

HCBS Analysis and Case Study, an example from California

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Introduction

“Final Rule” is a set of requirements that must be applied to any organization receiving Medicaid Federal funds from the organization's state for Home and Community Based Services (HCBS). The aim of these regulations is to move services for individuals with Intellectual Disabilities from institutional-like services, and receive more community-based and person-centered services. One of the key factors in implementing these requirements is a person-centered plan for individuals with disabilities. All programs receiving HCBS Medicaid funds must be in compliance with the “Final Rule” by March 17, 2023, and then sustain compliance. This has meant that many providers have had to redo their program designs, and rethink the way they provide services to the disability community. From 2014 to 2023, providers have been working towards becoming compliant with the “Final Rule” in order to keep their state funding, and have submitted transition plans to their local Regional Centers for approval. While this change in legislation and services is much needed, there have also been difficulties within the transition period.

Which Programs are Required to Meet Final the Rule Regulations

HCBS services are defined as:

“...long-term services & supports provided in home and community-based settings, as recognized under the federal Medicaid (Medi-Cal) Program. These services can be a combination of both standard medical services and non-medical services. Standard services can include, but are not limited to, case management (i.e. supports and service coordination), homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care” (DDS, 2020).

There are programs that are not included in HCBS, such as nursing homes, hospitals, intermediate care facility for individuals with intellectual disabilities, and institutions for mentally ill patients (DDS, 2020). There are programs that must be approved by CMS, and the Regional Center of the provider's catchment area to demonstrate compliance with the HCBS Final Rule. Programs may be flagged for heightened scrutiny if they have qualities that resemble an institution, and isolate members of the Disability Community. The heightened scrutiny process will determine:

“...whether the state can demonstrate that people receiving services are not isolated from the greater community of individuals not receiving Medicaid Home and Community Based Services, and whether CMS concludes that the information indicates that there is strong

evidence that the setting does not meet the criteria for a setting that has the qualities of an institution” (Bergard 2015).

HCBS Final Rule Regulations

Final Rule Requirements are broken down into ten rules that can be applied to any Medicaid funded Home and Community Based Service (see Appendix A). For any day program, only rules 1-5 and 10 must be met, and any residential facility must meet all of the requirements.

Person-Centered Planning

In general, Person-Centered Planning aims to normalize the idea of inclusion for individuals with disabilities (Claes et al., 2010). Person-Centered Planning is a cornerstone of HCBS planning to ensure that individuals receiving any disability programming are able to receive the most personalized services possible, and reach their own goals. This type of planning also ensures that the program is catered to fit the individual rather than the individual being forced to fit the expectations of the program.

One of the keys to Person-Centered Planning is identifying the interests and goals of the person receiving services, and creating a plan or program that best supports these interests and goals. Up until “Final Rule,” the associate or participant was expected to fit the expectations and standards of the program. The purpose of this approach to planning is to “...develop collaborative, goal-oriented, and individualized programs that are focused on community presence, community participation, positive relationships, respect, and competence” (Claes et al., 2010). Not only does Person-Centered Planning allow for customizable services, but it also leads to integration outside of the programs the individuals are a part of, “the use of person-centered planning was associated with an improvement in social networks, closer contact with family and friends, or greater involvement and engagement in group activities....community involvement...significantly more likely to leave the developmental center for a community living arrangement...” (Claes et al., 2010). With Person-Centered Planning providing guidance for programs receiving HCBS funds, Final Rule ensures that the services provided to the disability community encourage programs fitting individuals rather than the other way around.

Difficulties with HCBS Final Rule Implementation

One of the biggest hurdles to overcome is understanding the different state transition plans. CMS provides federal funds and uses to help implement the Final Rules. These changes apply not just in one state, but in all states. Furthermore, it is required that each state submits a transition plan. Currently, different states are at different stages in their transition programs, with no state receiving approval of their plans as of 2022, but the final deadline for HCBS Final Rule

compliance continues to be March 17, 2023. With different states having different plans to reach compliance, and being at different stages in the transition process, it is hard to gauge where all 50 states will be at the March 17, 2023 deadline.

Another concern with implementing the “Final Rule” is the ability to provide staff for all HCBS recipients. The state of California implemented a rate study to determine the sustainable quality of services provided by the Department of Developmental Services (DDS). This rate study found that, with the rates being paid to providers in the 2019 fiscal year, providers could not provide quality or sustainable services to individuals with intellectual disabilities. This has led to a rate increase for providers to be implemented in the fiscal year 2021.

With the implementation of HCBS Final Rule regulations, services are to be individualized, but this does not mean that services need to be provided at a 1:1 ratio. It means services must be directly related to IPP or PCP goals set up by the individual receiving services. Additionally, there must be flexibility in support services provided by the program of choice on the daily basis. For example, if one individual wants to go to a coffee shop one day, and two other members of the group want to go to a community college to take a resume writing class, the program will have to accommodate the respective choices of each participant. The DSP profession is already understaffed, and with the implementation of the “Final Rule,” more staff will be needed to meet the individual needs of those they work with. With the implementation of policy changes as a consequence of the rate study, the state of California is working towards creating a sustainable program for people living with disabilities.

Another financial strain on programs is required Person-Centered Planning training. A typical program may need to complete a full 2-day training from person-centered thinking trainers, which can cost approximately \$6,000. Becoming a person-centered thinking trainer can be anywhere between \$12,500 and \$30,000. While HCBS vendors do not have to become certified trainers, going through person centered thinking training is essential to implement HCBS Final Rule regulations.

With the new Final Rule regulations, many vendors are going to have to completely rethink and redo how they provide services to the intellectually disabled population. Many people have been providing the same programming for upwards of 30 years and now must redo their program to be in compliance with final rule. This is not only a program shift, but a mindset shift. The purpose of Final Rule is to create quality services for people with disabilities and to reduce the instances of institutionalization. For anyone who is a part of the developmental disability community, this is going to change to what service delivery looks like in an effort to increase the quality of supports. This also means that if a vendor chooses not to change their program design to meet Final Rule requirements, then the program will no longer receive funding from Medicaid funds after March 17, 2023. The programs that are not compliant by the March 2023 deadline can still continue to run, but they will need to find another source of funding. This could lead to less program options for individuals receiving HCBS Medicaid funds depending on how many programs decide to become HCBS Final Rule compliant.

HCBS Final Rule focuses on community integration as a key principle for all services receiving HCBS Medicaid funds. While services are being moved into the community rather than in a

setting only for people with developmental disabilities, there is a concern that changing the location of services will not result in true community integration.

Considerations for Implementation

Tierra del Sol is a non-profit based in the San Fernando Valley that provides services for individuals with disabilities to live independently. This can be through vocational services, college to career, and independent living services. Tierra del Sol is an example of one organization that restructured their programming with HCBS Final Rule as their basis for all services provided to individuals with developmental disabilities.

With so many requirements for “Final Rule” it becomes difficult to believe that any program can meet each requirement. Tierra del Sol Foundation provides a variety of supports for individuals with Developmental Disabilities to provide pathways toward a purposeful life. Today, Tierra offers a variety of programming that caters to the Tierra Associate (program participant) through their College to Career Program (NEXUS), Workforce Development, and Career in the Arts. When HCBS passed the “Final Rule” in 2014, Tierra began adjusting their programming to ensure compliance. Rebecca Lienhard, CEO of Tierra del Sol, led Tierra through their programming reinvention process.

Implementing a Mindset Shift

Tierra del Sol [Tierra] took the view that “Final Rule” is the baseline for services, not the outcome. The “Final Rule” is about more than just “meeting the mandate,” but about providing the best quality of services to support individuals with developmental disabilities. The mandate is very vague, and gives agencies a sense of choice. Rather than look at the “Final Rule” as a mandate, Rebecca broke it down into the intention behind it to guide decisions about programming moving forward. In the past, the Federal Government has attempted to instill quality of services in service providers for the Disability Community by using an “inspiration to action” approach, but until now, there has not been legislation targeted to provide Person-Centered Services for people with disabilities. Since the “Final Rule” was more than just a mandate, Rebecca met with management to redo the mission and vision statement to ensure it reflected the intention of “Final Rule.” The intention behind the organization did not change, but the mission statement and values were now more succinct and in line with where disability services wanted to be.

Tierra del Sol has multiple types of programs and when reshaping their programming to reflect being person-centered and community-based, they had to examine where all of the programs were at in terms of “Final Rule” compliance and they were all in different stages. For example, the College to Career program was already on college campuses, but the day program was still on the Tierra del Sol Sunland Campus. Tierra moved forward creating different goals for each program. For the College to Career program, the goal became how to do more. How can they become more integrated? Are all Tierra Associates meeting in the same place? Can we meet at different places in the community or on campus? For the day programs still meeting on the Sunland campus, at the time of the passage of “Final Rule” there were 200 associates still receiving services on the isolated Sunland Campus. The goal became moving 100 participants from the Sunland Campus to participating within the community off campus.

In order to have staff actively implement program changes, Rebecca hired Tom Pomeranz of Universal Enhancement to provide training about what it means to be Person-Centered and how to support their associates in living a meaningful life. The goal of the training was not to tell staff that what they were doing to support Associates is “wrong,” but rather to reflect on what services for the Disability Community looked like yesterday and how to move forward with new services tomorrow. It was important to not “shame” staff for how they had been working, but rather to provide staff with the knowledge and encouragement to provide more quality services for their associates.

In general, there are well-meaning people who work in the Developmental Disability Community who divide people with disabilities into two categories: can and can’t. Those who are deemed “can’t” are not pushed or given the opportunities to work or seek the independence they want. Tierra is striving to work under the impression that all can, but the challenge is how do we get there.

Implementing Practical Changes

Once employees and management were aware of the programming changes, it was time to implement daily changes to become more person-centered in compliance with “Final Rule.” Prior to “Final Rule” Tierra used an Individual Support Plan (ISP) known as “1-5s” where Direct Support Professionals (DSPs) would rate the associates on their performance in various areas such as punctuality, attention to tasks, hygiene, etc. While Tierra had a key for DSPs to use to rate associates, this was an example of taking the associate and fitting it to the program, rather than taking the program and adapting it to the associate. Tierra looked at the funding that was coming from Regional Centers for programming and decided to pool funds rather than send funds to specific programs. Prior to this change, if an associate needed Independent Living Services (ILS) but were being funded for the NEXUS program, they would have to wait for staffing and funding for ILS programming. Now, if ILS services are needed, they can be funded through the College to Career program since all funding from Regional Centers is pooled and does not go to one program. The funding stream does not define the service received. Not only is this more person-centered, but breaks down a barrier for individuals with disabilities to receive services.

In 2016, Tierra implemented a person-centered planning process. Each associate receiving services from Tierra created an individualized plan centered for the goals they wanted to achieve. This plan became the blueprint from which Tierra staff to determine and build a program to best support the associate in achieving their goal. Tierra implemented this by having a meeting with only the associate with no parents or guardians to learn what the associate wanted without outside influence. By addressing the associate individually, Tierra could switch from being a program driven agency to a person centered agency.

Financial Consideration During Final Rule Implementation

Rebecca Lienhard, believes that when implementing Final Rule it is more important to consider the spirit of Final Rule rather than to focus on the financial implications of the programmatic changes. Generally, the system to provide individuals with Developmental Disabilities with

services and supports in California is underfunded. DDS has attempted to remedy this with the rate study to determine how much funding should be provided to the disability community to sustain their services and supports. After the study concluded, DDS determined they would only fund 90% of what the agency should be making to pay staff (*Rate Study - ca Department of Developmental Services*, 2019).

Since funding from the state is not a complete source of funding, no one can rely on State Funding to sustain their program. In order to sustain a program, there must be a belief in the abilities of those you serve, and not be afraid to fundraise. According to Lienhard “there are other ways for money than funding” (R. Lienhard, personal communication, October 7, 2022). While working through the programmatic changes to better align with Final Rule, Ms. Leinhard determined that the transition into HCBS Final Rule compliance was more about a philosophical mindshift of programs, rather than juggling financial logistics to maintain the baseline Final Rule requirements. While Rebecca was working with another agency moving towards Final Rule she was asked “you don’t believe all people [can work].” This statement proves that it is more of a philosophical change in programs than financial.

Challenges During the Transition Process

While Tierra has made strides in providing more person-centered services aligned with Final Rule, there has been pushback from stakeholders. Because Final Rule regulations are so broad, there is no one single issue to address. The only way to address adversity is on a person by person basis. The focus becomes how to make the associate overcome the barrier and not how the agency or a policy can overcome the barrier.

Overtime has become a financial burden when it comes to Final Rule. Since services are now person-centered, the individual directs when they receive supports. For example, if a cab drops off a associate 1 hour early, the staff need to be compensated overtime to be there to support them.

Logistics has also become a challenge as all programming is person-centered and not agency-centered, whether it is college to career or career in the arts. This leads to a variety of procedures across different programs, for example, one program’s staff call out procedure may not be the same for all programming as all of it is person-centered. The challenge is making sure all aspects of the agency are person-centered, while also being realistic to run as a non-profit with multiple staff. Staffing all comes back to the associate needing staff, what does the person-centered plan says, how to accommodate, and if there is no plan, get one in place.

The COVID-19 Pandemic added additional challenges to transitioning to Final Rule regulations. When services became remote due to Stay-at-Home Orders, associates lost the physicality of working and volunteering in their programs. Once services resumed in person, the variety of campuses for programs became the meeting ground for groups rather than the community where associates were working or volunteering. In essence, when in person-supports could be provided, Tierra staff and associates needed to work together to determine how to provide, receive, and meet within their communities rather than on an isolated campus in the post-COVID world.

To facilitate moving from virtual to in-person services, Rebecca hired a coordinator whose sole job is ensuring that services in a post-pandemic world would not remain on campus, but would branch out and be provided in the community. The goal is not to be on campus exclusively just because of COVID, but to be back to where the organization was heading prior to the pandemic.

Facilitation for Implementation

While Tierra demonstrates a success story of transition from pre-HCBS Final Rule Services to post-HCBS Final Rule Services, there are resources that would have made the transition easier and more efficient. Investment in the direct-care workforce would have helped mitigate the high turnover rates and promoted a more person-centered approach to service delivery. Like many programs that serve the Developmental Disability Community, there is high turnover of the Direct Support Staff who provide a majority of the support during program hours. DDS' rate study was implemented as a way of "addressing the sustainability, quality, and transparency of community-based services for individuals with developmental disabilities to the Legislature in March 1, 2019" (*Rate Study - CA Department of Developmental Services*, 2019). The rate study collected information from vendors providing services and families and determined that the current rates that the vendors were being paid by the state were not high enough to ensure continued quality of services. As a result, DDS proposed rate increases for all service providers from 2022-2024: providers will receive an increase in reimbursement on the following schedule:

- Effective April 1, 2022, the department shall implement a rate increase for service providers that equals one-quarter of the difference between current rates and the fully-funded rate model for each provider.
- Effective January 1, 2023, the department shall adjust rates to equal one-half of the difference between rates in effect March 31, 2022, and the fully-funded rate model for each provider, and additional funding shall be available for the quality incentive program described in subdivision (e).
- Commencing July 1, 2024, the department shall implement the fully-funded rate models using two payment components, a base rate equaling 90 percent of the rate model, and a quality incentive payment, equaling up to 10 percent of the rate model, to be implemented through the quality incentive program described in subdivision (e) (*Rate Study Implementation - CA Department of Developmental Services*, 2021).

While DDS has committed to only 90% of what the rate study determined would be needed to sustain the DDS system, the transition to HCBS Final Rule compliance has the potential to be more difficult due to staff turnover due to low pay and the financial need to implement PCP practices, staff training, and program restructuring. While 10% may seem like a low number, 100% funding is needed to ensure quality of services for all individuals with Developmental Disabilities. Tierra is experiencing a 40% turn over in their direct support staff. This not only affects the agency's ability to provide support, but also their ability to continue to move into a Final Rule mindset with their programming. Tierra has found that Person-Centered Planning is impossible with such high staff turnover. Simply put, if Associates are constantly going through the PCP process and opening up to different DSPs over and over again (R. Lienhard, personal communication, October 7, 2022). After the results of the Rate Study, Tierra raised the hourly

rate of their DSPs from \$16 to \$19 dollars an hour. This was done as a message to DDS to invest in the DSP workforce and invest in the staff working to keep the programs going everyday (R. Liendhard, personal communication, October 7, 2022).

Learning and development of staff is a necessity when transitioning to Final Rule compliance. Tierra implemented a program through National Alliance of Direct Support Professionals (NADSP) where DSPs could earn badges to take extra training. Once an employee completed their course, they would receive a 2,000 dollar bonus. Tierra saw this as a way to invest in their employees while also allowing for professional development and contributing to quality of services with employee training. With investing in their DSPs and providing specific job training skills, Tierra is able to provide person-centered services, quality services, and monetarily show their employees that they are valued (R. Liendhard, personal communication, October 7, 2022).

Advice to Programs Implementing Final Rule Requirements

A program that needs to become HCBS Final Rule Compliant may have to redo how they have been providing services in order to receive state funds past the March 2023 deadline to become compliant. Tierra recommends looking at the basic and baseline requirements of HCBS Final Rule. Ask questions like what does person-centeredness and choice for participants really mean. The spirit of the Final Rule makes it easier to make the transition in services. Choice is a key when implementing Final Rule programming. Because the “Final Rule” legislation is vague, each program will need to determine what does “choice” actually means in the spirit of Final Rule. Choice cannot be an either or question, the same choices offered to every program participant, or a list of things to choose from without taking individual choice into consideration.

It is essential that any one working in the Developmental Disability Community sees that people with disabilities are human. Tierra has found the concept of “choice” and maximizing individual choice has been difficult for a lot of people to implement into programming. For example, an associate was working as janitorial staff, and has a tight schedule to ensure they do not miss the bus after their shift, and it might be difficult to return to a meeting point within program time constraints, so, the associate and DSP were at odds when it comes to time management. The associate asked appropriately to change their pants after work as it was summer and it was hot out. They were told they could not as they would miss the bus and be late returning to campus within the programs designated time. The associate asked a total of three times to change their pants and was denied. So, the associate took matters into their own hands and peed their pants so they would have to change into the shorts they wanted to wear. This is an example of the associate being encouraged to conform to program standards rather than having the program conform to the needs of the client. If any other person was on the job and wanted to change after their shift, they would. There is the risk of missing a bus and not making it to the final destination by a certain time, but it is still a choice that anyone as an individual can make. The spirit of HCBS Final Rule would look at this example as an opportunity to maximize choice. The associate made a choice to make their clothing change rather than return to campus on time. The associate prioritized their need for shorts over punctuality, and this was still the choice they are entitled to make, no matter the program constraints.

HCBS Final Rule may seem exciting, scary, unattainable, and unnecessary to a lot of program specialists, clients, advocates, and families because these standards are changing what Federal Funds will provide. It will be different, much like when people with Developmental Disabilities were no longer institutionalized. The Lanterman Act was passed in 1969 for programs that were in existence at that time. Without updates to programming, any program funded by the Lanterman Act will be aimed at programs that were in existence in 1969 and not necessarily apply for a 2022 program in the process of moving towards HCBS Final Rule Compliance. Based on the rate study and updates to federal requirements, the current legislature and funding cannot sustain the changes in programming for people with Developmental Disabilities.

Advice to Programs Moving Toward Final Rule Compliance

For a program like Tierra which had to restructure how they provided services, program designs, internal hierarchy, and mindsets, Mrs. Lienhard recommends not looking at Final Rule as a set of requirements or a checklist, but looking at the spirit and reason behind Final Rule when beginning to implement Final Rule into a program. Tierra sees the center of Final Rule as person-centeredness and choice of the individual. In order for a program to begin to implement changes, they need to ask what choices do the participants have and are they the same choices for everyone attending the program? If the program participants have a laundry list of choices, such as going to the grocery store or going to the library, and those are their only options, it is not a person-centered programming choice. When taking person-centered programming choices into consideration, the most important thing is to ask the individual what they want to do and look at their person-centered plan to see how program activities can best contribute to their plan. If there is not a person-centered plan in place, get one in place. If there is not a person on staff who can conduct a person-centered plan, get someone the training to do so.

The second piece of advice from Tierra is to recognize that people with disabilities are people (R. Liendhard, personal communication, October 7, 2022). If a neurotypical person would be bored during programming, then program participants are also likely bored. If it is not good enough for a neurotypical person, it is not good enough for a person with a disability. If the person with a disability does not have the opportunity to communicate their wants and needs in any programming choice, then it is not a choice. Any programming choice should center on the individual receiving the programming's preferences.

Conclusion

Successful implementation of Final Rule into any programming is going to depend on financial and mindset support. HCBS Final Rule is an opportunity for others to grow and provide better quality of services for people with disabilities. Final Rule is "...an evolution, not a revolution. In the past good people believed they were doing what was right at the time." The goal for anyone moving forward with HCBS Final Rule programming should be to continue to grow as the system changes and to place people at the center of all programming decisions (R. Liendhard, personal communication, October 7, 2022). There should be no shaming or living with regret, but rather a change in mindset to move forward with a new spirit that Final Rule is providing.

Ultimately, HCBS Final Rule is not being implemented to place more requirements or restrictions on any program providing services for individuals with Developmental Disabilities. The spirit of HCBS Final Rule is to improve the quality of service for people with Developmental Disabilities through person-centered planning and community-integrated programming. The aim of Final Rule is not to close programs or make it impossible to provide programs for people with Developmental Disabilities, but rather to change what public funds will provide to this community. With a history of low quality servicing, it is imperative that the state and federal government intervene to ensure that they would only provide funding for services that were of a high quality. There is the opportunity to receive programming that is not HCBS Final Rule compliant, however, that programming will have to be paid for out of pocket and will not be paid for by government funds.

HCBS Final Rule is an example of an evolution of the disability service system. In the past, services were provided according to the standards of the times, which does not excuse institutionalized abuse, but a reason. In the past, some people working with people with disabilities believed they were doing the “right” thing. HCBS Final Rule is in place to ensure that people accessing disability services are able to grow and provide person-centered services free of isolation and focus on community integration. Disability services has been moving towards the idea that people with disabilities are not different from anyone else, but rather individuals who can thrive with support through programming. Hopefully, passage of the HCBS Final Rule will mean better programs moving towards a more inclusive society where people with disabilities are not seen as different or less than others, but just as people.

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Appendix A

The Setting:

1. Is integrated in, and supports full access of individuals receiving Medicaid HCBS to the greater community to the same degree of access as individuals not receiving Medicaid HCBS.
2. Is selected by the individual from among setting options including non-disability-specific settings and an option for a private unit in a residential setting.
3. Ensures an individual's rights of privacy, dignity and respect, as well as freedom from coercion and restraint.
4. Optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to: daily activities, physical environment, and with whom to interact.
5. Facilitates individual choice regarding services and supports, and who provides them.

In provider-owned or controlled residential settings:

6. The unit or dwelling is a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services.
 7. Each individual has privacy in their sleeping or living unit; including doors lockable by the individual, choice of roommate if sharing a unit, and the freedom to furnish and decorate their sleeping or living units within the lease or other agreement.
 8. Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time.
 9. Individuals are able to have visitors of their choosing at any time.
 10. The setting is physically accessible to the individual.
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