap, go to the Zoo with him, watch Elmo at night, sing silly songs etc. I fear the new rules will somehow be used to call such a place as "out of compliance", and he will end up in his bedroom, listening to music or watching TV when he is home. WORK: As for work, we have tried "integrating" him into "typical" work settings with a coach..massive fail, no matter how kind the "typical" people are, they are simply not going to have lunch with him, and joke and play with him. They have no idea how, nor should they be expected to. BUT when he works with others "like him", they can interact at their level, have lunch together, and have a type of social life on the job, like the rest of us. I don't want that ability taken from him or others like him. I fear the disdain I sense coming from those in DC making these regulations for what they consider "workshops" or other similar settings will result in the loss of many peoples' ability to choose meaningful work with their peers. Again, I am ALL FOR people being able to choose their work environment to be fully integrated into a typical work place, but that is not for EVERY person there is in our State. Thank you for reading this. I apologize I am not able to know where to put such thoughts into the actual language of the regulations. But, I trust, given my attendance now at 2 phone conferences and one in-person conference with this Department and Rebecca Shoup, that YOU will know where such language must change to help assure that real choices are not taken from our loved ones.</p> <p>Best wishes to all of you. Thank you again for all your tremendous work. I hear loudly and clearly, each time I participate in these webinars and conferences, that you are on our side.</p>	

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<p>55. While the August 29, 2016 revised State Transition Plan pushes California forward in a number of areas in order to meet the federal guidelines for ensuring that individuals with disabilities have opportunities to fully integrate into their communities, we are concerned that the latest changes and lack of recent activity still far short in several critical ways.</p> <p>Our primary concerns lie in the areas of the lack of prioritization of educating individuals with disabilities (the STP calls them “members”) and the lack of clear partnerships with local communities to ensure that no individual is left behind as this transition moves forward. Consumers and families should not be the last to know about the new rules since it affects them the most. It also runs counter to the philosophy behind the new rules, which is about person-centeredness and the individual in charge. Education, Outreach and Training</p> <p>The STP states that “As an important early step, information and education on the requirements of the HCB setting requirements and the regulations generally has been provided to State departments/entities, members and families, care-coordination agencies, regional centers, providers, advocacy groups and other interested stakeholders throughout the State on a continuous and ongoing basis.” In fact, very few consumers and families in the DD system are even aware of the HCBS setting rules despite the fact that they were established more than 2 ½ years ago. Moreover, many regional center service coordinators are either unaware of the rules or don’t understand them, which means consumers and families are not working with their regional centers to make changes for the future, if necessary.</p> <p>In addition, the STP lays out who will be trained for the assessment of providers and it never mentions that families and consumers should receive training as well. A critical piece of provider compliance is verifying that the setting is truly meeting the HCBS rules and not just relying on what the provider states. Consumers and families need to understand their rights and the expectations for integration under the new rules so that they are able to provide that verification. Compliance Determination Process for HCB Settings.</p> <p>There has not been enough effort to develop the member survey in the DD community. ASLA was not invited or informed of any convenings to elicit suggestions for the survey. It is also critical that a draft survey is shared with focus groups of consumers and family members in simple language and takes into account cultural differences and language barriers.</p> <p>It is also unclear in what environment the member survey will take place and who will conduct them. Some consumers and families express concern about complaining or telling the truth to their regional centers or if they feel there will be retribution from the provider. This may elicit false information. These cultural differences must be considered. We recommend that the member surveys be conducted by parent advocacy organizations or support groups if there is a concern about receiving truthful responses. We are also concerned that DHCS and DDS are getting a late start. Developing surveys in simple language and ensuring that they are effective is extremely time-consuming, if done well. These efforts need to begin immediately in order to ensure their usefulness during the assessment process. Changes in Members’ Services or Providers. Currently, many consumers/families are offered few choices of providers for a particular service. Regional Centers have their preferred agencies and, in some cases, offer only one choice to the consumer. This runs</p>	<p>Advocate, Autism Society of LA</p>

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<p>counter to the HCBS rules, which mandate that the consumer have a choice from among different setting options. DDS needs to provide ongoing monitoring of this issue.</p> <p>ASLA is also concerned that when a setting is deemed to be non-compliant, the STP requires “written notification to the member and the provider ...at least 30 days in advance of the effective date of the change.” This notice is not close to sufficient to allow the consumer and family time to explore other options. We recommend the notice be provided at least 90 days in advance. In addition, the consumer must be provided with a choice of settings and providers that will help them meet the goals laid out in their person-centered plans. For example, instead of congregate day programs, consumers may want to fund an aide to support them to access unique activities in the community.</p>	
<p>56. Milestones and Timelines</p> <p>Outreach and Training are to be conducted 3rd and 4th Quarters of 2016, including scheduling and holding training sessions for members and families, providers, and the public. We are currently in the 3rd quarter of 2016 and we are unaware of any of these trainings being scheduled. Considering they are supposed to be completed by the end of 1st quarter of 2017 and we haven't heard that materials or curriculum are being developed, it is unclear how this milestone will be met.</p> <p>In addition, the timeline states that Members Surveys will be conducted and then matched with provider self-assessments as late as 3rd quarter 2018. This is far too late and could leave consumers and families without services as the new rule goes into effect. Role of Person-Centered Planning</p> <p>There is a distinct difference between the person-centered plan described in the HCBS rules and the Individual Program Plan (IPP) laid out in the Lanterman Act. While the Lanterman Act requires that IPPs be centered on the person, in practice there are significant differences than the requirements defined in the HCBS rules. The significant differences include:</p> <p>Person-Centered Plan (PCP) Individual Program Plan (IPP)</p> <p>Driven by the individual Centered on the individual</p> <p>Includes people chosen by the individual Individuals' parents/conservator shall have the opportunity to participate. (IPP does NOT require that the individual even attend their IPP.)</p> <p>Occurs at times/locations convenient to individual Often at the convenience of service coordinator's schedule</p> <p>Uses plain language Silent on issue</p> <p>Must be reviewed at least every 12 months Reviewed every 1 - 3 years. It will be impossible to change statutory language so that the IPP becomes equal to the requirements of the PCP. They are not the same thing. Here are two examples: 1.</p>	N/A

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<p>The rules state that the PCP includes people chosen by the individual. What if the individual (or family) doesn't want their service coordinator at their Person-Centered Plan? 2. Many regional centers instruct service coordinators to write in the IPP only those services/programs that they agree to fund. (For example, several regional centers will not allow consumers to put their desire to be in the Self-Determination Program in their IPPs since there is no guarantee they will be in it.) The Person-Centered Planning process is about what's possible, not just what's available. IPPs are about services and authorizations. PCPs are about dreaming big.</p> <p>ASLA is requesting that DHCS and DDS look closely at the language in the Self-Determination Law, which states that the PCP informs the IPP. They are two separate processes. This would require that the state fund a Person-Centered Planning process for each consumer and that the consumer/family can choose whether they will have their regional center service coordinator lead this plan or have an independent person facilitate the planning process. We believe that this would be the only way to implement the new rules with integrity.</p>	
<p>57. On behalf of The Arc California, the state's oldest and largest membership association of people with intellectual and developmental disabilities and their families, I am submitting our comments on the Revised California Statewide Transition Plan (August 29, 2016). While our association has been given ample opportunity to provide feedback as a stakeholder, which we have taken advantage of throughout the process to develop the transition plan, we would like to comment on the resulting draft. Unless otherwise specified our comments are directed at the transition plan in the context of developmental services.</p> <p>Member Assessment</p> <p>As an association made up of both families and people with disabilities we are keenly aware that both groups periodically have differing opinions about the quality of services and different perspectives on the outcomes of the services. We recommend that while adults with disabilities are the primary source of member feedback, we feel the input from families should be solicited as well and included as valuable information in assessing provider services. This is not to suggest that family input should in any way override or even receive equal value of a non-conserved adult, but we believe should be able to voluntarily provide feedback, especially when the member is residing in the family home. We agree that the providers are the backbone of the developmental services system but with just over half the adults living at home with their families, the family caregivers still play a significant role in this system of supports.</p> <p>The process for the member assessment still needs more details for how the information will be solicited, protections in place to prevent coercion, training to inform people with disabilities of the new expectations under the HCB services rules, and training and protections for their participation in the on-site assessments.</p> <p>Recommendations:</p>	<p>Executive Director, The Arc California, "advocates for people with intellectual and developmental disabilities and their families since 1950"</p>

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	<ul style="list-style-type: none"> - Include families and adults with disabilities in the assessment, not or. - Provide for training for families and people with disabilities to fully understand the transition and the purpose of the assessment. - Develop protocols for protections for people with disabilities against coercion. 	
58.	<p>Stakeholder Feedback and Preparation</p> <p>Because of the size of the state and the developmental services system, with tens of thousands of community providers, efforts to this point have not been adequate to prepare our community for the transition. Stakeholder participation and training still requires significantly more outreach and more intentional partnerships with statewide groups to reach all those impacted in our state. The state should develop a comprehensive communications plan, in conjunction with representative stakeholders, to reach all parts of the community. The plan requires several potential changes to statute, on a tight timeline, and if the state does not communicate early as to why these changes are necessary the community feedback will get mixed into the legislative process which could be very unpredictable and cause further delays.</p> <p>Finally, local community direct support professionals will provide the direct contact for implementing the principles in the HCBS rules but there is no statewide effort to inform and retrain the most important touch point for people with developmental disabilities to achieve the level of community integration, access, and inclusion intended in the transition plan.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> - The state should develop a strategic communications plan for the transition plan with stakeholders. - The state needs a training initiative for understanding the transition plan. - Statewide training for Direct Support Professionals. 	N/A
59.	<p>Using the Assessment Information to Make Improvements</p> <p>We commend the state for its interest in using the member input to “play an essential role in quality assurance and program improvement efforts” but we believe there is not enough in the transition plan to describe how that will be achieved. We believe a robust and transparent process for publicly reporting feedback and progress from assessment data could provide potential members information necessary for them to drive the decision of whether or not to select a provider. Providers with remediation plans should have their plans public so members can monitor progress and other providers with similar services can be informed of typical approaches for remediation.</p>	N/A

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	<p>Also in the decision of whether or not to engage in an on-site assessment, information from licensing and credentialing entities (licensing boards, CCL, CARF, etc.) should be considered.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> - Publicly post member assessments and provider progress in remediating during heightened scrutiny. - Incorporate licensing and credentialing information into the decision of on-site assessments. 	
60.	<p>Changes in Member Services</p> <p>Regarding changes in member services or providers the transition plan states that, "The person-centered plan meeting would include the member, involved family members, conservators, authorized representatives, advocates, the care management agency or regional center coordinator, and provider staff who know the member well. To ensure a smooth transition from one provider to another, a transition plan outlining the specific transition activities, including any necessary supports and services needed to ensure a successful and person-centered transition, is incorporated into the person-centered plan."</p> <p>The process described in this section is not in line with the CMS description of the person centered planning process. This is not reflective of the member "driving" the process and takes away their ability to choose who will attend. Also, while not related to HCBS, this section assumes the member will stop receiving services from a non-compliant provider but disregards the state entitlement of the IPP in the Lanterman Act and the potential to receive services funded outside the waiver (i.e., state general fund, other sections of the social security act, education, etc.).</p> <p>Recommendations:</p> <ul style="list-style-type: none"> - The language should not be prescriptive of who will be in a member's person-centered plan meeting. - The language should not presume the state will remove a service from a member's individualized program plan. - This section should describe the informed choice process instead. 	N/A

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<p>61. PERSON CENTERED PLANNING PROCESS</p> <p>The person centered planning process is critical in all areas of providing services and supports that are compliant under the Final Rule, and especially so when allowing for any health and safety exceptions for an individual.</p> <p>Urge that the revised draft State Transition Plan put additional emphasis on the person centered planning process for the State and the various departments responsible for specific HCBS funded programs and services to provide services and supports to people in a person centered plan, as required by the Final Rule..</p> <p>Urge that the revised draft State Transition Pan (and the individual departments) include the need for training on person centered planning for state agencies, contracted entities responsible for eligibility (including regional centers), people who receive services and providers.</p> <p>OVERSIGHT - HIGH SCRUTINY</p> <p>Urge the revised draft Statewide Transition Plan address with more details on how issues related to higher scrutiny as I mentioned in my comments during the September 27, 2016 webinar and conference call held by the Department of Health Care Services, including public posting of decisions made on settings in that process; public posting of corrective actions that a provider can take; providing more details and guidance on what settings will not be considered compliant under the Final Rule in California that will help providers and individuals with developmental disabilities and their families in those settings to transition to settings that are.</p> <p>OVERSIGHT - HIGH SCRUTINY</p> <p>Urge the revised draft Statewide Transition Plan address with more details on how issues related to higher scrutiny as I mentioned in my comments during the September 27, 2016 webinar and conference call held by the Department of Health Care Services, including public posting of decisions made on settings in that process; public posting of corrective actions that a provider can take; providing more details and guidance on what settings will not be considered compliant under the Final Rule in California that will help providers and individuals with developmental disabilities and their families in those settings to transition to settings that are.</p>	<p>CDCAN (California Disability-Senior Community Action Network and the California Person Centered Advocacy Partnership)</p>

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<p>62. Stakeholder Involvement through HCBS Plan Implementation</p> <p>The plan indicates that California will “strongly emphasize inclusive stakeholder processes that analyze and guide implementation.” However the plan is vague about the mechanism of engagement beyond conference calls and webinars. We recommend that the state provide additional detail regarding the stakeholder process throughout STP implementation. Specifically, we encourage the state to engage consumers, providers, and state staff in workgroups and/or existing committees throughout STP implementation, as it did in convening the Community-Based Adult Services’ HCB Setting Workgroup and the Department of Developmental Services’ HCBS Advisory Workgroup for purposes of developing the STP. We believe that stakeholder workgroups/committees provide a useful forum for focused discussion on implementation issue identification and resolution.</p> <p>HCBS Plan Implementation – Education, Outreach and Training</p> <p>Member (Consumer) Input: The state indicates that HCBS programs will conduct surveys to elicit members’ thoughts and feelings about the HCBS they receive. HCBS programs willconduct surveys by adding core questions to individuals’ recertification or reassessment process. The instruments will be tailored to the different service populations (older adults, individuals with physical disabilities, developmental or disease-specific disabilities such as HIV/AIDS). We concur that these surveys should not be distributed en mass through regular mail or electronic media, and we appreciate the plan to engage individuals directly through face-to-face interviews with members or their authorized representatives.Range of Providers and Services: The STP indicates that for individuals receiving multiple HCB services, the state’s focus will be on the HCBS provider with which the member resides or spends a significant amount of time. However, we believe members should have opportunity to provide feedback on all aspects of HCBS service delivery and providers. We recommend the state clarify how the survey process will enable feedback on the range of programs/servicesmembers access.</p> <p>Confidentiality in Survey Process: Members may be concerned that expressing dissatisfaction with his/her provider or services delivered could create conflict beetween him/herself and the provider. We recommend that the state develop safeguards to ensure members can express opinions and respond to surveys in confidence, without provider involvement.Survey Reliability: While the surveys consist of standardized core questions, issues of interrater or inter-observer reliability could impact the consistency of responses as viewed by the interviewer. We recommend that the state train program staff administering the surveys on survey methods and reliability in recording responses.</p> <p>Person-Centered Planning: Considerations for Universal Assessment</p>	<p>The SCAN Foundation</p>

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The state notes that person-centered planning (PCP) is inextricably linked to HCBS setting requirements. The STP indicates that a stakeholder process will be conducted to evaluate the role of PCP as it relates to determining compliance with the federal regulations, assessing member satisfaction with the setting options and other community integration issues. Person-Centered Planning in relation to Person-Centered Care: We recommend that the state clearly define and establish standards for PCP as it relates to broader concepts of personcentered care. In 2015, the Foundation partnered with the American Geriatrics Society and University of Southern California to convene experts to create a formal, actionable definition of person-centered care. Recent articles published in the Journal of the American Geriatrics Society defined person-centered care, which means that individuals' values and preferences are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals. These articles also describe ways organizations are using a personcentered care approach for a high-need/high-risk older populations, which may be useful for conceptualizing PCP in the STP.

Role of Universal Assessment: Over the past four years, the Foundation has invested significant resources toward supporting the state's efforts in developing a legislatively-mandated Universal Assessment (UA) for LTSS spanning across the Department of Health Care Services, the Department of Social Services, and the Department of Aging. The UA draft content provided by the state's contractor includes assessment questions drawn from legacy California assessments as well as validated measures from federal tools and high-performing states. Stakeholders from across the care delivery spectrum have invested time and expertise to assist the state in identifying meaningful and relevant questions. We recommend that the state finalize and implement the UA to identify LTSS needs and help inform the PCP process in accordance with W&I Code section 14186.36(b)-(i). We also recommend that the state clarify how its UA instrument, process, and implementation fit into the STP.

Background

Comments on Draft STP		Proposed Revisions	Organization/Relationship to the HCBS Program
1.	<p>I appreciate all the work going into this process. I am nearly 60 years old, and my "little" sister has rather severe cognitive impairment, about like a 5 year old. I have watched the pendulum swing far and wide, literally moving with my family when I was 10 years old across the nation to Santa Barbara, California, where there was one of the two places in the nation near a job for my father that taught children with special needs. Now, I have a son with Down Syndrome and Autism who functions roughly like a non-verbal, happy 3-4 year old. His life has had so many more educational and social opportunities than my sister's, and I am grateful to have been here, now, with my son.</p>	N/A	Mother of child with Down Syndrome and Autism.
2.	<p>We have just begun to truly understand the history of the rulemaking. But, we know that it went through 5 years of public notice, comments and extensive scrutiny. Many important revisions were made along the way. Most importantly, CMS turned away from defining the specific physical attributes of settings and chose to focus on the qualities of settings.</p> <p>By 2014, CMS had rationally concluded that both disability-specific housing and congregate settings were permissible – provided they did not isolate persons. CMS did not see the need to “blackball” any settings beyond those identified in the statute. The definition of “home-and-community based” can take several physical forms.</p> <p>But, CMS did issue subsequent guidance about “settings that isolate” after the fact. This guidance conflicts with the settings rules established already. It improperly points a finger at settings with “may” or “typically” isolate which is: (a) against the intent of the rules and (b) was substantive enough that it should have gone through public comment. The final rules are the only ones that have actual legal standing.</p> <p>DD individuals are protected by the Americans With Disabilities Act. CMS may NOT withhold HCBS funding to any DD individual merely because the other person with whom they associate is also has a DD (either at home or at work). This would violate ADA in more ways than one. It also is objectionable to suggest that interactions with neuro-typical persons are superior to those with DD persons. Forced integration is as bad as forced segregation – even the court recognized this in the Olmstead Decision.</p>	N/A	Parent & conservator of an adult child with developmental disabilities

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3.	<p>Devising these CMS rules has been a thorough process with public comments at many stages. My understanding of the final definition of HCBS settings is that disability-specific housing and congregate settings are permissible, and that there is no singular definition of home-and-community based. In the event of conflict between the final rules and additional guidance issued by CMS, the final rules should be followed as they have legal standing.</p> <p>As I noted in my general comments, individuals with DD should have the same rights to choice and self-determination as non-disabled individuals. This is a civil right, protected by the Americans with Disabilities Act. Services cannot be denied based solely on the housemates or co-workers one chooses.</p>	N/A	Parent & conservator of a member who has developmental disabilities
4.	<p>As a general comment, I call attention to the fact that the new CMS rules which clarify acceptable HCBS settings were put in motion back in June 2009 with an advance notice of proposed rulemaking 74 FR 29453. The final rules went through almost 5 years of revisions after extensive review and public comment. During that period, CMS specifically fine-tuned both the language and intent of the new rules in critical areas as follows in the final rules (Federal Register, Vol. 79, No.11 of 1/16/14):</p> <p>1. Page 2973-74 states: Comment: We received many comments both in support of and opposition to the requirement that would have resulted in heightened scrutiny over a disability-specific housing complex. The comments we received on this provision are reflected as follows: Several commenters recommend the regulation be revised to remove “disability specific housing complex” as a setting in which HCBS may not be provided. Response: As a result of comments we received on the use of the term disability specific-complex, we have revised the rule to remove the term “disability-specific housing complex”... We plan to issue future guidance to provide examples of the types of settings that will be subject to heightened scrutiny.</p> <p>2. Page 2967 - Comment: Several commenters requested the regulation be revised to add “Board and Care homes” for people with disabilities to the list of excluded settings, because of the institutional manner in which they operate. Response: We do not believe it is necessary to identify specific settings, beyond what is specified in statute. We believe the most effective and consistent way to assure that individuals receiving Medicaid HCBS, regardless of age or type of disability, are offered HCBS in the most integrated setting appropriate to their needs and preferences, is to focus on</p>	N/A	Parent & conservator of a consumer accessing the HCBS Waiver for Persons with Developmental Disabilities (DD Waiver)

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<p>the qualities of “home” and “community” that assure independence and integration from the perspective of the individuals.</p> <p>3. Page 2956 - "Instead of attempting to provide one singular definition to encompass all settings that are home and community based, we described the qualities that apply in determining whether a setting is community-based."</p> <p>4. CMS has also 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.</p> <p>In summary, CMS intentionally determined in its Final rule that: (1) disability-specific housing were permissible, (2) settings beyond those identified in the statute were not needed to be identified, (3) there should be no singular definition of home-and-community based and (4) congregate settings are not automatically disqualified from receiving HCBS funds.</p> <p>CMS issued a subsequent Informational Bulletin entitled "Guidance on Settings That Have the Effect of Isolating Individuals Receiving HCBS from the Broader Community" which conflicts with the original intent of CMS which was derived from years of public comment. In the event of conflict between the final rules and this Bulletin, the final rules should be followed first and foremost as they have legal standing.</p> <p>On a related note, I encourage the DHCS to respect the rights of DD individuals provided under the Americans With Disabilities Act of 1990 (ADA). ADA is a law that was enacted by the U.S. Congress and is a wide-ranging civil rights law that is intended to protect against discrimination based on disability. Title II of the Act prohibits disability discrimination by all public entities at the local level, e.g., school district, municipal, city, or county, and at state level. Public entities must comply with Title II regulations by the U.S. Department of Justice. These regulations cover access to all programs and services offered by a public entity. Specific references are as follows.</p> <p>1. Section 35.130(a) No qualified individual with a disability shall, on the basis of disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any public entity.</p>		

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<p>2. Section 35.130(b) (4) A public entity may not, in determining the site or location of a facility, make selections: (i) That have the effect of excluding individuals with disabilities from, denying them the benefits of, or otherwise subjecting them to discrimination</p> <p>3. Section 35.130(g) A public entity shall not exclude or otherwise deny equal services, programs, or activities to an individual or entity because of the known disability of an individual with whom the individual or entity is known to have a relationship or association.</p> <p>CMS cannot deny HCBS services to a DD individual solely because the other person with whom they associate (either in a residential as a housemate or in an employment setting as a fellow worker) has a DD - ie. delineating any setting as "disability-specific" violates ADA. . Similarly, CMS cannot dictate that a specific location or setting is not permissible under the rules – especially without evidence to justify that the setting is not appropriate for each single individual accessing that setting.</p> <p>Research from the National Core Indicators (collaboration of the National Association of State Directors of Developmental Disability Services and the Human Services Research Institute) indicates that many individuals in congregate settings report feeling less lonely less than those persons with disabilities living in other settings.</p>		

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5.	<p>Ostensibly California's rationale for adopting the transition plan is twofold: To fully integrate all clients of regional centers into their communities by allowing them to personally plan and select their CHOICES from the array of services and supports that will to meet their unique needs and desires. To supplement California's general fund budget dollars with federal funds from CMA for categories of supports and services needed by 309,000 infants, children and adults who are clients of California's 21 regional centers which will reduce costs . The unfortunate flaw with these reasoning's is CHOICES made through the person centered planning process on behalf of . every regional centers client while, at the same time setting arbitrary program limitations regarding how "integrated" the program is to the community and who is allowed to participate In a program or activity will seriously limit or eliminate resources and prevent people from being allowed to make actual CHOICES. Preaching independence while reducing or taking away options cancels CHOICE out. The two are incompatible. california's embrace of CMS regulations that are disrespectful of persons who are developmentally disabled is baffling. Seeking to control or take away living, working and recreational activity options in order to promote a public policy that claims it is based on the need to promote integration is discriminatory. We know of no other system that seeks this kind of control. Seniors who chose to live together in communities that cater to their needs do so if they wish. Other than persons incarcerated, what other class of U.S. citizens are not allowed to live where and with whom they wish? FEDERAL DOLLARS: The presumption that when CMS offers States the promise of supplemental funding in response to compliance with Home and Community Based Service waivers that, if strictly followed, will result in long range costs savings is false. When have federally funded matches ever .kept pace with a federally initiated program that states must match with General Fund dollars. Short term supplemental federal funding typically results in a long term commitment of State funding allocations minus the increase of federal dollars necessary to keep the program afloat. Anyone remember PL 94-142?</p> <p>Equally important is the fact that this plan requires the availability of affordable community housing. Where is it? Is CMS (Not our responsibility) or DDS (Isn't that a HUD problem?) actually going to resolve this huge lack of resource for all the populations in need of housing Right now, here in Orange County there are over 800 clients of the local regional center who are 45 years of age and older STILL living with their aging parents. And what of the 18,000 clients of this regionaf center, most of</p>	<p>N/A</p> <p>1) Parent of client of the Regional Center of Orange County, diagnosed with Rett syndrome, lives at home, 2) Advocate on behalf of infants, children and adults with developmental disabilities and their families during the past 44 years, 3) Representative of California's CHOICE Coalition</p>

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<p>whom will require low income housing? This is a State issue that, to our knowledge, being ignored.</p> <p>Home and Community Based .Services waiver regulations appear to put a stop to what little housing a few families are able to finance because a great many families and consumers want communities developed that will allow people having like-needs to live in what they consider a far more welcoming community that is safe, where services are more readily available, friends are close by, activities are accessible; very much like the senior assisted living model communities. Such communities are believed to be "Institutional" according to CMS waiver regulations. Apparently CMS feels they have the authority to decline payment for services in locations when viewed "institutional" even though provision of services to a group of people who are allowed to make their own CHOICE about where they live should it be at one location results in more efficient coordination, greater choice of quality providers and a serious reduction in overall cost. The cost benefit of serving reasonably large groups of people at one location is indisputable when compared with provision of resources on a one-by-one basis- for individuals living by themselves or with up to three other people scattered all over a county.</p> <p>We absolutely support and advocate integration of persons with developmental disabilities into our communities. This transition plan, based upon what appears to be either a naive attempt at forced integration or a means to reduce CMS costs for CMS funded waiver services that can be denied based on arbitrary location and participants is ridiculous.</p>		

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6.	<p>I am hoping that we are wrong about all of this. Perhaps someone has located that benevolent community where people with developmental disabilities, even those most challenged, have lead normal lives these past 40 years. A Shangri-La where 40-some years of integration onto normal public education campuses where parents of regular students are not angry and do not resent what they feel Is a disproportionate amount of money being spent on "those kids" while their children go without an individualized education plan. Where dentists are grateful to provide dental care to people who are unable to cooperate, unable to point out where it hurts and glad to receive 30% of what they are reimbursed for the average patient. Where MDs and specialists have lots of time and are equitably reimbursed for their devotion to patients with special needs. A community where In-Home-Support care givers clamor for the opportunity to work for the pitifully inadequate wages paid; there's more low cost housing than anyone could hope for with neighbors who actually speak to each other and residents, include them in the neighborhood BBQs, invite them to go shopping, skating, camping and sky diving and don't call the police or city council when someone yells in the back yard. Please share where this place is - we would be so grateful.</p> <p>If no such place exists, should we not have learned by now that it is time to close the gaps that have played a major role in preventing community integration such as the expectation that the public will voluntarily open their arms, step up to the plate and assume responsibility for the many systems challenges that we have failed to address these many decades?</p>	N/A	N/A
7.	<p>Under 1915(k) Community First Choice (CFC) State Plan Program, CFC members select their residential setting. If this choice is one that includes living with others who share the same disability, so be it as it is the member's choice. If such a living environment is one that includes supported living services, so be it as it is the member's choice. We agree that the final rule should outcome oriented and guided by the member's choice.</p>	N/A	Aging Parent of a current HCBS Waiver Participant

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8.	<p>I am the parent of a child with a developmental disability. To the best of my ability, I have worked to provide an environment meets her medical, social, emotional, and intellectual needs. My daughter currently lives with me, but as I am now a senior citizen, the issue of planning for her safety and care when I am no longer alive or able to care for her has taken on particular urgency. She has many skills which allow her to function with a moderate degree of independence in the community, but has a combination of intellectual and physical/medical limitations which will require her to live in a supported setting. Like many others with developmental disabilities, she will need assistance assured by government policies if she is to live a life in which she is not not constantly fearful for her safety and the meeting of her basic needs. I have spent much time researching residence options for my daughter and have found the options desperately low in number, with waiting lists so lengthy as to render them irrelevant in my attempts to plan for my daughter's future. Wealthy parents of children with developmental disabilities are able to find independent or supportive residential settings which meet the varied needs of their adult children, although even these settings are likely to have lengthy waiting lists. As new models are proposed and considered for government-funded housing and support for individuals with disabilities, I am concerned by the following restriction placed on what could be considered a non-provider-owned or controlled private residential home settings:</p> <p>"The dwellings are not limited to or designed specifically for people with disabilities. Rather, the members chose to live in the private residences in integrated settings with other people from the community and their families."</p> <p>Requiring non-provider-owned or controlled private home settings to be open to those without disabilities will further limit the critically low number of housing options available to California's citizens with developmental disabilities. Many residential settings in which the residents or consumers receive government assistance are able to limit availability to the "target" group whose needs the residence is geared to meet, such as senior citizens, recovering substance abusers, those with mental illnesses, "halfway houses" for those recently released from incarceration, and so on. I understand and support this. To include residents who are not part of the "target" group would not only limit the number of the number of housing opportunities available to the special population in need of housing, but would also dilute the necessary specialized services and supports in place in these residences to help those</p>	<p>2) - 3. "Private residences chosen by the member" to "Private residences chosen by the member or legal conservator"</p> <p>3) "The dwellings are not limited to or designed specifically for people with disabilities."</p>	Parent of HCBS Waiver participant

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	<p>affected lead fulfilling lives in the community. Why deny this option to individuals with developmental disabilities?</p> <p>I appreciate your efforts as you strive to provide a continuum of residential options for persons with developmental disabilities. I know well the concerted effort and support necessary for people with developmental disabilities to lead a life with a degree of independence, dignity, and at least some of the choices that those without disabilities take for granted. Please do not take steps that further limit those with developmental disabilities the opportunity to live as independently as possible in a safe and affordable home. Please allow non-provider owned or controlled private residential home settings to limit residence to those with disabilities as one housing option for this vulnerable group in our society.</p>		
9.	SEE ABOVE	Eliminate restrictions upon housing which meets the needs of any particular group by removing the language which defines private housing as that which is not designed for or limited to people with disabilities. Stop defining "people from the community" as only those who are not disabled, as if they are the most appropriate members of our society and the disabled are not.	Attorney representing individuals with developmental disabilities
10.	<p>We understand that the new CMS rules went through five years of revisions after extensive review and public comment.</p> <p>CMS determined in its final HCBS settings definition that: (1) disability-specific housing and congregate settings were permissible, (2) settings beyond those identified in the statute were not needed to be identified and (3) there should be no singular definition of home-and-community based.</p> <p>In the event of conflict between the final rules and additional guidance issued by CMS, the final rules should be followed first and foremost as they have legal standing.</p> <p>On a related note, we encourage the DHCS to honor the rights of DD individuals</p>	N/A	Parents of a member who has developmental disabilities

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	provided under the Americans With Disabilities Act. CMS cannot deny HCBS services to a DD individual solely because the other person with whom they associate (either in a residential as a housemate or in an employment setting as a fellow worker) has a DD - ie. calling out any setting as "disability-specific" violates ADA.		
11.	<p>There is a dire need to expand residential and nonresidential capacity to serve the burgeoning numbers of adults with autism and DD.</p> <ul style="list-style-type: none"> • We must minimize bureaucratic hurdles and foster the creation of many different types of projects and programs to meet a wide variety of needs. • For housing, we must expand both provider-controlled and privately-controlled residential options. • For private residential options, CMS has no authority to conduct systemwide inspections of private residences or impose heightened scrutiny on those homes. • Any review of the quality of a beneficiary's plan, and any examination of undue restraints via HCBS services, must occur through the individual's person-centered plan, not at the level of an unauthorized private property review. • A beneficiary and landlord whose private residential property is deemed "noncompliant" in any way must be accorded the full protections of due process, and the procedures for due process and appeal must be spelled out in legally valid regulations following required notice and comment. <p>DD consumers need a spectrum of services and one size does not fill all. No two IPP's or ISP's are alike. Also, attaching labels and or stigmas to types of settings often results in the individual needs of a consumer not being met. The term "appropriate to their needs" should be kept in the forefront of all decisions. This is a fundamental principle established by the Olmstead Decisions that often gets lost in the mix. The Court held that public entities must provide community-based services to persons with disabilities when: (1) such services are appropriate and (2) the affected persons do not oppose community-based treatment.</p> <p>Consumers deserve choice and services to their needs.</p>	N/A	Parent of HCBS Waiver participant, Advocate

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12.	<p>In general, I am concerned that my son might be discriminated against based upon his choice to live with other young people who have developmental disability. I encourage the DHCS to honor the rights of DD individuals provided under the Americans With Disabilities Act of 1990 (ADA). ADA is a law that was enacted by the U.S. Congress and is a wide-ranging civil rights law that is intended to protect against discrimination based on disability. Title II of the Act prohibits disability discrimination by all public entities at the local level, e.g., school district, municipal, city, or county, and at state level. Public entities must comply with Title II regulations by the U.S. Department of Justice. These regulations cover access to all programs and services offered by a public entity. Specific references are as follows.</p> <p>1. Section 35.130(a) No qualified individual with a disability shall, on the basis of disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any public entity.</p> <p>2. Section 35.130(b) (4) A public entity may not, in determining the site or location of a facility, make selections: (i) That have the effect of excluding individuals with disabilities from, denying them the benefits of, or otherwise subjecting them to discrimination</p> <p>3. Section 35.130(g) A public entity shall not exclude or otherwise deny equal services, programs, or activities to an individual or entity because of the known disability of an individual with whom the individual or entity is known to have a relationship or association.</p> <p>CMS cannot deny HCBS services to a DD individual solely because the other person with whom they associate (either in a residential as a housemate or in an employment setting as a fellow worker) has a DD - ie. delineating any setting as "disability-specific" violates ADA. . Similarly, CMS cannot dictate that a specific location or setting is not permissible under the rules – especially without evidence to justify that the setting is not appropriate for each single individual accessing that setting. My son would like to live in a farm like setting with other young men and women who enjoy nature and farming. Please do not deny him services, a future or any opportunities solely based upon his own interests!</p>	<p>N/A</p> <p>Parent of HCBS Waiver participant</p>

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<p>13.</p> <ul style="list-style-type: none"> • On page 5 last paragraph item 1, the term “greater community” is used. What does this mean? In discussions with Regional Center staff, they often interpret this from a viewpoint of one living in an urban environment where the client often has easy access to transportation, grocery stores, entertainment, etc. They tend to impose these features on clients currently living in a rural environment and if these features don’t exist, they label the setting as “isolating”. For a client who has grown up in a rural environment, this is his home and the lack of urban conveniences should not disqualify him from services in this setting. • It should be noted that housing options in the state are minimal. To emphasize the need for a client to have several choices is setting the stage for failure. I had to wait four years for a group home opening that met my son’s needs. There was only one option given and we are pleased with the placement. • I noticed the omission of addressing cultural needs and the fact that most clients want to live with their friends and to be in long term relationships. I think language should be added to encourage this. • I did not see any language regarding the option for a client to live in a gated community in this section. Is it acceptable for a client to choose such a setting? 	N/A	Parents of HCBS Waiver provider and residential care facility
<p>14.</p> <p>I think it is very important to recognize that one size does not fit all. Since my son is particularly social and interested in living with as many of his friends as would be willing to live with him, I do not want to see any restrictions on this desire. Specifically, I would like to see assurances built into the process of determining HCBS compliance that follows the decision to scrutinize "disability-specific settings." If he ends up wanting to live with many of his peers, and they are offered access to the community to the extent they desire, I believe HCBS and its agents in every part of CA should support and encourage this and not limit their choices. I would hope the person-centered planning process will be sufficient to ensure such choices, but given the variability of interpretations and conduct by RC directors thus far, consumers and their family members remain concerned that the spirit of the new regulations not be lost or people's lives and choices be curtailed because a non-disabled person or an unrelated bureaucrat has his/her own notions of what choices are permissible for the consumer to make.</p>	N/A	Parent of a future HCBS waiver participant.

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	I also think it is critical that the variety of options include a means of serving people throughout the life span, and across the spectrum of I/DD. Normal aging will occur to everyone and services, housing and supports should be relevant to the differing needs that occur as we age. Serving only those who are young, or not being able to support the same consumers as they age and their needs change, would be a short-sighted approach. Many advocates are focused on young adults, or just for those able to speak for themselves directly, but we need to address lifespan needs for ALL Californians with I/DD.		
15.	Licensing plays a huge rule in all the long term care support programs and they too seem to be largely missing. Their roles and responsibility are huge for both residential and day programs and as a result need to be a leader in this change process. The STP should clarify their role and expand on explanations of how they will support the move to changing the service provision mind-set away from program driven and institutional driven models.	N/A	Advocates and providers
16.	<p>We agree that the assessment tools and systems of accountability including the PCP must be individualized and outcome-oriented. Each PCP will be unique, based on different goals, preferences, and support needs.</p> <p>Page 9: “There is no wait list for eligible beneficiaries.”</p> <p>This statement is misleading as in reality the regional centers are increasingly informing consumers there are no available options for programs, services or housing, particularly for housing or programs serving those with more severe forms of autism and DD.</p> <p>DHCS and DDS should document all cases where a placement or program has been requested and denied, as demand currently outstrips access to services and affordable and appropriate housing options. The “waiting list” exists yet is not documented by the state.</p>	N/A	Advocacy organization for HCBS waiver participants and their families

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17.	<p>CMS 2249F was subject to heavy scrutiny over 5 years of public notice, comments and revisions. Critical changes were negotiated during that long period. By January 2014, CMS had turned away from defining the specific physical attributes of settings and chose to focus on the qualities of settings.</p> <p>Both disability-specific housing and congregate settings were now permitted by the regulations provided they are not isolating. CMS chose NOT to target any settings beyond those identified in the statute. Settings which qualify as “home-and-community based” can take several forms.</p> <p>But, something unsettling and illegal occurred after the new regulations were codified into law. CMS opted to issue additional guidance about “settings that isolate. This guidance is in direct conflict with the new settings rules established. The guidance targets settings (farm communities, gated communities, etc.) with “may” or “typically” isolate – it chose to “label” settings after explicitly stating it would do no such thing. Aside from going against the intent of the rules, this guidance attempts to create new laws and was of substance that merited going through public comment. We hope that DHCS recognizes this fact and that the final rules are the only ones that have actual legal standing.</p> <p>The Americans With Disabilities Act protects my daughter. CMS may NOT withhold HCBS funding to her merely because she has chosen to live with other women with autism. This violates ADA in multiple ways. Her choice to live with others with autism is NOT inferior to living with non-DD persons. Loneliness is prevalent among persons with autism and she now has more friends in her home than ever before. The Olmstead Decision does not force integration – it merely gives people like my daughter options and choices.</p>	N/A	HCBS waivers provide funding for our daughter with autism

HCBS Programs

HCBS Programs		
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1. Page 9/Line 7 – “There is no wait list for eligible beneficiaries.” This statement flies in the face of reality. Numerous regional centers in California have issued RFPs for new services in 2016 and received no proposals. The median rate structure used to pay vendors in California stifles any interest in providers expanding services. Providers have stopped bidding to provide services where they are guaranteed to lose money. This statement is also fallacious in particular when it comes to supported and independent living options. The only reason “there is no waiting list” is because California no longer provides any support for individuals to find their own homes. No one argues that California housing and/or rental prices prevent many from leaving their homes – SSI payments don’t even cover the cost of rent in our state. But, California has reached a point where 82% of DD persons between the ages of 18-31 are living in their parent’s home – back in 2002 that figure was 71%. Each year the percentage goes up. Aging parents cannot care for their adult children forever and California is facing a wave of aging DD persons with no housing options.	N/A	Parent & conservator of a consumer accessing the HCBS Waiver for Persons with Developmental Disabilities (DD Waiver)
2. HCBS Waiver for Persons with Developmental Disabilities (DD Waiver) Adult Residential Facilities (CCF) are currently included in the list of DD Waiver providers and should continue to be an option, past March 28, 2017. Living in a setting with others of the same disabilities does NOT limit integration and interaction with a larger community of non-disabled citizens. And, indeed may enhance interaction by providing a site for interaction and safe base within a larger, integrated community. Again, the emphasis is on choice, made from an assortment of other living choices/environments. Any list of ‘homes’ needs to include as many variations as possible so as to optimize the array of choices.	N/A	Aging Parent of a current HCBS Waiver Participant
3. On. p. 9, the statement that "there is no waitlist for eligible beneficiaries" implies that there are no known shortages of services, which is known to be untrue, so this statement should be removed. Also, camping is included as a provider type but California removed this as a benefit in the 2009 Trailer bill and regional centers deny this benefit for HCBS-DD waiver participants even when requested as a respite solution in a camp location, so it should be omitted. On p. 11, under Nursing Facility/Acute Hospital NF/AH, the last listed provider type has a typo and should read "Waiver Personal Care Services Provider", not "Waiver Personal Care Services Provide"	see above.	Parent of HCBS Waiver participant. While I am a member of a regional advisory committee of the State Council on Developmental Disabilities, I am commenting as a parent, not on behalf of the SCDD.

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<p>4. It seems a grave potential injustice to suggest that if a person with I/DD chooses to live with, work or socialize with others with I/DD they would be denied access to needed support services under HCBS implementation. I caution the state to take every step necessary to ensure individual rights and freedoms of association are not violated by an overzealous, mis-interpretation of the CMS guidelines.</p> <p>There is a looming, if not already present crisis in affordable housing in many counties of CA. The bay area, where I live, is particularly out of reach, financially, for many non-disabled individuals to afford housing and they do not experience the same barriers to full employment, compensation, and opportunity that people with I/DD do. The further reality is that people like my severely disabled son cannot reasonably be expected to find a job paying the needed salary to afford to live in the bay area. He and the thousands like him in our state need creative solutions and very likely the financial help of parents, family members, and the state just to survive.</p> <p>While I understand CMS' concern that persons with I/DD who have neighbors or housemates who work as support staff could be segregating, the reality is that this is being done all over our state. Those who receive supported living services often live with their client in reduced rent situations because providers cannot earn sufficient wages doing this work to also afford to live in the high priced markets of much of CA. Wholesale preclusion of settings that also attempt to address this reality by stabilizing support staff, reducing turnover, and providing affordable housing to this workforce seems short-sighted and unrealistic.</p> <p>I fully support a consumer's right to choose his/her provider, including changing providers if a suitable match is not maintained. However, precluding that selected provider from accessing neighboring affordable housing should not, in my estimation, result in non-compliance with HCBS. If the outcome of the setting and supports result in the consumer accessing the broader community in a meaningful way, according to his/her preferences, then I think our state should encourage stabilizing EVERY facet of life for a person with I/DD and this must include looking at the critically important component of providers of care and support.</p>	N/A	Parent of a future HCBS waiver participant.
5. Community based day program, employment programs and residential services.	N/A	Advocates and providers

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6.	While there is technically no per se waitlist in California, the reality is otherwise given the dearth of quality living options and day programs.	N/A	Parent of a consumer and volunteer Board Member of Sunflower Hill. Sunflower Hill is a 501(c)3 nonprofit organization working to create a sustainable residential community for individuals with special needs.

Monitoring and Oversight Process			
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1.	All monitoring and oversight should ensure safety of those with developmental disabilities and freedom of choice based on personal outcomes and reasonable costs.	N/A	Aging Parent of a current HCBS Waiver Participant
2.	<p>Please consider adding to this section that the State's intends to facilitate formation of review site (perhaps by issuance of a nonfunded RFP), where members may provide reviews of providers. This will be an important tool in monitoring under the pending Self Determination program; this platform may also provide a marketplace for potential non-vendored service providers to offer services.</p> <p>(I believe such a marketplace will likely evolve with or without State involvement, but a proactive effort on the State's part will enable California to set privacy requirements, and tap the reviews to comply with CMS requirements.)</p>	California will issue a nonfunded request for proposal for third party operators of a site for Members to post reviews of CMS compliant providers, which data shall augment monitoring input from regional center and licensing divisions.	Parent of HCBS Waiver participant.
3.	Monitoring and oversight are extremely important, but as underfunding needs to be addressed otherwise measures will be implemented inadequately and will undermine the goals and effectiveness of the regulations. Monitoring and oversight can occur in many settings and we should not assume that they require a urban/city setting.	N/A	Parent of future HCBS Waiver participant
4.	I have no professional experience with this activity and yet it seems to me that the most critical aspect of any monitoring is that it be fair and never arbitrary or capricious.	N/A	Parent of a future HCBS waiver participant.
5.	<p>It would be helpful to clarify the steps, the sample sizes, the options for what's to happen following each step, and what will happen if the problems identified are systemic and beyond the control of the provider being assessed in either the Self Survey or the Provider Survey or within the State Sample Surveys. Without a more specific roadmap it does not appear to be a fair system. Also, will there be an appeal process at each step along the way?</p> <p>Every provider would love to fully implement a person center planned for every individual they serve. The primary barriers may in fact end up being systemic. Thus far I'm not seeing how the questions are getting this information, much less doing so in a way that aggregates data into a meaningful way to collectively advocate for positive changes in our state.</p>	N/A	Advocates and providers

Monitoring and Oversight Process		
Comments on Draft STP		Organization/Relationship to the HCBS Program
6.	Additional clarity is needed on who the team members will be that perform enhanced monitoring and oversight of providers in the DD Waiver. While the regional center system received enough funding for twenty-one positions statewide to assist providers with HCBS compliance, these resources are insufficient to complete the reviews of the provider self-assessments, the development of corrective action plans, the onsite provider reviews, and the ongoing monitoring that this plan will require.	<p>N/A</p> <p>The Association of Regional Center Agencies (ARCA) represents the network of twenty-one non-profit regional centers that coordinate services for, and advocate on behalf of, California's nearly 300,000 people with developmental disabilities.</p>

Private Residences Presumed to be in Compliance			
Comments on Draft STP		Proposed Revisions	Organization/Relationship to the HCBS Program
1.	<p>Page 15, line 23 says, “dwellings are not limited to or designed specifically for people with disabilities.”</p> <p>This contradicts the Final Rule of the CMS, which removed the term “disability-specific housing complex” and replaced it with “any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS...”</p>	<p>Page 15 – Line 23</p> <p>Delete - The dwellings are not limited to or designed specifically for people with disabilities. Rather, the members chose to live in the private residences in integrated settings with other people from the community and their families.</p> <p>Add - The dwellings may be specifically designed for people with disabilities, or may provide a mix of housing for people with DD and others.</p>	Parent of a young adult woman with developmental disabilities (DD)
2.	<p>Pages 14-15 – Thank for recognizing that private residences are presumed to be compliant with the regulations – our son lives in such a residence. He chose his home, his housemates, his daily living regiment and who supports him. However, the STP should be revised in a few areas.</p> <p>On Page 14 – Line 6, the language should be changed to allow homes to be owned OR leased. Either option should be permissible – the legal form of occupancy should not matter.</p> <p>On Page 15 – Line 23, we object to the sentence that reads “dwellings are not limited to or designed specifically for people with disabilities.” Did this truly mean that DD persons cannot choose to live with other DD persons nor in homes designed for people with DD? Hopefully, this is not the intent and we have these comments. First, DD individuals should be free to live with as many other or any percentage of DD persons as they choose – especially in private, non-licensed residences. CMS has et not threshold on the number of DD persons who may occupy a home. Second, this sentence violates ADA regulations. Third, many persons choose “disability-specific design” for good reasons and it may be “appropriate to their needs.” For example, our son’s house has special soundproofing which helps his sensory issues around noise. He also has gates</p>	<p>Page 14 – Line 6</p> <p>Amend as follows - Private residences owned or leased by the member, or a relative of the member, conservator or any other individual legally authorized to represent the member.</p> <p>Page 15 – Line 23</p> <p>Delete - The dwellings are not limited to or designed specifically for people with disabilities. Rather, the members chose to live in the private residences in integrated settings with other people from the community and their families.</p>	Parent & conservator of an adult child with developmental disabilities

Private Residences Presumed to be in Compliance		
Comments on Draft STP		Organization/Relationship to the HCBS Program
	which keep him safe from wandering. And finally, after 5 years of public feedback, CMS made a conscious effort to “remove the term “disability-specific housing complex”. It should be kept out of the STP also.	
3.	<p>Page 14-15 – Generally, I applaud the revised STP for recognizing that private residences are presumed to be compliant with the regulations. It recognizes the right of DD persons to choose their homes, where and with whom they live, how they live and who supports them. In California, we call this model “supported living.” The STP needs to clarify a couple specific areas though.</p> <p>1. Page 14 – Line 6 - Homes can be owned OR leased/rented. Either option should be acceptable.</p> <p>2. Page 15 – Line 23 – I disagree with the sentence “dwellings are not limited to or designed specifically for people with disabilities.” I have multiple comments.</p> <ul style="list-style-type: none"> • First, DD individuals should be allowed to choose their housemates (as I’ve noted previously). Living with non-DD peers is NOT superior to having housemates with DD. To state otherwise is patronizing, discriminatory and disrespectful of individuals with DD, and surely violates the ADA. • Second, disability-specific design is precisely what many DD persons require and choose “as appropriate to their needs.” Design items might be for safety or a mere matter of convenience to allow DD persons to live the most-unrestricted lives. This might be secure access gates for safety or something as simple as additional soundproofing for individuals with sensory processing issues. • Third, the notion that disability-specific settings are undesirable is directly contrary to the new CMS rules. CMS has stated that “we have revised the rule to remove the term “disability-specific housing complex”. • Finally and appropriately, CMS has not placed a limit on the number of DD persons who can occupy a setting. Page 14 – Line 6 <p>Amend as follows - Private residences owned or leased by the member, or a relative of the member, conservator or any other individual legally authorized to represent the member.</p>	<p>N/A</p> <p>Parent & conservator of a member who has developmental disabilities</p>

Private Residences Presumed to be in Compliance		
Comments on Draft STP		Organization/Relationship to the HCBS Program
	<p>Page 15 – Line 23</p> <p>Delete - The dwellings are not limited to or designed specifically for people with disabilities. Rather, the members chose to live in the private residences in integrated settings with other people from the community and their families.</p> <p>Add – Dwellings may be limited to or designed for people with DD provided the dwellings satisfy the other requirements of the new HCBS regulations.</p>	

Private Residences Presumed to be in Compliance		
Comments on Draft STP	Proposed Revisions	Organization/Relationship to the HCBS Program
<p>4. Page 14-15 – Generally, I applaud the revised STP for recognizing that private residences are presumed to be compliant with the regulations. It recognizes the right of DD persons to choose their homes, with whom they live, how they live and who supports them. The STP needs to clarify a couple specific areas though.</p> <p>1. Page 14 – Line 6 - Homes can be owned OR leased. Either option should be acceptable.</p> <p>2. Page 14 – Line 7 – “Unlicensed room and board homes” is a vague definition. It does not reference apartments or other rental options that might exist. Adding the mention of social security payments is unnecessary - the source of rent payments is not relevant. Also, licensing should not matter as well – a member may choose to pay rent in a licensed community but it is still their own residence.</p> <p>3. Page 15 – Line 23 – There is an unclear section that states that “dwellings are not limited to or designed specifically for people with disabilities.” On first reading, the implication is that people with DD cannot choose to live in private residences that are 100% occupied or designed for people with DD. I have multiple comments and hope that was not the true intent of the language as written.</p> <ul style="list-style-type: none"> • First, DD individuals should not be shamed if they opt to live with others who have DD in private residences. The language as written promotes an abilist ideal that living with non-DD peers is superior to having housemates with DD. • Second, it violates ADA Sections 35.130(a), (b) and (g) that I referenced in the Background section earlier. CMS cannot deny HCBS services to a DD individual solely because the other person with whom they associate (either in residential or employment setting) has a DD. • Third, disability-specific design is precisely what many DD persons require “as appropriate to their needs.” Design items might be for safety or a mere matter of convenience to allow DD persons to live the most-unrestricted lives. This might be secure access gates for safety or something as simple as additional soundproofing for individuals with sensory processing issues. All DD persons are entitled to reasonable accommodations from a landlord under ADA in any event. • Fourth, the notion that disability-specific settings are undesirable is directly contrary to the new CMS rules. As mentioned earlier, CMS intentionally removed this limiting 	<p>Page 14 – Line 6 Amend as follows - Private residences owned or leased by the member, or a relative of the member, conservator or any other individual legally authorized to represent the member.</p> <p>Page 14 – Line 7 Delete - Unlicensed room and board homes chosen by the member and paid for by the member with his or her own money, sometimes using their Social Security payments. These homes are not limited to a category of residents, and both disabled and non-disabled individuals are free to reside in these homes.</p> <p>Add – Private residences may take a variety of forms provided they still afford members with access to the community as required by the new HCBS definitions. A private residence may be a single family home, apartment, rental unit or any other space in the greater community without regard to the geographic location or number of DD members residing at the residence.</p>	<p>Parent & conservator of a consumer accessing the HCBS Waiver for Persons with Developmental Disabilities (DD Waiver)</p>

Private Residences Presumed to be in Compliance		
Comments on Draft STP		Organization/Relationship to the HCBS Program
	<p>language in Page 2973-74 of the rules by stating “we have revised the rule to remove the term “disability-specific housing complex”.</p> <ul style="list-style-type: none"> Finally, CMS has not placed a limit on the number of DD persons who can occupy a setting. On page 2967 of the rule, CMS also stated that “we do not believe there is a maximum number beneath which we could determine with certainty that the setting would meet the requirements of HCB settings. The focus should be on the experience of the individual in the setting.” <p>Page 15 - Line 36 – The restriction should not restrict interaction with BOTH DD and non-DD people. I will suggest language below.</p>	<p>Page 15 – Line 23 Delete - The dwellings are not limited to or designed specifically for people with disabilities. Rather, the members chose to live in the private residences in integrated settings with other people from the community and their families.</p> <p>Add – Dwellings may be limited to or designed for people with DD provided the dwellings satisfy the other requirements of the new HCBS regulations. Rather, the members chose to live in the private residences in integrated settings with other people (both DD and non-disabled) from the community and their families.</p> <p>Page 15 – Line 36. Amend as follows - The settings do not restrict the member from interaction with other non-disabled people or other persons with DD in the broader community.</p>

Private Residences Presumed to be in Compliance			
Comments on Draft STP		Proposed Revisions	Organization/Relationship to the HCBS Program
5.	<p>CMS issued home and community-based settings regulations based on “individual experience and outcomes with the purpose of maximizing the opportunities for members receiving Medicaid HCB services...”(emphasis added) California should NOT create barricades to living solutions with language that limits choices. Just as seniors, families, pet and non-pet owners and students, etc. choose to live with one another in complexes limited to their designated/delineated group, so should individuals with developmental and other disabilities be able to so choose. Often such groupings allow economies of scale and thus lower costs. Whether or not a community has a license, should not dictate whether such a residence qualifies for coverage. The CHOICE is up to the member supported by their personal outcomes.</p> <p>NOTE: I could not strike out the words "unlicensed" so have just ADDED the option for a LICENSED room and board home. Also, the last phrase of paragraph 2., I could not strike out "and both disabled and non disabled individuals are free to reside in these homes" ... I wish this language to be removed below...so I have deleted this phrase below.</p>	<p>2. LICENSED OR unlicensed room and board homes OR COMMUNITIES chosen by the member and paid for by the member with his or her own money, sometimes using their Social Security payments. These homes MAY OR MAY not BE limited to a category of residents.</p>	Aging Parent of a current HCBS Waiver Participant
6.	<p>Per above, private residences should simply be that: privately owned and not defined by whether they are "designed" for or limited to the disabled, because on the one hand you state a person should be able to choose housing and programs but on the other, the only thing they will be allowed to choose is to live as HCBS decides which is with the non-disabled according to some vague formula or description. Also, what is meant by "designed"? Is it physical or something else? For a population with many special needs, how is it logical to create housing that is actually not designed for their needs and to exclude that which is designed for them?</p> <p>The push for everyone with DD to have "integration" by being forced to live in rented apartments with only the non DD puts many with severe behaviors at risk of eviction and homelessness. No landlord has to rent to them and no one has to allow them to remain if they cause property damage, cause problems in their interactions with others etc. I can assure you, this happens. You would "integrate" the most vulnerable portion of the DD community right out of a place to live with such policies.</p>	<p>.=Define private housing as simply privately owned property without restrictions and vague language regarding design and integration with "others from the community" as if DD peers are not part of our society or are to be prevented or not counted as appropriate.</p>	Attorney representing individuals with developmental disabilities

Private Residences Presumed to be in Compliance			
Comments on Draft STP		Proposed Revisions	Organization/Relationship to the HCBS Program
7.	When the STP refers to "chosen by the member" or "members chose to live," it must acknowledge the power of a conservator "to fix the residence or specific dwelling of the limited conservatee."	For "chosen by the member," write "chosend by the member or the member's conservator." For "members chose to live," write "the members or their conservators chose for them to live."	Parent of HCBS Waiver participant
8.	California will issue a nonfunded request for proposal for third party operators of a site for Members to post reviews of CMS compliant providers, which data shall augment monitoring input from regional center and licensing divisions.	Private residences owned in whole or in part by the member, or a relative of the member, or a special needs trust held for the benefit of the member's special needs, or a limited liability partnership owned by any of the above entities.	Parent of HCBS Waiver participant.
9.	<p>Page 14-15 – We are in agreement with the revised STP for recognizing that private residences are presumed to be compliant with the regulations. It recognizes the right of DD persons to choose their homes, with whom they live, how they live and who supports them. There are however some specific areas that STP needs to clarify.</p> <p>1. Page 14 – Line 6 - Homes can be owned OR leased. Either option should be acceptable.</p> <p>2. Page 15 – Line 23 – The sentence reads “dwellings are not limited to or designed specifically for people with disabilities.” The implication is that people with developmental disabilities cannot choose to live in private residences that are 100% occupied or designed for people with DD. Ewe hope that is not the intent of the language as written.</p> <ul style="list-style-type: none"> • This seems to violate ADA. CMS cannot deny HCBS services to a DD individual solely because the other person with whom they associate (either in residential or employment setting) has a DD. • Disability-specific design is what many DD persons require and choose as being appropriate to their individual needs. Design items might be for safety or a matter of convenience allowing DD persons to live a less restrictive life. 	<p>Page 14 – Line 6 Amend as follows - Private residences owned or leased by the member, or a relative of the member, conservator or any other individual legally authorized to represent the member.</p> <p>Page 15 – Line 23 Delete - The dwellings are not limited to or designed specifically for people with disabilities. Rather, the members chose to live in the private residences in integrated settings with other people from the community and their families.</p>	Parents of a member who has developmental disabilities

Private Residences Presumed to be in Compliance			
Comments on Draft STP		Proposed Revisions	Organization/Relationship to the HCBS Program
	<ul style="list-style-type: none"> The implication that disability-specific settings are undesirable is contrary to the new CMS rules. CMS has stated that “we have revised the rule to remove the term “disability-specific housing complex”. 	Add – Dwellings may be limited to or designed for people with DD provided the dwellings satisfy the other requirements of the new HCBS regulations.	
10.	For private residential options, CMS has no authority to conduct systemwide inspections of private residences or impose heightened scrutiny on those homes.	<p>Page 14 – Line 6 Amend as follows - Private residences owned or leased by the member, or a relative of the member, conservator or any other individual legally authorized to represent the member.</p> <p>Page 14 – Line 7 Delete - Unlicensed room and board homes chosen by the member and paid for by the member with his or her own money, sometimes using their Social Security payments. These homes are not limited to a category of residents, and both disabled and non-disabled individuals are free to reside in these homes.</p> <p>Add – Private residences may take a variety of forms provided they still afford members with access to the community as required by the new HCBS definitions. A private residence may be a single family home, apartment, rental unit or any</p>	Parent of HCBS Waiver participant, Advocate

Private Residences Presumed to be in Compliance		
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		<p>other space in the greater community without regard to the geographic location or number of DD members residing at the residence.</p> <p>Page 15 – Line 23 Delete - The dwellings are not limited to or designed specifically for people with disabilities. Rather, the members chose to live in the private residences in integrated settings with other people from the community and their families.</p> <p>Add – Dwellings may be limited to or designed for people with DD provided the dwellings satisfy the other requirements of the new HCBS regulations. Rather, the members chose to live in the private residences in integrated settings with other people (both DD and non-disabled) from the community and their families.</p> <p>Page 15 – Line 36. Amend as follows - The settings do not restrict the member from interaction with other non-disabled people or other persons with DD in the broader community.</p>

Private Residences Presumed to be in Compliance		
Comments on Draft STP		Organization/Relationship to the HCBS Program
11.	<p>We believe it is problematic to presume that all private residences are presumed to be in compliance. The STP states, “Consistent with CMS’ HCB setting rules, California presumes that these non-provider owned or controlled private residential home settings qualify as HCB settings.” Not all “private residences chosen by the member” allow for full integration into the community. Just because a provider doesn’t control the residence doesn’t mean that integration is being achieved if desired by the consumer. For example, ASLA has worked with a consumer in the South Central Regional Center that lived for 12 years in an unlicensed room and board home. She felt she had no privacy and was “trapped” because of her lack of access to the general community. There needs to be more assurances that these settings, even in non-provider controlled residences, provide privacy and access to the community when desired.</p>	<p>N/A</p> <p>Advocate, Autism Society of LA</p>
12.	<p>The comments below I copied from a vender’s response that I completely agree with. I wanted to emphasize and support her comments so I am including them:</p> <p>“There is a lot of confusion around what "provider owned or controlled" means. Please clarify whether “provider” in the STP means a Medicaid/Medicare or Waiver (i.e. DD Waiver) services provider to HCB Services recipients or includes other types of providers. For example, is a private pay service provider who receives no HCBS funding considered “provider” in this context? Also, why is it necessary to state that "the dwellings are not limited to or designed specifically for people with disabilities."? Eliminating services for those who choose to occupy dwellings that “are not limited to or designed specifically for people with disabilities” intentionally places even more housing out of reach for those who need it the most. The disabled have the fewest options and resources in a competitive housing market, especially when their disability requires the very design and amenities that they would be forbidden to access by this rule as written. In the midst of scarce housing options, there are not enough dwellings set aside for people with disabilities. The competition for affordable dwellings in urban areas near jobs and transportation includes the growing homeless in California and the employed who cannot afford skyrocketing rents that are becoming the norm. These populations are often the focus of housing set-asides when affordable housing is to be built. If you impose this design restriction, it will become a mechanism to cut-off access to precious housing resources for one of the most vulnerable populations. Without any affordable and viable living options, individuals with developmental disabilities will be</p>	<p>N/A</p> <p>Parents of HCBS Waiver provider and residential care facility</p>

Private Residences Presumed to be in Compliance		
Comments on Draft STP		Organization/Relationship to the HCBS Program
<p>next wave of the homeless population. All affordable housing projects in California are categorized. They fall into one of many categories: special needs, seniors, low income families, etc. The special needs sub-category includes homeless, at-risk youth, developmental disabilities, mentally ill, formerly homeless and more. Some of the major funding sources actually give preferences to special needs projects. In fact, in some cases with HUD project vouchers which provides rental subsidies, only special needs projects can apply up to 100% of the units for these vouchers and other categories can only be limited to a certain portion of the units. Recognizing the scarcity of affordable housing for individuals with developmental disabilities, some jurisdictions offer public funding in a form of capital or land on the condition that the majority or all of the units must be set aside for developmentally disabled population. Even so, the housing need is much greater than the current level of existing supplies. Simply eliminating access to housing because it is limited to the disabled without requiring some standard by which other housing is assured, simply exacerbates the problem of scarcity. It ignores all other considerations that should determine quality of life issues: affordability, location, safety, quality, access to the community and peers, etc. The concept of being part of a community is an illusion if housing is not available. Then the alternative is homelessness. Furthermore, some jurisdictions and public funding sources encourage and favor universal design to enable aging in place for the elderly and people with disabilities. In fact, some public funding opportunities are contingent upon this design. If the developers must rely on these major public funding sources and implement universal design and set aside a majority of the units for people with developmental disabilities, how is it that individuals with developmental disabilities are to be punished with the loss of funding for much needed services regardless of the outcome of their life experiences? Also, the federal Fair Housing Act makes it unlawful to refuse to make reasonable accommodations in rules, policies, practices, or services when such accommodations may be necessary to afford a person with a disability the equal opportunity to use and enjoy a dwelling.</p> <p>The focus should be on whether the dwellings could properly support the individual's need and allow the individual an opportunity to integrate and have access to the greater community. Please remove any restrictive standard that focuses on physical characteristics of a setting. Restrictive criteria like this will discourage new housing developments for people with developmental disabilities in California at a time when</p>		

Private Residences Presumed to be in Compliance		
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	<p>the developmentally disabled adult population is growing, parent care-givers are aging, and the cost of existing and new housing in urban areas is rising. This is not an option.”</p> <ul style="list-style-type: none"> • Low income housing developers would love to design and build more apartment style homes specifically for the DD population, but they must be assured that Regional Centers will fund the SLS and ILS services needed for most DD clients to be successful. With millions of dollars at stake, it is obvious that developers will not take the risk unless they have a commitment for these services. I have personally experienced Regional Center staff refusing to make such as commitment citing the new CMS regulations as the reason. The Regional Centers often would like to make such commitments, but they need language in the regulations and in the transition plan to empower and support their decisions. • The term “broader community” is used again in this section and I would request that a distinction be made between an urban community and a rural community • Some of the “Planned DD Communities” that have been developed across the county have incorporated a work/live design along with a “reverse integration” approach. Clients live in an apartment located on a second story above a commercial/retail space where they are free to interact with the public as they choose. The commercial renters are required to provide competitive and integrated employment to the clients in exchange for reduced rent. This is a very successful model and one that addresses both employment and housing needs. I believe this model will accomplish the goals of the HCBS regulations and enable a higher number of DD clients to live in close proximity with each other. 	
13.	I fully support that private residences should be presumed compliant and anything other than this assertion seems completely outside the intent and spirit of the regulations as well as unjustified.	N/A
		Parent of a future HCBS waiver participant.

Private Residences Presumed to be in Compliance			
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14.	<p>Thank you for recognizing various models of private residences and that there is no one particular model that supports all different needs. However, as noted in the general comments section, the implication that a housing model that is 100% occupied or designed for individuals with developmental disabilities is subject to further review, scrutiny or does not fall under the automatic presumption is troubling at best, likely illegal, and contradicts CMS' own rules.</p> <p>As a threshold matter, the Americans with Disabilities Act prohibits discrimination on the basis of disability and applies to both private and public entities. Restricting the percentage or number of individuals with disabilities who can live together violates the ADA. Requiring a residential community to go through an additional level of scrutiny or review and/or denying HCBS services solely based on whom a resident chooses to live with is discriminatory. Simply put, a setting that is occupied by 100% of residents with disabilities is entitled to the same presumption of HCBS compliance that a setting that is occupied by 75% of residents with disabilities. Holding otherwise is arbitrary and capricious and opens a Pandora's box – a "numbers" focus instead of the experience. Moreover, the current language promotes the indefensible assumption that living with individuals without disabilities is superior to the alternative.</p> <p>Additionally, the state and federal fair housing laws and ADA require reasonable accommodations from landlords so language applying a different criteria, test or presumption because a residence has "a disability-specific design" should be removed from the STP.</p>	<p>In regards to the non-provider owned or controlled private residential settings: I'd like to propose the following revision and removal:</p> <p>1) 1. "Private residences owned by the member or a relative of the member." to "Private residences owned or rented by the member, a relative or legal guardian or conservator of the member."</p> <p>2) - 3. "Private residences chosen by the member" to "Private residences chosen by the member or legal conservator"</p> <p>3) "The dwellings are not limited to or designed specifically for people with disabilities."</p>	<p>Parent of a consumer and volunteer Board Member of Sunflower Hill. Sunflower Hill is a 501(c)3 nonprofit organization working to create a sustainable residential community for individuals with special needs.</p>
15.	<p>In its November 16, 2015 letter to California, CMS indicated that the state may presume the compliance of private homes but "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..." The draft STP does not address how California will make this assurance for communities comprised entirely of Waiver recipients.</p>	<p>Page 14 – 1. Private residences owned rented, or leased by the member or a relative of the member that are not owned or controlled by a service provider who is not a relative of the member.</p>	<p>The Association of Regional Center Agencies (ARCA) represents the network of twenty-one non-profit regional centers that coordinate services for, and advocate on behalf of, California's nearly 300,000 people with developmental disabilities.</p>

Private Residences Presumed to be in Compliance			
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16.	<p>Any non provider owned or controlled private residential home setting should qualify as an HCB setting. The state Medicaid authority does not have the authority to conduct investigations into private properties to determine compliance or noncompliance as a quasi "licensing" scheme. This mandate does not appear in the federal regulations but was concocted ad hoc after the fact in various non-regulatory informal statements issued by CMS, and in any event does not lie within the legal jurisdiction of activities CMS is authorized to undertake.</p> <p>Under the regulations the sole "setting" inquiry takes place at the level of the individual PCP. The regional centers may take steps to ensure the PCP does not entail unwanted or inappropriate isolation of the individual. But neither DDS, DHCS nor the regional center has any authority whatsoever to conduct independent investigations of any private properties.</p> <p>Furthermore, we strongly oppose the "DD quota" that has been implied in various nonregulatory statements by CMS. Not only does the DD quota make no appearance in any CMS regulation, it is outright discrimination to impose express or implicit limits on the numbers of persons with DD who may reside in proximity to each other. In fact, on page 2967 of the HCBS rule, CMS stated “we do not believe there is a maximum number beneath which we could determine with certainty that the setting would meet the requirements of HCB settings. The focus should be on the experience of the individual in the setting.”</p> <p>We also reject CMS' premise that living with non disabled peers is superior to having neighbors with disabilities. This is an ableist idea that California must not embrace. Furthermore there is nothing inherently negative, undesirable or isolating about dwellings or programs designed to address the unique needs of people with disabilities. Owing to the severity of their functional limitations and behaviors, virtually all regional center-qualified adults will need intentionally autism-friendly aspects of their living arrangements, which may include special amenities, materials, safety devices or monitors, common spaces, programmatic aspects, on-site supervision, and legal constructs that protect them from eviction to which they are extremely vulnerable in generic homes or apartments (especially if they are seen as disturbing the peace or safety of their neighbors). Any attempt by CMS or the state of California to reduce or</p>	<p>Page 14 – Line 6 Amend as follows - Private residences owned or leased by the member, or a relative of the member, conservator or any other individual legally authorized to represent the member.</p> <p>Page 14 – Line 7 Delete - Unlicensed room and board homes chosen by the member and paid for by the member with his or her own money, sometimes using their Social Security payments. These homes are not limited to a category of residents, and both disabled and non-disabled individuals are free to reside in these homes.</p> <p>Add – A private residence may include single family homes, condominiums, townhouses, apartments, rental units, mobile homes, shared homes or any other space in the greater community not owned or controlled by a government or HCBS service provider, without regard to the geographic location or number of DD members residing at the residence.</p>	Advocacy organization for HCBS waiver participants and their families

Private Residences Presumed to be in Compliance			
Comments on Draft STP		Proposed Revisions	Organization/Relationship to the HCBS Program
	eliminate access of adults with autism to the special amenities and protections they need, both in residential and nonresidential environments, will be met with legal action.	Page 15 – Line 23 Delete - The dwellings are not limited to or designed specifically for people with disabilities. Rather, the members chose to live in the private residences in integrated settings with other people from the community and their families. Add – Dwellings may be limited to or designed for individuals with DD provided that the recipient’s PCP specifies that this option is desired and appropriate.	
17.	<p>Pages 14-15 – We applaud the recognition of private residences as being compliant with HCBS – our daughter lives in such a residence. She makes choices in every single aspect of her life – she lives the same life as anyone residing in a home in her community. However, the STP must be corrected in some key areas.</p> <p>On Page 14 – Line 6, the language should be changed to allow homes to be leased as well – not JUST owned. Both options afford the same level of integration – the legal occupancy type of the setting should not matter.</p> <p>On Page 15 – Line 23, the sentence that reads “dwellings are not limited to or designed specifically for people with disabilities” does not make any logical sense. First, it implies that someone with DD cannot choose to live with other DD persons. And second, it suggests that homes cannot be designed for people with DD. Neither of these is legal or desirable. DD individuals can choose to live with any number of DD persons as they choose – especially in private, non-licensed residences. CMS has no maximum threshold on the number of DD persons who may occupy a home. The language, as written, violates ADA regulations. Many persons opt for “disability-specific design” for very good reasons. The design might be important and be “appropriate to their needs.” For example, our daughter’s house has special paint colors which help her sensory</p>	<p>Page 14 – Line 6 Amend as follows - Private residences owned or leased by the member, or a relative of the member, conservator or any other individual legally authorized to represent the member.</p> <p>Page 15 – Line 23 Delete - The dwellings are not limited to or designed specifically for people with disabilities. Rather, the members chose to live in the private residences in integrated settings with other people from</p>	HCBS waivers provide funding for our daughter with autism

Private Residences Presumed to be in Compliance		
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	issues around colors. She also has a quiet HVAC system which helps with her sensory issues around noise. And finally, after 5 years of public feedback, CMS made a conscious effort to “remove the term “disability-specific housing complex” from CMS 2249F. It should be kept out of the STP also.	the community and their families.
18.	<p>Thank you for recognizing various models of private residences and that there is no one particular model that supports all different needs. There is a lot of confusion around what "provider owned or controlled" means. Please clarify whether “provider” in the STP means a Medicaid/Medicare or Waiver (i.e. DD Waiver) services provider to HCB Services recipients or includes other types of providers. For example, is a private pay service provider who receives no HCBS funding considered “provider” in this context? Also, why is it necessary to state that "the dwellings are not limited to or designed specifically for people with disabilities."? Eliminating services for those who choose to occupy dwellings that “are not limited to or designed specifically for people with disabilities” intentionally places even more housing out of reach for those who need it the most. The disabled have the fewest options and resources in a competitive housing market, especially when their disability requires the very design and amenities that they would be forbidden to access by this rule as written. In the midst of scarce housing options, there are not enough dwellings set aside for people with disabilities. The competition for affordable dwellings in urban areas near jobs and transportation includes the growing homeless in California and the employed who cannot afford skyrocketing rents that are becoming the norm. These populations are often the focus of housing set-asides when affordable housing is to be built. If you impose this design restriction, it will become a mechanism to cut-off access to precious housing resources for one of the most vulnerable populations. Without any affordable and viable living options, individuals with developmental disabilities will be next wave of the homeless population. All affordable housing projects in California are categorized. They fall into one of many categories: special needs, seniors, low income families, etc. The special needs sub-category includes homeless, at-risk youth, developmental disabilities, mentally ill, Thank you for recognizing various models of private residences and that there is no one particular model that supports all different needs. There is a lot of confusion around what "provider owned or controlled" means. Please clarify whether “provider” in the STP means a Medicaid/Medicare or Waiver (i.e. DD Waiver) services provider to HCB Services recipients or includes other types of providers. For example, is a private pay service provider who receives no HCBS funding considered “provider” in</p>	<p>In regards to the non-provider owned or controlled private residential settings: I'd like to propose the following revision and removal:</p> <p>1) 1. "Private residences owned by the member or a relative of the member." to "Private residences owned or rented by the member, a relative or legal guardian or conservator of the member."</p> <p>2) - 3. "Private residences chosen by the member" to "Private residences chosen by the member or legal conservator"</p> <p>3) "The dwellings are not limited to or designed specifically for people with disabilities."</p>

Private Residences Presumed to be in Compliance		
Comments on Draft STP		Organization/Relationship to the HCBS Program
<p>this context? Also, why is it necessary to state that "the dwellings are not limited to or designed specifically for people with disabilities."? Eliminating services for those who choose to occupy dwellings that "are not limited to or designed specifically for people with disabilities" intentionally places even more housing out of reach for those who need it the most. The disabled have the fewest options and resources in a competitive housing market, especially when their disability requires the very design and amenities that they would be forbidden to access by this rule as written. In the midst of scarce housing options, there are not enough dwellings set aside for people with disabilities. The competition for affordable dwellings in urban areas near jobs and transportation includes the growing homeless in California and the employed who cannot afford skyrocketing rents that are becoming the norm. These populations are often the focus of housing set-asides when affordable housing is to be built. If you impose this design restriction, it will become a mechanism to cut-off access to precious housing resources for one of the most vulnerable populations. Without any affordable and viable living options, individuals with developmental disabilities will be next wave of the homeless population. All affordable housing projects in California are categorized. They fall into one of many categories: special needs, seniors, low income families, etc. The special needs sub-category includes homeless, at-risk youth, developmental disabilities, mentally ill, formerly homeless and more. Some of the major funding sources actually give preferences to special needs projects. In fact, in some cases with HUD project vouchers which provides rental subsidies, only special needs projects can apply up to 100% of the units for these vouchers and other categories can only be limited to a certain portion of the units. Recognizing the scarcity of affordable housing for individuals with developmental disabilities, some jurisdictions offer public funding in a form of capital or land on the condition that the majority or all of the units must be set aside for developmentally disabled population. Even so, the housing need is much greater than the current level of existing supplies. Simply eliminating access to housing because it is limited to the disabled without requiring some standard by which other housing is assured, simply exacerbates the problem of scarcity. It ignores all other considerations that should determine quality of life issues: affordability, location, safety, quality, access to the community and peers, etc. The concept of being part of a community is an illusion if housing is not available.</p>		

Private Residences Presumed to be in Compliance		
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	<p>Then the alternative is homelessness. Furthermore, some jurisdictions and public funding sources encourage and favor universal design to enable aging in place for the elderly and people with disabilities. In fact, some public funding opportunities are contingent upon this design. If the developers must rely on these major public funding sources and implement universal design and set aside a majority of the units for people with developmental disabilities, how is it that individuals with developmental disabilities are to be punished with the loss of funding for much needed services regardless of the outcome of their life experiences? Also, the federal Fair Housing Act makes it unlawful to refuse to make reasonable accommodations in rules, policies, practices, or services when such accommodations may be necessary to afford a person with a disability the equal opportunity to use and enjoy a dwelling. The focus should be on whether the dwellings could properly support the individual's need and allow the individual an opportunity to integrate and have access to the greater community. Please remove any restrictive standard that focuses on physical characteristics of a setting. Restrictive criteria like this will discourage new housing developments for people with developmental disabilities in California at a time when the developmentally disabled adult population is growing, parent care-givers are aging, and the cost of existing and new housing in urban areas is rising. This is not an option.</p>	

California's Statewide Transition Plan

Comments on Draft STP		Proposed Revisions	Organization/Relationship to the HCBS Program
1.	Page 19 – Paragraph 4 – I mention this section due to violations contained in CMS's letter to DHCS from 11/16/15. According to the new HCBS rules, states have sole jurisdiction in determining which settings are submitted for heightened scrutiny. In addition, I attended the national HCBS Conference in Washington DC in August where the audience was assured by the very author of that letter that CMS would not target specific settings by name. BUT, in that letter, CMS went to extreme and unauthorized lengths to direct DHCS to examine 2 specific settings for heightened scrutiny (FYI – one name was wrong and the other setting does not even exist yet). Also, these settings would be deemed private residences anyway and receive no HCBS funds whatsoever. By asking for scrutiny of 2 specific settings, CMS has overstepped its jurisdiction and undermined the authority that CMS has given the DHCS 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 cannot become compliant as if deemed institutional in nature. CMS has inappropriately singled out these two settings among the thousands of homes providing residences for developmentally disabled adults in California.	No revisions – just an observation that CMS should not be permitted leeway in this regard.	Parent & conservator of a consumer accessing the HCBS Waiver for Persons with Developmental Disabilities (DD Waiver)
2.	Compliance evaluation of settings must include consideration of the people being served and their person-centered plans. Evaluating settings based on the assumed needs of "higher-functioning" people with DD risks making the best settings for other people unavailable to them.	N/A	Parent of HCBS Waiver participant
3.	Although I agree each Regional Center has different communities and environments and, as such, will interpret the state rules according to their understanding but it feels unfair that some regional centers would accept certain settings while others would select them for Heightened Scrutiny for no other reason than a different agenda's of regional center staff and Board. Can we not as a State instruct all the Regional Centers to follow the rules with some consistency to allow more choice for people with DD across the State as a whole? It's hard as a consumer to know if I move to Y area will I not be able to choose a setting that I like because that Regional Center deems it non compliant whereas if I move to X area I can choose to live in the setting I want.	Page 26 - Who comprises the State's heightened scrutiny review committee. Is there an advocate who represents the DD consumer?	Parent of HCBS Waiver participant, Advocate

California's Statewide Transition Plan		
Comments on Draft STP		Organization/Relationship to the HCBS Program
4.	<p>Page 19 – Paragraph 4 – I mention this section due to violations contained in CMS's letter to DHCS from 11/16/15. According to the new HCBS rules, states have sole jurisdiction in determining which settings are submitted for heightened scrutiny. In that letter, CMS went to extreme and unauthorized lengths to direct DHCS to examine 2 specific settings for heightened scrutiny (FYI – one name was wrong and the other setting does not even exist yet). Also, these settings would be deemed private residences anyway and receive no HCBS funds whatsoever. By asking for scrutiny of 2 specific settings, CMS has overstepped its jurisdiction and undermined the authority that CMS has given the DHCS 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 cannot become compliant as if deemed institutional in nature. CMS has inappropriately singled out these two settings among the thousands of homes providing residences for developmentally disabled adults in California.</p>	<p>N/A</p> <p>Parent of HCBS Waiver participant</p>
5.	<p>So many regulation and rules and such low funding to make it all happen. Funding levels should be proportional to the level of regulations providers are expected to comply with. We want to provide a safe and meaningful life, but the plan is so complex and filled with technical terms that families can not make sense of what standard of care to expect nor what level of options should be provided to our special needs family members.</p>	<p>N/A</p> <p>Parent of future HCBS Waiver participant</p>

Stakeholder Input

Comments on Draft STP		Organization/Relationship to the HCBS Program
1.	Page 18 - Regarding Stakeholder Input, California needs to ensure that voices of California residents and consumers are used exclusively in revising and implementing the STP. Unfortunately, there is a small but vocal group of professional advocates, lobbying firms and non-state residents that often inject their opinions and agendas without knowing the laws of California or the needs of its DD persons. Many do not have offices in California and most certainly do not speak for the more-challenged end of the DD spectrum.	Parent & conservator of a consumer accessing the HCBS Waiver for Persons with Developmental Disabilities (DD Waiver)
2.	<ul style="list-style-type: none"> My son deserves the same rights of choice as anyone without a disability and to that end, I am very concerned the State will not allow him to choose to live in community with those he himself chooses to live with and in a setting of his own choice without losing all his benefits. He should be afforded the right to self determine where and with whom he lives as long as it is a safe and supportive home. His wishes should not be ignored by those who have more ability to self advocate or have more opportunities to live/work with less support than he. One size does not fit all and those that want to bend the regulations to their personal choice of independent lifestyle is not fair to those who wish to live independently in a different setting. 	Parent of HCBS Waiver participant, Advocate

Stakeholder Input

Comments on Draft STP	Organization/Relationship to the HCBS Program
<p>3. Page 14-15 – Generally, I applaud the revised STP for recognizing that private residences are presumed to be compliant with the regulations. It recognizes the right of DD persons to choose their homes, with whom they live, how they live and who supports them. The STP needs to clarify a couple specific areas though.</p> <ol style="list-style-type: none"> 1. Page 14 – Line 6 - Homes can be owned OR leased. Either option should be acceptable. 2. Page 14 – Line 7 – “Unlicensed room and board homes” is a vague definition. It does not reference apartments or other rental options that might exist. Adding the mention of social security payments is unnecessary - the source of rent payments is not relevant. Also, licensing should not matter as well – a member may choose to pay rent in some short of licensed community but it is still their own residence. 3. Page 15 – Line 23 – There is an unclear section that states that “dwellings are not limited to or designed specifically for people with disabilities.” On first reading, the implication is that people with DD cannot choose to live in private residences that are 100% occupied or designed for people with DD. I have multiple comments and hope that was not the true intent of the language as written. <ul style="list-style-type: none"> • First, DD individuals should not be shamed if they opt to live with others who have DD in private residences. The language as written promotes an abilist ideal that living with non-DD peers is superior to having housemates with DD. • Second, it violates ADA Sections 35.130(a), (b) and (g) that I referenced in the Background section earlier. CMS cannot deny HCBS services to a DD individual solely because the other person with whom they associate (either in residential or employment setting) has a DD. • Third, disability-specific design is precisely what many DD persons require “as appropriate to their needs.” Design items might be for safety or a mere matter of convenience to allow DD persons to live the most-unrestricted lives. This might be secure access gates for safety or something as simple as additional soundproofing for individuals with sensory processing issues. All DD persons are entitled to reasonable accommodations from a landlord under ADA in any event. • Fourth, the notion that disability-specific settings are undesirable is directly contrary to the new CMS rules. As mentioned earlier, CMS intentionally removed this limiting language in Page 2973-74 of the rules by stating “we have revised the rule to remove the term “disability-specific housing complex”. • Finally, CMS has not placed a limit on the number of DD persons who can occupy a setting. On page 2967 of the rule, CMS also stated that “we do not believe there is a maximum number beneath which we could determine with certainty that the setting would meet the requirements of HCB settings. The focus should be on the experience of the individual in the setting.” <p>Page 15 - Line 36 – The restriction should not restrict interaction with BOTH DD and non-DD people.</p>	<p>Parent of HCBS Waiver participant</p>

Stakeholder Input

Comments on Draft STP		Organization/Relationship to the HCBS Program
4.	While DHCS has offered several opportunities for stakeholder input through conference calls, webinars, and stakeholder meetings, these efforts have yet to truly gather input from diverse consumers and families. Distinctly missing have been the voices of Latino, African-American and immigrant families. These communities must be sought out because they are often the last to hear about changes that impact them. Most information is provided only in English and the form to provide public input is only offered in English. Consumer voices are also rarely heard through the stakeholder process with very few ever participating in the statewide advisory committee or on the phone calls.	N/A
5.	Many stakeholders are still unaware of the HCBS final rule. A comprehensive outreach strategy needs to be implemented. California also must ensure that it is addressing concerns by California residents and consumers – not professional advocates, lobbying firms and other non-state residents. Also, this public comment template is not user-friendly. Please create an easier platform or channel to submit public comments. Thank you.	Parent of a consumer and volunteer Board Member of Sunflower Hill. Sunflower Hill is a 501(c)3 nonprofit organization working to create a sustainable residential community for individuals with special needs.
6.	We ask that public comment for the CA STP give most weight to comments from residents of California. Public comment from professional advocates, lobbying firms, or non state residents, particularly those who are federally funded via legislation or grants, should not be considered.	Advocacy organization for HCBS waiver participants and their families

Implementation of HCB Setting Requirements		
Comments on Draft STP		Organization/Relationship to the HCBS Program
1.	<p>Page 25, second paragraph says, “dwellings are not limited to or designed specifically for people with disabilities.”</p> <p>This contradicts the Final Rule of the CMS, which removed the term “disability-specific housing complex” and replaced it with “any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS...”</p> <p>This paragraph should be removed.</p>	<p>N/A</p> <p>Parent of a young adult woman with developmental disabilities (DD)</p>
2.	<p>Page 25 – Paragraph 2 – We object to the second paragraph as written under the Heighted Scrutiny section. It makes broad assumptions without any statistical basis or actual review of these types of settings. This language does NOT exist in the new HCBS rules and is contrary to the intent of the rules. CMS did not originally call out specific settings except those identified in the Jan. 2014 rules. This language in the STP comes directly from the subsequent CMS Informational Bulletin entitled "Guidance on Settings That Have the Effect of Isolating Individuals Receiving HCBS from the Broader Community". It should be deleted.</p>	<p>Page 25 – Paragraph 2</p> <p>Delete - Settings that may have the effect of isolating HCBS members are settings specifically designed for people with disabilities, often for people with a certain type of disability, and on-site staff provides many of the services available. In addition, settings that isolate HCBS members from the broader community may also be designed to provide members with multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities. These settings provide little or no interaction with the broader community and use interventions or restrictions that are used in institutional settings.</p> <p>Parent & conservator of an adult child with developmental disabilities</p>

Implementation of HCB Setting Requirements		
Comments on Draft STP		Organization/Relationship to the HCBS Program
3.	<p>Page 25 – Paragraph 2 – The second paragraph under the Heighted Scrutiny section is language that is NOT contained in the new rules and is contrary to the intent of the rules. I understand that this language comes from the subsequent CMS Informational Bulletin entitled "Guidance on Settings That Have the Effect of Isolating Individuals Receiving HCBS from the Broader Community". It should be deleted in its entirety.</p>	<p>Page 25 – Paragraph 2</p> <p>Delete - Settings that may have the effect of isolating HCBS members are settings specifically designed for people with disabilities, often for people with a certain type of disability, and on-site staff provides many of the services available. In addition, settings that isolate HCBS members from the broader community may also be designed to provide members with multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities. These settings provide little or no interaction with the broader community and use interventions or restrictions that are used in institutional settings.</p>

Implementation of HCB Setting Requirements		
Comments on Draft STP	Proposed Revisions	Organization/Relationship to the HCBS Program
<p>4. Page 20 – Regarding Education, Outreach and Training – Please clarify that training will be provided by individuals and organizations familiar with the rights of California consumers and the service delivery model in our state. I attended a regional center meeting last year where the speaker (from the East Coast) had no knowledge of California’s DDS but made numerous suggestions about how to implement HCBS in our state – attendees received credit for this so-called “training”.</p> <p>Page 20-22 – Regarding Systematic Assessment of Settings – Does the list on page 21-22 represent a final list of all settings to be analyzed? The language on page 21 says it is an “initial list” but elsewhere on page 20, it states that DHCS “reviewed and analyzed the applicable statutes, regulations, and policies governing residential and nonresidential HCBS settings to determine the extent to which they comply with federal regulations.” Please advise when the final list is to be issued.</p> <p>Page 25 – Paragraph 2 – The second paragraph under the Heighted Scrutiny is language that is NOT contained in the new rules and is contrary to the intent of the rules. This language comes directly from the subsequent CMS Informational Bulletin entitled "Guidance on Settings That Have the Effect of Isolating Individuals Receiving HCBS from the Broader Community". For reasons already stated, it violate the language of the approved regulations and, therefore, should be null and void. The public also had no opportunity to comment on this guidance which is rule-making in disguise. My concerns are as flows.</p> <ul style="list-style-type: none"> • Section 552(a) of the Administrative Procedures Act states "Each agency shall make available to the public information as follows: (1) Each agency shall separately state and currently publish in the Federal Register for the guidance of the public..... (D) substantive rules of general applicability adopted as authorized by law, and statements of general policy or interpretations of general 	<p>Page 25 – Paragraph 2</p> <p>Delete - Settings that may have the effect of isolating HCBS members are settings specifically designed for people with disabilities, often for people with a certain type of disability, and on-site staff provides many of the services available. In addition, settings that isolate HCBS members from the broader community may also be designed to provide members with multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities. These settings provide little or no interaction with the broader community and use interventions or restrictions that are used in institutional settings.</p>	<p>Parent & conservator of a consumer accessing the HCBS Waiver for Persons with Developmental Disabilities (DD Waiver)</p>

Implementation of HCB Setting Requirements		
Comments on Draft STP	Proposed Revisions	Organization/Relationship to the HCBS Program
<p>applicability formulated and adopted by the agency and (E) each amendment, revision, or repeal of the foregoing."</p> <ul style="list-style-type: none"> • Created in late 2009, CMCS Informational Bulletins are used to communicate with states and other stakeholders interested in Medicaid and CHIP. These communications do not establish new policy; they are designed to highlight recently released policy guidance and regulations and also to share important operational and technical information related to Medicaid and CHIP. • Agencies sometimes issue a document purporting to be an interpretive rule, but which in fact creates new law, rights, or obligations. Indeed, as the notice and comment rulemaking process has become more onerous over time, agencies have a strong incentive to avoid the burdens of rulemaking if possible. If an agency issues a policy or guidance document that amounts to legislation without going through notice and comment rulemaking, the agency's action may be vacated. A legislative rule promulgated without proper notice and comment rulemaking is "procedurally invalid." <p>Page 26 - Who comprises the State's heightened scrutiny review committee. Is there an advocate who represents the DD consumer?</p> <p>Page 28 – Regarding Person-Centered Planning – As a general comment, California should consider developing a standardized form for the IPP. In the DDS system, regional centers all have different formats which makes it difficult for DD consumers who transfer between regions.</p> <p>Page 28 – THANK YOU FOR THIS SECTION - "DHCS believes community is not the mere physical presence of other buildings and people. It includes a safe and purposeful environment where individuals have needed support and safety, and the greatest freedom to live productive, connected lives according to their own desires."</p>		

Implementation of HCB Setting Requirements			
Comments on Draft STP		Proposed Revisions	Organization/Relationship to the HCBS Program
5.	<p>P. 22, 3rd paragraph; 30-60 days for providers to complete self assessment is not enough time. Recommend 90-120 with goal of having all self assessments by 180 days.</p> <p>P.24, 1st paragraph states licensing agencies will be part of onsite assessment teams; does this include CCL?</p>	Depending on provider type, providers will have 90 to 120 days to complete and return their self-surveys. Programs will follow up with providers with reminder emails and phone calls. With the exception of programs like CBAS, which is integrating the provider self-surveys with other information required from CBAS centers in preparation for their biennial certification visits through 2018, completion of provider self-surveys is targeted for the third quarter 2017 (See Attachment VII - Statewide Transition Plan Milestones and Timeline for detailed timeline).	San Gabriel/Pomona Regional Center
6.	<p>1. Consider requesting that CMS agree that beds for out of home (OOH) respite will not be considered residential beds for purposes of the 4-bed occupancy limit. OOH respite is already exceedingly difficult to obtain, and the 4-bed limit will make it financially infeasible to leave a facility bed open for respite.</p> <p>2. On. p. 27, the plan states: "However, if the provider owned and operated residence or day program provider cannot come into compliance with the HCBS Settings Rule by March 2019, the program will initiate its policies and procedures to transition, if possible, affected members to compliant settings so they can continue to receive federally funded HCBS services."</p> <p>Today, virtually all licensed and vendored residential care facilities (RCF) for IDD members are designed only for a certain level of developmental disability (level 2-4(A-I)) and a certain age group (kids, seniors, and others.) Current RCF models are therefore highly segregated, do not allow for public residency, or even residency from others on a different waiver, and may not be deemed settings compliant. While a setting under supported living services (SLS) will clearly comply with the CMS settings requirement, today there are no HCBS programs other than RCFs that pay for the cost of housing</p>	<p>2. for p. 27:</p> <p>"In order to address the need for housing support for displaced IDD members, California will request Federal funding for a program similar to HUD's Veteran's Affairs Supported Housing program, whereby the federal government would issue section 8 vouchers earmarked for those consumers currently residing in a residential care facility (RCF) that could be displaced due to the new settings requirements (either a reduction in the maximum number of allowed beds in the RCF from 6 to 4, or a reduction in bedroom occupancy from 2 to 1.) Such vouchers would enable consumers to live in another residence of their choosing, complemented by SLS or other generic services."</p>	Parent of HCBS Waiver participant. While I am a member of a regional advisory committee of the State Council on Developmental Disabilities, I am commenting as a parent, not on behalf of the SCDD.

Implementation of HCB Setting Requirements			
Comments on Draft STP		Proposed Revisions	Organization/Relationship to the HCBS Program
	<p>for impoverished consumers if a Member must move out of an RCF that fails the settings compliance test.</p> <p>In order to address the need for funded housing for such consumers who lose their RCF residence and must move to SLS supported housing, please consider adding to the plan the language below.</p>		
7.	<p>Page 25 – Paragraph 2 – The second paragraph under the Heighted Scrutiny section is language that is NOT contained in the new rules and is contrary to the intent of the rules. This language comes directly from the subsequent CMS Informational Bulletin entitled "Guidance on Settings That Have the Effect of Isolating Individuals Receiving HCBS from the Broader Community". It should be deleted.</p>	<p>Page 25 – Paragraph 2</p> <p>Delete - Settings that may have the effect of isolating HCBS members are settings specifically designed for people with disabilities, often for people with a certain type of disability, and on-site staff provides many of the services available. In addition, settings that isolate HCBS members from the broader community may also be designed to provide members with multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities. These settings provide little or no interaction with the broader community and use interventions or restrictions that are used in institutional settings.</p>	<p>Parents of a member who has developmental disabilities</p>

Implementation of HCB Setting Requirements		
Comments on Draft STP	Proposed Revisions	Organization/Relationship to the HCBS Program
<p>8. Secured Perimeters and Delayed Egress: Health Net has a concern surrounding non-residential settings and the concept of CBAS and "secure perimeter technology" on page 17 of 30 of the Revised Draft CBAS HCB Settings Transition Plan. There has been much discussion about "delayed egress" as an essential safety mechanism for specified CBAS members at specified facilities. Given today's increasing notice of public safety risks, can the Settings and Transition Plan include comments or requirements about "entrance door safety mechanisms" for community based non-residential CBAS facilities?</p> <p>According to 42 CFR 441.301(c)(4)(vi)(B)(1) "entrance doors lockability" is a documented regulation for controlled residential settings, but there does not appear to be a similar regulation for community based non-residential facilities. Furthermore, we support the comments note on page 30 of 32 in Appendix III (Analysis of Laws, Regulations, Waiver, Policies, and Other Requirements) "program requirements do not prohibit visitors" and the resulting addition of a question on the Provider Assessment Tool to validate visitor access. Safety is need for both entrance and exit security.</p>	N/A	Government Programs Policy and Strategic Initiatives, Health Net, Inc.
<p>9. All criteria for HCBS settings and assessment tools should be based on waiver recipient experiences and outcomes. Criteria and assessments should NOT be based on physical characteristics, such as population density of waiver recipients or proximity to other services. Rather home and community settings should be individually assessed for quality based on feedback from the waiver recipient. The protections under the Olmstead Decision, The ADA and the Developmental Disabilities Assistance and Bill of Rights Act are not mandates for forced integration: Olmstead expressly cautions against such an interpretation. A least restrictive environment for one person may not be the least restrictive environment for another with different needs or choices. Those who choose to live or work on a campus, in a farm based or</p>	N/A	Parent of HCBS Waiver participant, Advocate

Implementation of HCB Setting Requirements			
Comments on Draft STP		Proposed Revisions	Organization/Relationship to the HCBS Program
	intentional community setting should not be forced to change or limit their preference to be supported in such a setting.		
10.	<p>Page 25 – Paragraph 2 – The second paragraph under the Heighted Scrutiny is language that is NOT contained in the new rules and is contrary to the intent of the rules. This language comes directly from the subsequent CMS Informational Bulletin entitled "Guidance on Settings That Have the Effect of Isolating Individuals Receiving HCBS from the Broader Community". For reasons already stated, it violates the language of the approved regulations and, therefore, should be null and void. The public also had no opportunity to comment on this guidance which is rule-making in disguise. My concerns are as follows.</p> <ul style="list-style-type: none"> • Section 552(a) of the Administrative Procedures Act states "Each agency shall make available to the public information as follows: (1) Each agency shall separately state and currently publish in the Federal Register for the guidance of the public..... (D) substantive rules of general applicability adopted as authorized by law, and statements of general policy or interpretations of general applicability formulated and adopted by the agency and (E) each amendment, revision, or repeal of the foregoing." • Created in late 2009, CMCS Informational Bulletins are used to communicate with states and other stakeholders interested in Medicaid and CHIP. These communications do not establish new policy; they are designed to highlight recently released policy guidance and regulations and also to share important operational and technical information related to Medicaid and CHIP. • Agencies sometimes issue a document purporting to be an interpretive rule, but which in fact creates new law, rights, or obligations. Indeed, as the notice and comment rulemaking process has become more onerous over time, agencies have a strong incentive to avoid the burdens of rulemaking if possible. If an agency issues a policy or guidance document that amounts to 	<p>Page 25 – Paragraph 2</p> <p>Delete - Settings that may have the effect of isolating HCBS members are settings specifically designed for people with disabilities, often for people with a certain type of disability, and on-site staff provides many of the services available. In addition, settings that isolate HCBS members from the broader community may also be designed to provide members with multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities. These settings provide little or no interaction with the broader community and use interventions or restrictions that are used in institutional settings.</p>	Parent of HCBS Waiver participant

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	<p>legislation without going through notice and comment rulemaking, the agency’s action may be vacated. A legislative rule promulgated without proper notice and comment rulemaking is “procedurally invalid.</p> <p>Page 26 - Who comprises the State’s heightened scrutiny review committee. Is there an advocate who represents the DD consumer?</p> <p>Page 28 – Regarding Person-Centered Planning – As a general comment, California should consider developing a standardized form for the IPP. In the DDS system, regional centers all have different formats which makes it difficult for DD consumers who transfer between regions.</p> <p>Page 28 – THANK YOU FOR THIS SECTION - “DHCS believes community is not the mere physical presence of other buildings and people. It includes a safe and purposeful environment where individuals have needed support and safety, and the greatest freedom to live productive, connected lives according to their own desires.”</p>		
11.	<p>I think the state is to be applauded for presumptive compliance for private residences. Again, it is important not to circumscribe the wishes or civil rights of people with disabilities by presuming that if their housing includes peers, or has features that benefit them (just like housing for non disabled people can have added features like clubhouses, gyms, etc.) that somehow their setting is non compliant. People living with I/DD should be allowed to enjoy those amenities without forgoing HCBS eligibility. Making it easier</p>	N/A	Parent of a future HCBS waiver participant. Son is 20 now.

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	to access services or amenities is not a bad thing and certainly does not cause isolation or segregation!		
12.	The STP references a process for reviewing settings presumed to be institutional in nature, but does not seem to have a system for addressing living situations which are by definition institutional in nature. Adults who participate in HCBS work or day activities but reside in an ICF or other institutions have verified they can function and benefit from the community based waivers bringing into question the appropriateness of their residential setting. In some cases there may be reasons for this, but the STP does not have a process to assure that each of these cases is also reviewed. It is assumed the Person Centered Plan will articulate the best plan for the individual; however, the review of the provider for the settings requirement is another issue and in the current draft appears to have no process.	N/A	Advocates and providers
13.	According to this section, extensive "Education, Outreach, and Training" of the numerous stakeholders is to occur over the course of the next year. The plan also indicates that the training will occur "as the various HCBS programs roll out Provider Self Surveys, Member Surveys and On-Site Assessment activities." In conducting the trainings and the assessments congruently, providers may have a difficult time acquiring accurate information from the program providing monitoring and oversight. In addition, the "Provider Self-Survey Tool, which will be forwarded to all HCB settings" is to be forwarded out simultaneously during the second quarter of 2017. The HCB program's response to the initial survey is crucial as it could result in unnecessary remediation or a corrective action plan. On pages 21-22, the list of HCB settings that have been assessed through the systemic assessment process should include supported employment settings as well, particularly because group supported employment may be considered to regiment daily schedules. Page 22 indicates that the completion of provider self-surveys is anticipated to be during Page 5 of 6 the third quarter of 2017. This	<p>Page 29 – Members looking to dispute an HCBS-setting determination by the state resulting in a loss of services and/or unwanted relocation of residence may file an appeal through the Medi-Cal or regional center Fair Hearing process as appropriate.</p> <p>For more information regarding the Fair Hearing processes, members may visit http://www.dhcs.ca.gov/services/medi-cal/Pages/Medi-CalFairHearing.aspx or http://www.dds.ca.gov/complaints/complt_fh.cfm</p>	The Association of Regional Center Agencies (ARCA) represents the network of twenty-one non-profit regional centers that coordinate services for, and advocate on behalf of, California's nearly 300,000 people with developmental disabilities, including approximately 130,000 who receive services funded through the developmental disabilities HCBS Waiver and the 1915(i) State Plan Amendment.

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<p>is too late to be able to achieve compliance by March 2019.</p> <p>Page 23 indicates that existing processes will be enhanced in order to moitor compliance with HCBS requirements on an ongoing basis. Additional details regarding this are needed in order to ascertain the impact this will have on regional center operations given that the DD Waiver is by far the state's largest.</p> <p>Page 24 lists the professionals that will be responsible for monitoring activities. Given the Final Rule's emphasis on a number of qualitative features, consideration should be given to expanding these teams to include members and their relatives in this process.</p> <p>Page 25 outlines the heightened scrutiny process and notes that this can be triggered either by a setting's location or its "effect of isolating individuals." In the interest of time, consideration should be given to beginning the heightened scrutiny process as soon as possible for those settings whose location will trigger the review.</p> <p>Page 26 makes reference to the "settings' contractor," but this term is not used or defined elsewhere. Additional clarity regarding this entity is needed.</p> <p>Page 27 outlines the process for relocating individuals from non-HCBS compliant settings to settings that are HCBS compliant. While some members receive only services eligible for federal funding, members who are regional center-eligible have historically had more service options. While the use of federally eligible services in the regional center system has been encouraged for some time, it has not been required. A change to that policy will likely require statutory changes to implement. In some instances, this requirement may conflict with existing statute regarding the use of the least costly vendor.</p>		

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14.	<p>California has so far not conducted any meaningful trainings with waiver recipients or their conservators and families. That is mostly forgivable since the content of the STP is not yet finalized. To address the public alarm and confusion and culture of fear created by the CMS rules, following the approval of the STP the state should conduct online trainings that are also archived and easy to find, for example, on YouTube. It is crucial that advocates, including federally funded advocates, who have ideological approaches to HCBS, NOT conduct any official trainings (though of course they have their first amendment rights to voice their opinions through nonofficial channels). The webinars, videos and other materials online should be translated into multiple languages prevalent in the state.</p> <p>The most problematic and potentially unlawful piece of the STP appears on page 25: “Settings that may have the effect of isolating HCBS members are settings specifically designed for people with disabilities, often for people with a certain type of disability, and onsite staff provides many of the services available. In addition, settings that isolate HCBS members from the broader community may also be designed to provide members with multiple types of services and activities onsite, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities. These settings provide little or no interaction with the broader community and use interventions or restrictions that are used in institutional settings.”</p> <p>We strongly disagree with this paragraph; it must be struck in its entirety. This language cited by California does not appear in the CMS regulations. There is nothing inherently isolating about a private or provider-controlled residence featuring any particular size, location, physical characteristics, or disability-friendly amenities. Rather, the proper procedure for determination of the existence of unwanted isolation is via the individual’s PCP, which must contain appropriate transportation, staffing and programs to</p>	<p>N/A</p> <p>Advocacy organization for HCBS waiver participants and their families</p>

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	<p>promote community engagement to the level desired and appropriate.</p> <p>Furthermore, as stated earlier, government-led systemwide ascertainment of private residential “compliance” with HCBS rules is an unlawful, unauthorized government action.</p> <p>Finally, while we commend the draft STP for incorporating notions of due process for recipients, these due process procedures are inadequate given the punishing effects of denying a severely disabled individual the supports he needs to survive. If a residence is deemed “noncompliant,” who has the right to appeal? The landlord? The provider? The recipient? How do those entities come to know the nature of the charges against them? Through what legal mechanism does DHCS exercise jurisdiction over a private residence? Can allegedly “noncompliant” parties recover attorney’s fees if they prevail against the state or CMS? Few fundamental due process questions are answered by the draft STP.</p>		
15.	<p>Page 25 – Paragraph 2 – The second paragraph under the Heighted Scrutiny section conflicts directly with the codified regulations. This language does NOT exist in the new HCBS rules and is contrary to the intent of the rules. CMS does not label specific settings except those identified in the CMS 2249F rules. This proposed language in the STP mirrors the subsequent CMS Informational Bulletin entitled "Guidance on Settings That Have the Effect of Isolating Individuals Receiving HCBS from the Broader Community". It should be deleted.</p>	<p>Page 25 – Paragraph 2 Delete - Settings that may have the effect of isolating HCBS members are settings specifically designed for people with disabilities, often for people with a certain type of disability, and on-site staff provides many of the services available. In addition, settings that isolate HCBS members from the broader community may also be designed to provide members with multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities. These settings provide little or no interaction with the broader community and use interventions or restrictions that are used in institutional settings.</p>	<p>HCBS waivers provide funding for our daughter with autism</p>

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1.	<p>The language is vague and inappropriate as it fails to distinguish between services and supports which are the responsibility of third parties versus a particular provider, esp. a private entity. You will end up with file drawers full of reports that accomplish nothing if they indicate that there is no bus nearby, the client lacks funds for taxi services, the client can't use a cell phone to call a cab for a return trip to X, the client cannot walk X distances, the regional center or county mental health or X has refused the services of an aide to take the person to the city for the day or on the train to visit a relative, or to allow the person to be out in the community and be safe crossing the street etc when they wish to o out and the facility staff cannot leave the building at will. If you want to assess programs and access, be honest about how this is to actually happen for individuals with different levels of need.</p> <p>Instead the assessment will simply say whether there is a bus line, there are taxi's, there is a movie theater, there is a park, we have a bulletin board where we post notices of concerts or festivals, but not whether or how it is accessible if supports by third parties are needed and not funded.</p>	N/A	Attorney representing individuals with developmental disabilities
2.	<p>When evaluating the HCB Setting Requirements, an assessment must take into account people (that is, "individuals") who have limited capacity to make decisions, include those who are conserved. For example, a conserved person might not have the power to "select from among various setting options," significant "autonomy and independence in making life choices," or "options ... to control their own schedules."</p> <p>Furthermore, compliance evaluation of settings must include consideration of the prople being served and their person-centered plans. Evaluating settings based on the assumed needs of "higher-funcitoning" people with DD risks making the best settings for other people unavailable to them.</p>	N/A	Parent of HCBS Waiver participant

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3.	<p>p. 35: #7 Please note that in non-ambulatory settings, per California law, a Member may escape through an adjoining door to another Member's bedroom to the outdoors. If CMS does not provide for an exception in an emergency, many existing RCFs will not meet new settings requirements. See a backgrounder at http://osfm.fire.ca.gov/advisorycommittees/pdf/rcfac/September%202011%20RCF%20Provider%20Presentation.ppt.</p> <p>#8. There are many Members that are on restricted or special diets, and it should not be mandatory that food which they are required to avoid should be put temptingly in front of them. Obesity statistics tell us that neurotypicals don't have that level of discipline.</p> <p>#9. Does "accessible" mean non-ambulatory? If it does, say so. Consider that:</p> <p>a. In urban areas, single story residences can be rare, and first floors are often elevated due to local off-street parking codes which often require that ground levels be dedicated to garages. If CMS wants HCBS compliant RCFs in urban areas, a 100% non-ambulatory requirement will nix most RCFs.</p> <p>b. Non-ambulatory bedrooms have rigid exit requirements which many of today's RCF bedrooms will not meet.</p>	<p>p. 35 #7: "Except in case of emergencies or where fire safety regulations dictate otherwise, privacy in units including locable doors, choice of roommates and freedom to furnish and decorate units." #8. "Options for individuals to control their own schedules including access to food at any time, provided that Member access to food shall not impair the setting for another Member on a restricted diet."</p>	<p>Parent of HCBS Waiver participant.</p>
4.	<ul style="list-style-type: none"> • There are no indications as to how the assessments are scored. Are they pass/fail? • If one of the "planned community" complexes were to be assessed, they would need to be able to explain how they are integrating clients into a work/live environment. The setting could have a commercial center, a spectrum of employment options, a farm and a residential/housing area. The assessment tool should be flexible to incorporate creative ideas. The setting should be defined as the entire complex and not just the housing component. If this were the case, hypothetically, the commercial area could be visited by 500 members of the public on a daily basis and the DD housing component was 30 units. Add into the setting adequate transportation, off site Day Programs and outside services not provided by the housing/commercial landlord/contractor and one would have a very strong case that this would not be a setting presumed to have institutional qualities. 	N/A	<p>Parents of HCBS Waiver provider and residential care facility</p>

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5.	In listening to others speak about the choice and heightened scrutiny there may be major misperceptions. Specifically, if someone chooses an institutional model (or in this case an arrangements with the characteristics of an institution) then it's OK for them to get services under this model indefinitely. The second possible misperception is that "the worst that can happen is heightened scrutiny". If these are misperceptions they should be clearly identified as such with the STP.	N/A	Advocates and providers
6.	Day-Type Services - Concern that the timeline for completion of legislative/regulatory remedial strategies are targeted for the fourth quarter of 2018, when the compliance target is March 2019. Three months seems to be a highly unlikely target to support programs to move into compliance, as they will have to comply with current regulations and statutes until the new ones are adopted unless the State adopts emergency authority to start moving sooner. Page 57 Work Activity Program - Same concerns as noted above.	N/A	Futures Explored provides services to over 650 individuals every day in day and employment services.

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<p>7. Please eliminate the language under Heightened Scrutiny that comes from the CMS Informational Bulletin “Guidance on Settings That Have the Effect of Isolating Individuals Receiving HCBS from the Broader Community.” The public has had no opportunity to comment on this and it violates the language of the earlier approved regulations. Also see above general comments and private residence presumption comments.</p>	<p>Delete – Settings that may have the effect of isolating HCBS members are settings specifically designed for people with disabilities, often for people with a certain type of disability, and on site staff provides many of the services available. In addition, settings that isolate HCBS members from the broader community may also be designed to provide members with multiple types of services and activities on site, including housing, day services, medical, behavioral, and therapeutic services and/or social and recreational activities. These settings provide little or no interaction with the broader community and use interventions or restrictions that are used in institutional settings.</p>	<p>Parent of a consumer and volunteer Board Member of Sunflower Hill. Sunflower Hill is a 501(c)3 nonprofit organization working to create a sustainable residential community for individuals with special needs.</p>

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8.	An analysis of supported employment settings should be completed. Completing needed changes to laws and regulations governing settings included in the DD Waiver during the 4th Quarter of 2018 is too late to expect full compliance by March 2019. This is particularly true for allowing lockable interior doors as local Fire Marshalls will need to adapt to this change.	N/A	The Association of Regional Center Agencies (ARCA) represents the network of twenty-one non-profit regional centers that coordinate services for, and advocate on behalf of, California's nearly 300,000 people with developmental disabilities.
9.	Again, under law the state is neither required nor authorized to conduct any systematic assessment of private residential properties. Review of the appropriateness of those "settings" may only occur, if at all, in the context of an individual's PCP. Finally, we commend the STP for this language, which perfectly sums up the purpose of the new CMS rules: "DHCS believes community is not the mere physical presence of other buildings and people. It includes a safe and purposeful environment where individuals have needed support and safety, and the greatest freedom to live productive, connected lives according to their own desires."	N/A	Advocacy organization for HCBS waiver participants and their families