

HCBS Final Rule: It's Really Final!

Hawaii DOH, Developmental Disabilities Division Webinar
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Hello! Who is here today?

A quick poll - please select the answer that best describes you:

- I am a person with a disability who receives waiver services
- I am a family member of a person who receives waiver services
- I am a non-family guardian for a person who receives waiver services
- I am a caregiver living in an AFH, DD Dom or ARCH home
- I work for a provider agency that delivers waiver services
- I am an advocate for people with disabilities who is not any of the above
- I am state staff
- Other

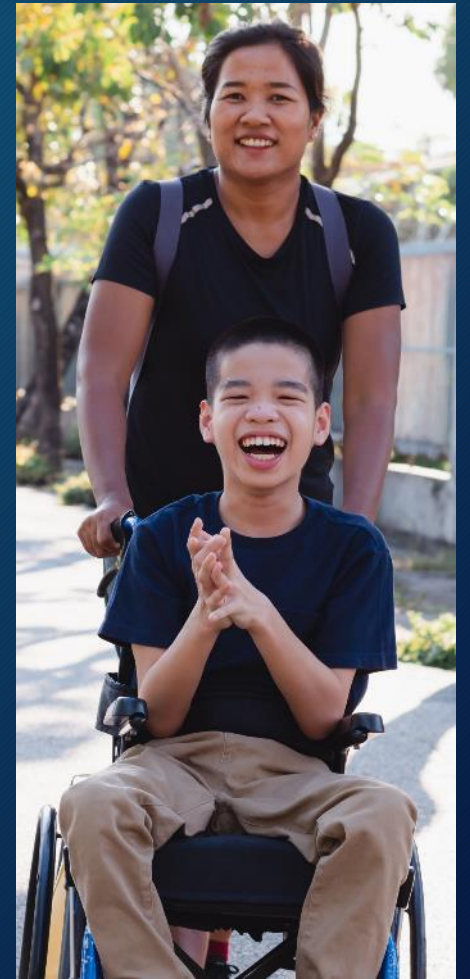
Today's Webinar Topics



- What is the HCBS Final Rule, again?
- Supporting community integration
- Expectations of providers and caregivers
- Example Scenarios
- Ongoing compliance
- Opportunities for participants (and families) to share their experiences

HCBS Settings Final Rule: What is it, again?

- In 2014, the federal Centers for Medicare & Medicaid Services (CMS) defined the differences between HCBS and institutional care for the first time, with a focus on Community Integration in HCBS
- The goal of the rule is to make sure people receiving HCBS can live and work and spend time in the greater community in the ways they want, including with people who are not involved in services
- EVERY person's experience, and their opportunity for community integration and participation is very important
- The HCBS Final Rule transition period (began in March 2014) ended March 17, 2023 and the rule is now in effect



An institution or a home?



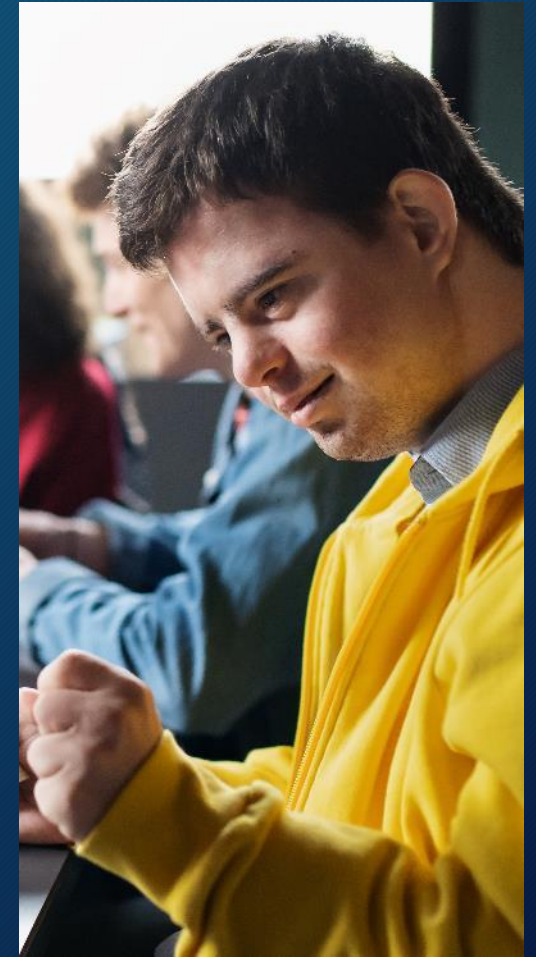
The HCBS Rule requires all settings to:

- Be integrated in and support access to the greater community
- Provide opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources
- Ensure the individual receives services in the community to the same degree of access as individuals not receiving Medicaid home and community-based services
- Be selected by the individual from among setting options, including non-disability specific settings and an option for a private unit in a residential setting
- Ensure an individual's rights of privacy, dignity, respect, and freedom from coercion and restraint
- Optimize individual initiative, autonomy, and independence in making life choices
- Facilitate individual choice regarding services and supports, and who provides them

So, what does the Rule mean for me?

In other words, as a Waiver participant you have the right to:

- Be part of your local community, be connected to other people
- Do the things you want to do, like volunteering or making friends or shopping or learning something new
- Have the chance to look for a job and be paid a regular wage
- Pick the place(s) where you want to receive services - including “non-disability” places where anyone might live or work or hang out
- Have privacy, dignity and to be treated with respect
- Make the day-to-day decisions that are important to you, including your schedule and how you spend your time
- Make choices about services and supports and who provides them to you



Residential Rights and Freedoms

In a provider-controlled home you have the right to:

- Be able to come and go from your home, make your own schedule, and decide what you want to do and when you want to do it, including working in a job
- Privacy, including the ability to lock your bedroom door, be alone in your room, entertain visitors, pick your roommate, and use the phone or internet without interference
- Access food at any time, make choices about food
- Express yourself through what you choose to wear, how you want to decorate your room, who you want to associate with
- Have a lease or residency agreement that protects your rights

If you require an individual modification to your rights for health and safety reasons, the modification must be developed through the person-centered plan and you/your representative must agree!



What is your experience?

Poll: Which parts of the HCBS Rule are still challenging?

Each person's right to:

- access the broader community (with support as needed)
- choose where and how to live, how to spend their time, what community activities they want to do, who provides support
- seek a paid community job within the regular workforce
- be treated with dignity and respect, be supported to make decisions and choices
- privacy, including doors that lock, and opportunities to communicate in private (phone, internet, mail, visits)
- decorate their room as they choose
- access food at any time
- visitors of their choosing at any time, 24/7
- physical accessibility at home

Questions



Community Integration

HCBS Settings and service delivery should facilitate and encourage participation, opportunities and relationships in the greater community.

HCBS Settings and service delivery should not create barriers to accessing and participating in the greater community.

Lynne

- Lynne is able to express her wants and needs verbally, but sometimes can be difficult to understand.
- She enjoys journaling, shopping for bracelets, eating Dim Sum and going to McDonalds to buy her favorite breakfast items.
- She has a wallet where she keeps her money.
- Lynne likes to show people her room, where she proudly shares all her bracelets, hung nicely and ready to be worn. She selects what bracelet she wants to wear each day.
- In her room there is a picture of Lynne smiling widely eating dim sum surrounded by her caregiver and caregiver's family members at a Chinese restaurant.
- During a certification visit, Lynne decided that she was tired being around the certifier and preferred to sit at her desk to write in her journal with the bedroom door closed, and so she did.
- Lynne likes to visit with her neighbor's dog and has learned how to get the dog to sit, and to give her treats. The neighbor welcomes Lynne's visits.

Poll: Do Lynne's services encourage community integration and meet Rule compliance?

1 = create barriers to community (not compliant)

3 = support some community access (mostly compliant)

5 = foster community participation (fully compliant)



Michael

- Michael communicates with his caregiver and others through his gestures and facial expressions. He uses a wheelchair and his caregiver arranges for the handivan to take him to his medical appointments.
- Michael has a schedule that the caregiver has determined is best for him, with set times to get up, eat, and go to bed.
- Michael goes out a twice a week with his PAB worker and enjoys this, smiling and showing his happiness through his gestures.
- The residential caregiver says that Michael's preference is otherwise to stay home and watch television or listen to the radio. When asked, the caregiver could not describe what other activities she has tried with Michael.
- Michael's bedroom has bare walls. The furnishings and décor are limited and do not tell a visitor anything about Michael.
- The path to Michael's room and bathroom are accessible for a wheelchair but Michael cannot get into the kitchen or the laundry area.

Poll: Do Michael's services encourage community integration and meet Rule compliance?

1 = create barriers to community (not compliant)

3 = support some community access (mostly compliant)

5 = foster community participation (fully compliant)



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Ben

- Ben is very social and likes to go out with his friends. He prefers to spend time out in the community without his paid caregivers.
- Ben is adept at using technology, often taking pictures and posting to social media. He has occasionally over-shared sensitive personal information on FaceBook or Instagram. His circle of support, including his caregiver, guardian and friends, helped Ben make a list of “do’s and don’ts” to better manage his information sharing.
- Sometimes Ben stays up well into the night on his phone or computer. Often he is engaged with various online groups and friends he has made through the

internet, in his room with the door closed. His caregiver has not noticed any problems or issues caused by Ben’s online relationships (other than occasional tiredness if he stays up too late.) Once in a while, she checks in with Ben about his activities. She respects his privacy and does not seek to limit his access to technology.

Poll: Do Ben’s services encourage community integration and meet Rule compliance?

1 = create barriers to community (not compliant)

3 = support some community access (mostly compliant)

5 = foster community participation (fully compliant)



Kai

- Kai can be a silly and outgoing guy most of the time, but he has demonstrated some challenging behaviors when he is frustrated.
- He likes to interact with other people and go out of the house. His caregiver takes him to the store to see other people and sees this as a good recreational activity, but does not support other individual activities.
- Kai doesn't belong to any groups or clubs or a spiritual community, and does not seem to have any hobbies or outside activities.
- Kai does not work in a job. He goes to an Adult Day Health center where he often tries to leave, or he acts out towards staff by hitting or spitting.
- A site visitor noted that Kai does have access to a computer and the internet, and he said he likes to facetime with new people he meets online.
- Kai doesn't have any dietary restrictions from a doctor or nutritionist. His guardian worries about Kai's weight and has asked providers to restrict his access to food.

Poll: Do Kai's services encourage community integration and meet Rule compliance?

1 = create barriers to community (not compliant)

3 = support some community access (mostly compliant)

5 = foster community participation (fully compliant)

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Leilani and Mary

- Leilani and Mary live together with a family. They asked to live together after they became friends when they were younger.
- When the certifier arrived to the AFH, they were with other family members at a table playing board games and listening to the radio. That day the women described doing manicures, dancing, drawing and enjoying themselves.
- The caregiving family members listen to Leilani and Mary individually. They try to support each of them when Leilani and Mary want to go different places, or do different things, even if at the same time.
- Leilani and Mary originally wanted to share a bedroom but when they both decided they wanted more privacy, the caregiver worked with the case manager to find a solution so they could live in the same home but not share a bedroom.
- Leilani works at a job in a hotel. Mary would like to work because she has seen how Leilani has extra money to shop and has made friends at work. The caregiver has asked Mary's case manager to help Mary explore employment options.

Poll: Do Leilani and Mary's services encourage community integration and meet Rule compliance?

1 = create barriers to community (not compliant)

3 = support some community access (mostly compliant)

5 = foster community participation (fully compliant)



Ongoing DDD Compliance

Collaboration

Provider Agencies and Caregivers work together to deliver compliant services

Case managers help create ISPs that promote opportunities for community integration

State Monitoring

AFH Certification Visits
Annual provider monitoring reviews including evidence updates and site visits
Service oversight as part of case management

Validation

Annual participant experience interviews with case managers
File and ISP reviews during provider monitoring

Participant Experiences

- Case managers will interview participants about their experiences at least annually to help validate HCBS Settings compliance.
- Concerns about access to community, rights restrictions, lack of privacy, or other potential HCBS Settings compliance issues will be used to inform continuous quality improvement, training needs, and provider monitoring.
- Waiver participants and families can notify their case manager of HCBS Settings compliance concerns to seek resolution. Formal complaints can be filed with the DDD Consumer Complaints Resolution Unit.

Questions?

- Please use Zoom Q&A feature to ask questions
- [More resources about the rule, including webinars, videos and other information](#)

Mahalo! Thank you!!

More Questions?

- Please email us with your questions:

DOH.DDDtraining@doh.hawaii.gov

Mahalo! Thank you!!