

Modifications and the Individual Service Plan

Video Transcript

Aloha everyone, and good afternoon!

Today we are honored to host Sharon Lewis.

Sharon is a national disability policy expert who advocates for people with disabilities to fully participate in all aspects of their community across the lifespan.

Sharon has previously served in presidentially-appointed roles at the U.S. Department of Health and Human Services.

More recently, Sharon has been working with DDD for the last few years as we collectively work towards final rule compliance.

It is with my honor that I hand over today's presentation over to Sharon Lewis.

Sharon, take it away!

Sharon: Well, hello everyone, and welcome to our presentation on Home and Community Based Services' Final Rule Implementation of HCBS Rights Modifications.

And Abby, if you could bring up the PowerPoint— that would be terrific.

[No Audio]

Why don't we go ahead and go to the first slide please?

So just... to give everybody a quick level set and a reminder of... what we're talking about today and why we're talking about it... is that we are talking about rights modifications— any modification to a person's rights or freedoms that are required to be documented consistent with the Medicaid requirements (the federal requirements), in part because of the home and community-based settings rule.

So, in order to have the conversation about modifications, we have to remember— what is the rule, and where are we, and why are we implementing the rule?

So again,... for those of you who may recall, and have joined us for prior presentations— the Home and Community-Based Services Settings Final Rule... was established in 2014.

And, it gave states several years to bring all of their systems into compliance.

That final deadline is coming up in March of 2023.

The state is currently working on ensuring that we are bringing all of the settings and all of the services into compliance.

What does the rule do? The rule really identifies what is considered Home and Community-Based Services and what is not.

The goal is really around making sure that people with intellectual and developmental disabilities, older adults and people with physical disabilities, and mental health disabilities (who receive Home and Community-Based Services are able to live, and work, and play, and love, and laugh, and enjoy community in the same way as everyone else.

In Hawaii, you've talked about the idea of Possibilities Now— that really supports these principles.

Under the rule, each person's experience, and their opportunity for community integration.... and the opportunity to fully participate in community is very important.

Central to the rule is the idea that each person has freedoms and rights that should be protected, and services and supports should not create barriers to the opportunity for people who are receiving services to exercise those freedoms and those rights.

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I'm going to play... we're going to play this short video— which does a better job than I do in talking about the specifics of all the parts of the rule, and why it's important.

The video also makes clear why this is really a rule around protecting your rights (as a participant who is receiving services).

So, Abby... why don't we go ahead and play the video?

[Music]

Recorded Voice: When we talk about the HCBS settings rule, most of the time we are talking about rules that other people have to follow.

But, we all know rules are there for a reason, right?

And, in this case, you (as a person receiving services) are the reason for the rules.

The HCBS Settings Rule is a set of rules that providers, case managers, and states must follow.

They are there to make sure that you get the best services for you.

The settings rule is also there to help remind people that you have rights.

What are some of those rights?

You have the right to privacy.

This means that you can be alone if you want to— whether this is in your own bedroom, or some other area of the house where you can get away from others (if you want).

Dignity— this means feeling good about yourself, and being treated like you're worth something.

Being free from coercion— this means that people cannot make you do something you don't want to do.

And, freedom from restraint.

Keep in mind there are different kinds of restraint including: physically holding someone to stop them from doing something, using devices like wrist cuffs or boards, tying your hands or wrists so you can't use them, using waist ties to keep you in bed, or mitts to cover your hands, locking you in a room so you can't get out, keeping food away from you as punishment, and using alarms to keep you in bed or in your house or giving you medicine to control your actions.

And there's one more, and it's a big one— respect.

Respect is treating other people with kindness and consideration.

And, it's about speaking up for ourselves and others— since we deserve other people's respect.

The settings rule says that your rights must be protected at the places you receive services.

This includes where you live, and where you work.

You have the same rights for privacy, dignity, and respect as any other person.

Your case manager, direct support staff, and the state help make sure your rights are protected.

The HCBS settings rule also says the places you receive supports should be integrated into the greater community.

This means that where you live or where you work (like your job or day program) is not in a place that is far away from other houses, stores, or other places people go every day.

You may want to go to a restaurant or to a store. You may want to go to a movie or play volleyball.

If you do, your service provider should support you in doing these things (not keep you from doing them).

HCBS services should support your full access to the greater community.

This means you should have opportunities to find a job, do things in the community, control your own money, get to know your neighbors, and visit friends.

When you develop your person-centered plan and pick your services, you should be given choices— including what are called "non-disability specific options."

This means that you may want to receive services or have a job in a place where other people may not have disabilities.

For instance, you may want to volunteer at your public library and spend your time there, or you may want to work at the Starbucks up the street, or you may want to live in an apartment or house— because it is close to your church or synagogue and other people without disabilities live there.

It is your right to have this option.

The services you are provided should optimize individual initiative— meaning you are supported to lead your life the way you want, and supported to make life choices.

This includes what you do each day, where you do it, and who you do it with.

You have a choice in what services you get, and who provides them.

You can learn more in the clip called "Your Life, Your Choice."

[Music] Remember these rules were made for you.

They were made so that everyone— including you, the state, and providers know that a Home and Community-Based Setting is more than where a building is, or what it looks like.

The HCBS settings rule helps us talk to each other about what we need to live a great life.

[Music]

Sharon: If any of you are interested in that... video— it is a video that was produced by the Council on Quality and Leadership.

It's not a video that we produced and... but it is available... on the DDD HCBS website.

And we think it's a great tool that can help individuals, families, providers, and others understand the rule.

So, as discussed in the video— really there are seven key pieces of... the rule and that services... delivered under the Waiver need to be delivered in settings (and through provider services) that ensure that people are able to be integrated in and access the greater community[that they are provided the opportunity to seek employment and work in competitive integrated employment, they can participate in community life and control their personal resources; that people receive services that are integrated into the community and allow them to access the community in the same way that somebody who doesn't receive services might; that they're selected by the individual, and people have choices (including non-disability specific choices), and that if they want to be in a room on their own (given and dependent upon their personal resources)— that that's an option for them; that people's privacy, dignity, respect, and freedom from coercion and restraint are protected; and that people have the opportunity to really make their own choices— that they are supported in... initiating and demonstrating their initiative and being able to articulate or say what's important to them, and that that autonomy and opportunity to do it in a very individualized way is supported.

And then, finally... the people have the choice of their service and supports, and who provides them.

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[No Audio]

So today, we're going to talk about the HCBS Rights Modification Policy.

One element of the HCBS Final Rule (as established by Medicaid) talks about a set of requirements that are specific to provider-controlled and operated settings, and the fact that there may be circumstances when an individual has health and safety needs that require some modification of the requirements (a change to the requirements) because there's a reason that the person may have (that's very specific to them) that may mean that that freedom or that right needs to be changed a little bit, needs to be restricted a little bit, needs to be modified.

And so, DDD has worked on a policy to support the implementation of this federal requirement, and laid out the elements of what need to be in place consistent with what the federal requirements are.

So, the three key pieces of the HCBS Rights Modification Policy (again) are aligned with these federal requirements.

Any modification (anytime we restrict the rights and freedoms of a Waiver participant)

137

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under... who is receiving... HCBS Medicaid-funded services— they have to be supported by a specific and assessed health and safety need, and have to be... that has to be incorporated into the ISP.

Providers and other individuals may not just implement a modification that has not been supported in the ISP.

The modification should be the least restrictive— we should make the modification the smallest thing we can do in order to maintain the biggest opportunity for rights and freedoms as possible.

And that, when we do implement a modification, it should be looked at frequently for whether or not it's working for its effectiveness.

And, when it is no longer working, or it needs to be modified or changed or adapted further— those things should occur.

We should always go for the least restrictive approach that will allow a person to exercise as many rights and as many freedoms and to continue to pursue the goals that they have decided on in their ISP.

The Hawaii HCBS Rights Modification Policy also describes which rights and freedoms may be modified and which may not, and the circumstances in which those modifications can be brought into somebody's ISP and all the things that need to happen (including the documentation requirements).

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So, what can be modified?

There are a few key rights and freedoms that are talked about in the HCBS rule and were mentioned in that video that may be modified (if a person has documented health and safety reasons) for restricting or limiting that right.

So, one of the rights... in the HCBS settings rule is that in someone's residence, they have the opportunity to have a door lock on their bedroom door or their bathroom door (or and their bathroom door)... and that they can close that door and lock that door with only appropriate staff having the key (excuse me keys) to those doors.

And, you know, that... staff are respectful of how they use those keys.

The providers should have policies and procedures around knocking on people's doors and... establishing the same kinds of common courtesies we would expect in someone's home (in any of our homes).

But people have that right to privacy— that includes the ability to lock their bedroom door.

If there's a health and safety reason that's been documented and assessed, that right might be modified.

Same with choice of roommates— if a person is in a residential setting where they are needing to share a room with another person— there may be that... the ability to choose who they're living with (may be modified based on health and safety needs).

The ability to... furnish and decorate their room may also be modified.

So, for example, if a person has Pica, and they have a tendency to put a lot of things in their mouth— we may restrict what kinds of things are easily accessible to them in their room (if those things create a health and safety problem for them).

Participants being able to control their own schedules and activities...

Now, again, I want to be really clear about this. When we talk about modifying someone's right to control their own schedule and activity (because of a health and safety need), we're not talking about— "because we can't find the staffing," "because it's easier for us," "because it's more convenient."

It literally has to be related to the individual person's health and safety... needs that then dictate... that a restriction of their ability to define their own schedules and activities.

Access to any... to food at any time— we'll talk about that in a minute (in terms of an example).

But again, there are ways to minimize the impact of a broad right or freedom being slightly restricted based on a health and safety need.

And finally, that access to visitors of the participants choosing at any time (24 hours a day, seven days a week) can only be restricted based on documented health and safety needs.

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There are some fundamental rights that may not be restricted unless there is... a court order or a legal document that says that this... the person has a health and safety reason for these items to be restricted.

It's important to remember that Hawaiians with intellectual and developmental disabilities are citizens first— they have the same human and civil rights as anyone else.

And, that is a core to the implementation of the Medicaid HCBS Final Rule.

These are the rights that cannot be modified: the right to access... and (oops we still didn't fix that that's got that typo)... the right to access and participate in the greater community and engage in community life (not participant... sorry about that).

The right to dignity, respect, and autonomy.

The right to freedom from coercion, abuse, neglect, or exploitation.

The video talked about that a little bit.

But really, this idea that people have the right to really live in fear (you know in in... without fear) of being coerced or harmed.

The right to seek employment, and work in competitive integrated settings.

Even for providers who are not providing employment services, the expectation is that there is nothing in the setting or in the service delivery that is creating a barrier to seeking employment and working in competitive integrated settings.

And that that's facilitated— the opportunity is encouraged and facilitated by the HCBS providers for people to seek employment.

The right to receive service and supports in places that are physically accessible.

It is absolutely... (and we've actually had this conversation in certain circumstances) that— if someone is living in a particular home, or they're participating in a day setting, that that setting needs to be accessible to them.

If a person is aging in place in a home that... when they first moved in they didn't require...use of a wheelchair, and then, as they age, perhaps they need to utilize a wheelchair— that home needs to be modified in order to address their physical mobility needs.

And, it's not okay to have someone living in a home where they can't physically access the home and the key parts of the home— including the kitchen, including bathrooms, including bedrooms, including shared living spaces, and other areas of the home.

People have the right to make informed choices about the services and supports they receive, and who provide them.

That is not... these are all rights that will not be modified for any individual.

Everyone has the right to freedom from seclusion, aversive procedures, and restraints / interventions in the state of Hawaii— as they're described and prohibited by DDD policy 2.02 on restrictive interventions.

This policy was written consistent with the federal requirements, and provides excellent guidance for providers around what is allowed and not allowed in terms of restrictive interventions.

And finally, there is no modifying the requirement... that people need to be free from any kind of restriction or intervention that's imposed for the purpose of discipline, retaliation, and or staff convenience.

So, there is no modification to any of the required pieces of the rule simply because it's easier. We don't make house rules.

We certainly do not do things like withhold food or... (excuse me) withhold participation in an activity as a matter of discipline.

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So, a few examples of rights modifications (before we talk about the specifics of the DDD policy)— so that you can understand what we're talking about.

So, for example, we might have a person who has Prater-Willi syndrome— which is a disorder that makes it hard for people to understand their food consumption.

And often, people with this disorder overeat, and may not be able to manage the amount of food that they should take in.

So perhaps there is a rights restriction related to their unfettered access (or their open access) to food until that person can develop the skills or tools related to food management.

Or, another person with dementia may be at risk when they are... leaving their home or leaving their day program, and may wander or get lost.

And so, their right to access the community (and depart without assistance) is limited.

Another person might have self-injurious behavior.

And so, the right to privacy (with a locked door) may be temporarily suspended until the behavior needs subside... or there is a positive behavior support plan in place that is working to reduce those behaviors.

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As I mentioned, restricting rights or freedoms based on house rules or because it's easier, or because it... someone just decides that this is... how we're going to do things, is not allowable under the Medicaid rule.

We can't restrict visitors unless there is a health and safety reason.

Now, that doesn't mean that we have to be completely unreasonable.

If individuals are living in a congregate setting, it's perfectly acceptable to say that people can come and go during typical wake hours.

And, if there are...if there is the need for someone to come and go during non-waking hours, there are ways to support the entry and exit of those people, and that it's done in a way that is respectful and safe for everyone in the home.

That's not a modification!

But a modification might, you know, to me but a disallowed or inappropriate restriction would be to say "we have visiting hours and people can only come into this home or into this setting to visit someone between (you know) 8 a.m. and 6 p.m."

That's not allowed under the HCBS rule.

Curfews— house rules that say "everyone in the house has to be home by eight o'clock"— not allowed.

Set meal times without flexibility, options, or individualization.

To be clear, if you are operating a DD-Dom or an ADH and there is a set time and you say (you know): "lunch is going to be at noon"— that's fine.

But, there has to be options for people if they can't make that noon time and or if they don't like what's being served.

So, people have to have the ability to access alternatives— you know, whether that is additional food or food that's set aside at a different time.

You know... if someone's... participating in a home, and dinner in that home is normally served at six, and they have plans with a friend, or they have choir practice, or they have something going on in the community that means that they can't get home to eat dinner until 7:30— it doesn't mean that they miss dinner, and it doesn't mean that they get... a punitive meal.

It means that that has to be accommodated and supported within the provider delivery of the service.

It's also unacceptable to make decisions for a participant without a health and safety reason.

For example, making decisions for them about their clothing or their hairstyles that are not decisions that they would make for themselves restricting their access to phones, computers, technology, their friends (again without a health and safety reason).

Those things should not be occurring.

And certainly, none of those things should be done on a punitive basis.

It's not okay to say... "you know, you can't get your cell phone back until you comply with X."

It's not acceptable under the Home and Community Settings Rule.

Establishing schedules and activity choices for an individual (without the person being able to participate or drive those choices— consistent with their interests, their ISP goals, etc.) again... though... anything that would restrict their rights, and you're making those decisions that are not consistent with their ISP, and / or you're restricting freedoms and rights (without a health and safety room reason)— not okay.

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So, again, the policy makes clear that restrictions on rights and freedoms can only be used to address health and safety (have to be established on an individual level).

You don't do it by house. You don't do it by program.

It has to be for an individual person.

Modification should really be considered a last option.

We should try everything we can to ensure that positive interventions and supports have been implemented, and that we're doing everything we can to facilitate the maximum opportunity for freedom and rights for the participant before we try a modification.

And, providers will be asked to sign a statement on any modification— that the modification that they are proposing does not cause any harm to the participant.

The decisions around modifications are made by the ISP team— the ISP team needs to include all the members of the team— including the case manager, the participant, their family or circle of support (or both), and their providers.

And so, the team works together to develop the modifications.

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So, how are we implementing modifications in Hawaii?

We'll talk about the specifics, but this is generally... there are three parts to the conversation that need to unfold. And, these are conversations.

First and foremost, any member of the team can... bring up a conversation related to risks and needs by raising it with the case manager.

Any need for a health and safety modification has to be identified in an assessment.

It becomes part of the ISP conversation and process— and once that need for a modification is raised by a team member... then the team needs to discuss "how do we address those risks and needs?"

And, do we need to do it through a modification? Are there other ways to do it?

In order to have that conversation, we have to be able to understand what's been tried.

What is least restrictive, and do we really need a modification?

If the team determines that there is a modification that's necessary, there is now a modification addendum that's available for the ISP.

The case manager can operationalize— that involves provider documentation and then the person (and their representative) providing informed consent, and the case manager approving the modification moving forward.

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So, what are those steps specifically?

As I noted, any member of the ISP team can request... that the case manager convene a discussion to consider whether a rights modification is necessary (based on a health and safety concern).

Once a member of the team has contacted the case manager and said "I'm ...I have this health and safety concern, and I think we need to modify this... specific right for this specific individual," the case manager shall determine if the request is for something that's allowable.

As we talked about— some of these requests may be allowable and some of them may not.

If the request is something that is allowable, the case manager will bring the team together to facilitate a person-centered discussion about the specific assessed health and safety needs of the person.

If the ISP team agrees that a modification is warranted, then the case manager creates the ISP addendum and shares with the providers within two weeks.

The provider then will have 30 days to complete the modification documentation and return it to the case manager.

And then, once the case manager receives that back, they'll take a look at it, decide if it's adequate or if it needs more information, and if they need more information from the provider.

And then, the case manager will share that with the... participant, and the... if applicable, if they have a legal representative, or guardian, then they need to provide informed consent, and sign off on that modification.

Once a modification is implemented and is approved,

the provider is obligated to continue to provide the data— which has to be reviewed by the team on a periodic basis (that might be monthly, that might be quarterly, that might be semi-annually).

And, that is something that gets defined in the addendum... to decide whether or not that modification needs to be maintained or changed or eliminated.

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When a case manager convenes and facilitates that conversation on rights modifications, there are several things that need to be discussed.

One is the situation or condition or behavior that creates the health and safety need. Why are we talking about this? What is it... that is happening in that environment or that... around that person that requires us to restrict their rights?

If there is that health and safety need, then it needs to be specifically assessed.

It has to be identified in a formal assessment specific to the person.

That might be a functional behavior assessment.

That might be a physician assessment. That might be something that came up in their SIS assessment.

There's lots of different ways we have to assess someone, but there does need to be an assessment. And if that assessment doesn't currently exist, then the case manager will work with the ISP team to ensure that there is an assessment that's completed.

The team needs to talk about how we're going to balance those health and safety needs with the person's rights.

And, that we're going to do everything we can to protect privacy, dignity, respect, autonomy, [Inaudible] choice, and the opportunity to be fully participating in the community.

It also has to be discussed and documented— what have we done, and what have we tried in the environment prior to requesting a modification.

You know, have we made sure that we've done everything to minimize our need to restrict someone's rights?

And then, what have we done in terms of positive interventions and supports, and less intrusive ways that this provider in the setting may try to use to meet the participants' needs.

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So again, in thinking through the process— after the team has met, and the case manager has completed the information about... the health and safety need, and the assessment— then the addendum moves over to the provider.

And, the provider has five areas on the addendum that they need to complete in order to implement a modification.

The description needs to... the steps of the modification description include these five things.

First and foremost— what is the modification?

Is it that Sharon will not have a lock on her door for three months— because she's experiencing self-injurious behaviors?

Who proposed it specifically? What is that modification?

How will it... how often will it be implemented? By whom?

If it's a particular intervention, or if it's a particular standing circumstance— for example, you know, the removal of a lock on the door.

But again, how long is that going to be in place?

And, is the decision proportionate to the risk?

Why do you think that taking the lock off the door is a better solution than saying: "gosh that behavior always takes place between 6 and 9 pm."

So, we're going to have an agreement that between 6 and 9 pm the door is going to be cracked, and that lock is not going to be locked.

Right? So, there's there are ways to think about that, but providers will have to be able to articulate that.

Providers will have to be able to talk about what they've tried, and what other options were ruled out in order to get to this modification?

And they'll... you'll have to... providers will have to include documentation of what they have done to ensure that this is the least restrictive way to support someone's health and safety needs.

Providers will also have to describe how that modification is the most appropriate option— and really is helpful to the person, and is not... and is allowing them to continue to pursue their goals and have their needs met (even though some of their rights and freedoms may be restricted).

Providers will need to describe how they're going to know whether or not that modification is working, and how they're going to back down from it, and how they're going to collect information or data to show that they can back down from it.

And finally, they're going to have to show how to create a plan on how they're going to monitor the safety effectiveness and the need for that modification.

And again, it can align with things that are going on.

So, for example, on-site monitoring that maybe is provided by a ResHab agency for an AFH— but articulating in that addendum— who's responsible for the monitoring, how often it'll happen, and how will the determination be made by the provider to present back to the team around continuing the need for the modification.

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So again, back to our example.

We'll say Joe (we'll call this person Joe). Joe has Prater-Willi Syndrome and has trouble with that management of food intake.

And so, the team has come together and said "gosh what are we going to do?"

We have to have a conversation— because Joe was hospitalized last week (because he had he got unfettered access to the kitchen and ate himself to a point that he made himself very very ill), and we had to make a trip to the emergency department.

So, how are we going to manage the situation?

First and foremost the team should be talking about making sure that the ISP has service and supports aligned to this need.

You know— is Joe in the right setting? Does Joe have the right supports?

Are there other things that we need to do to ensure that his ISP is aligned with his goals and his needs?

The team should be thinking about alternatives and processes.

Before we say "all the food in the house has to be locked away so Joe can't do this ever again," we have to think about— are there incremental pieces of this that we can do so that we're not taking away Joe's total access to food?

But maybe we're thinking about how do we support Joe to have safe access to food, and allow Joyce... Joe (excuse me) that autonomy that opportunity to initiate the opportunity to make choices... while still keeping Joe safe— so that Joe doesn't go into the kitchen and eat an entire refrigerator worth of food, right?

So, maybe small amounts of food may be available or accessible with cues and supports to help support and develop self-management, right?

So, maybe there's one cupboard where... the food is unlocked, and Joe learns that they... Joe can get into that cupboard during certain periods of time. But once the food is gone (in that cupboard)— the food is gone (you know) until another point in time.

And, as long as that's supported with development and cues, and we're trying to move Joe back towards self-management of the food— then that's an acceptable modification.

Maybe we want to make sure that Joe's getting the right assistance from a nutrition counselor or dietician for strategies.

Maybe we want to support and build out a positive behavior support plan on how Joe is going to be able to make good food choices (with support), and having the opportunity to make choices that begin to reinforce portion control and food selection at meals.

We know that biologically— Joe's not going to change.

Joe's not suddenly going to have the internal mechanisms and signals that are going to say "you're full".

You don't have... you need to stop eating.

But, we can give Joe some tools, and Joe can begin to self-manage.

In a way, that means that we're not just taking away all of his rights related to food.

And, maybe we come up with some creative solutions maybe we say: "Joanie's had a different relationship with food that's not just about putting everything in his mouth."

Maybe, part of what we need to do is teach Joe how to garden— if that's something that's consistent with Joe's interests and goals.

It's...and it may not be. But the whole point is to have a very person-centered and individualized conversation about solutioning.

And, if we're going to take away someone's rights— making sure that we're doing it as.... in the smallest way possible and making sure that we're beginning to... that we're developing those alternatives, and that that right is not something that is permanent— and we see it as something that is immovable, and... is ongoing forever.

Right? A modification to a right is something that is... periodic (periodically reviewed), and determined whether or not it actually needs to continue.

We don't just decide that we're going to restrict someone's rights, and simply be by virtue of some limitation or some capacity challenge that they have that for the rest of their lives.

They will live under that restrictive rate of freedom.

The provider is... really needs to find ways to reduce that modification, set some milestones, and be able to report back to the team on the progress or the challenges.

We tried [inaudible].

We tried to help Joe grow food in a garden, and he didn't really want to do it, and he started eating the plants.

I mean (you know)... that might be the result.

But you tried something, and that didn't work. So now, we've got to try something else.

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So, one last thing I want to say before we open the floor to questions.

Modifications should be reviewed as a last resort.

We do not anticipate (across the hundreds of people that are receiving services in provider-controlled settings) that everybody's going to come in needing a modification.

Most people should not.

Most people should be able to receive their services consistent with how the federal rule is written, and consistent with the Hawaii rules, and the Waiver standards and service definitions— without any restrictions to their freedoms or rights.

It should be a very small number of people who need this modification.

As I noted, modifications should very, very rarely be seen as an ongoing solution and have to be reviewed frequently.

They should be looked at... at ISP meetings, case management check-ins, or when requested by any team member.

This is... this should be living breathing ideas on how we support someone to exercise the maximum opportunity... to have their rights and freedoms supported by the services they're receiving.

Modifications should really only be narrowed. They should target the specific need.

When we build house rules, or make broad modifications, we create unintended consequences, and we often may violate the federal requirements.

Case managers are not going to approve modifications that are requested by guardians or representatives that don't adhere to the same policy requirements and are not aligned with specific health and safety needs.

Unless someone has a guardianship order that says "this is a particular health and safety need"— a provider may not violate the rule or implement a modification simply at the request of a guardian or a legal representative.

So, with that, I will open the floor for questions. I see there's some in the chat and Abby, I will turn to you to help... moderate... moderate this.

Abby: Awesome! So again, like what Sharon mentioned, we are going to go ahead and turn this over to the question and answer portion of the presentation.

If you are not familiar with our platform, you can go ahead and submit a question for our team in your zoom toolbar.

So, we do have a lot of questions that came in.

I am going to try to loop them together— based on what they look like.

First and foremost, here we go.

We recently got a positive behavior support plan that restricts preferred foods and activities until they comply with requests.

This is not a positive behavior support— it is punishment.

Another agency wrote the plan and it was approved by the guardian and case manager.

We do not want to implement this type of plan.

Is this plan appropriate for someone who is bed bound (or anyone for that matter)— and what can we do?

And, can we request a change to positive supports?

Sharon: So, I'm not going to comment on an individual circumstance— in terms of (you know) is this appropriate for a person who may have mobility issues or a person that lives in a particular setting?

But, what I will say is.... I agree with you that if someone's preferred food and activities are being withheld (so that they will become compliant)— that is not necessarily... (and again, I want to be careful because I have not seen the specifics of the particular of what was written), but it is unlikely that that aligns with the restrictive interventions policy in the state's positive behavior support approach.

And, I would suggest that (in this circumstance) the best solution is.... to re-engage with the case manager. And, if that is not working, I would seek to speak to the case manager supervisor.

I'll let other state staff jump in here (if I'm giving a direction here that you think is inappropriate).

But I... that would be my advice. I agree with you that... that would not be what we would want to see in a person-centered plan.

Sandy: Yeah, exactly what Sharon had just said.

You know... you would bump it up to the unit supervisor (I think).

You know, it's a matter of getting the circle back together again and have your little talk story session— whether it's a miscommunication (a misunderstanding).

But the way it came across, yeah, it doesn't seem acceptable.

But yeah, speak with your case manager and the supervisor and then... how that goes, then we will bump it up further.

Abby: Awesome.... as a follow-up to that ... when we're talking about monitoring the BSP—

is that the agency that is responsible for writing the BSP, or the agency providing... the service who is responsible for monitoring that?

Sharon: So... I don't know if Sandy or state staff want to jump in... in terms of your... processes for... writing and implementing positive behavior support plans?

I believe that positive behavior support plans are developed as a service as under the service.

Sandy: Yes. So, the behavior support plans are through the agency that the service was authorized for the TNC behaviors to write up.

You know, there are different scenarios where they have ongoing hours where the behaviorist will follow up with the service.. with the agencies that are implementing the plan.

So, you know, I mean they don't just train and walk away.

There still needs follow-up— if the behavior support plan was developed. So, once again, I think um there's something missing in that loop.

So, get back with your case manager and / or the supervisor.

Abby: Awesome!

All right! Next question that we have is... again, for a specific scenario for a 28 year-old male.

The ISP states that he must be supervised at all times on the phone so he does not engage in inappropriate behaviors.

We believe he has the right to engage in some of these behaviors.

However, mom says "no", and the case manager did put it in the ISP.

What are your thoughts?

So... and Abby, I appreciate your editing, but I think the context is important...

Abby: Ohh... OK.

Sharon: Because, I think it's a really important issue— which is the the specific behaviors that are being referenced in the question are masturbation or watching porn.

Unless (again) there is a demonstrated health and safety need— the person has a right to have privacy, and they have the right to masturbate, and they have the right to watch... legally available adult material (the same as anyone else does now).

If that behavior has become a health and safety concern (which again would be identified by the team), then it can be discussed by the team, and maybe there is a modification.

If the person has (you know) experienced sexual predation issues or has violated a law— then the same as anyone else, we might want to consider some restrictions.

But... simply by virtue of mom being uncomfortable with the sexuality of an adult person is not a reason to restrict someone's health and safety needs... (I mean their rights) and it has to be based on a health and safety need. Sorry....

Jenn: Abby, I'm just going to jump in really quick too... and I know because there's a couple other questions that follow similar lines of questioning. So, I just want to... state to everybody because we've had some conversations around this... with families and (you know) just outside of case managers or DDD and... providers... that this really is a shift in for very many, many people.

And so, in this next phase of... this transition for all of us as a system, we are planning on having other trainings and information and webinars that will be available to families, to guardians, to other persons who support... participants.

And so, I just wanted to put that out there, and (you know) we can continue to ask the questions.

But, I do want to let everyone know that additional education is going to be available in the coming months.

Abby: Thank you Jenn.

That took care of almost all the questions. Nah... just kidding.

[Laughing] Next, we have... "CM's are currently holding what they call 'Mini ISPs' to talk about these issues, and they do not invite the entire team. Can we request that all members be invited, and shouldn't it necessarily document in any way (except possibly in an email)? Shouldn't we have documentation of the changes agreed... with responsibilities identified?"

Sharon: Sandy, I'm going to punt that one to you, but I believe that your question is "yes".

Sandy: Yeah, and you know, I think what it is is... if the case manager is trying to find out the details— they'll have that one-on-one conversation. But, then again, they would have to bring the whole team

together. because it's involving the whole... (I mean, you know) it's maybe in different settings— but it still involves the participant, and we need to be consistent.

So, but we can do reminders.

And, I'll try to get feedback from the unit supervisors (as well) to discuss with their team.

Abby: Thank you Sandy! Next question. This is about additional life situation changes.

What about when life situation changes? For example, a participant is now... bed bound. I don't like saying that word. I'm sorry!

Sharon: Yeah... it's no longer ambulatory.

Abby: I don't like it. Okay. Shouldn't the ISP be modified to address the changes needed in programming... to take into consideration the changes in their life.

Sharon: Yes, absolutely. And (you know) again, an ISP (you know) and a LifeCourse approach... should be a living breathing document. It should change all the time.

And, I know sometimes it's very hard for case managers—because they have a big job and it's a lot of documentation.

But really, at the end of the day, the ISP should belong to the person.

And, as the person's life circumstance changes, then that ISP absolutely needs to change.

Abby: Then... all right!

Next question that we have is... oh it's more or less like a comment. "I think it is a good thing that providers have to respect a person's needs.

A lot of times providers call the shots so it is good that providers are reminded that my son has rights and it should be respected."

Thank you!

That's a great comment. Okay. Next, we have "is having services in the participants place of residence a right for the participant? If denied, doesn't mean that the participants' rights have been denied?"

Sharon: I guess I'm not a hundred percent.

Abby: Having services in the... To me... being able to receive services where they live at home... (I mean) I think that is again a little bit outside of the scope of our... of our webinar today.

But, in general, the right to receive services is based on (you know)... an assessed health and safety need, behavioral, medical, etc.

And really, that's a determination that case management has to make— in terms of looking at what is... what is it that the participant is looking for, and what is... what are their rights and (I mean, excuse me) what are their needs based on assessments

Regardless, not talking about modifications... talking generally.

And this... the case manager gets to authorize the services and help work with the team to establish a service plan.

If someone is not being... is not able to receive services in the place that they're... a resident (because a case manager can't authorize that service), there's lots of different reasons that that might be the case.

That setting might not be compliant with the requirements. That setting might not be able to meet the person's needs.

And, it is not a violation of the participants rights if they're not able to receive the service they want.

And there is, you know, a grievance and appeals process (if the participant doesn't agree with that decision).

Sandy: Yeah. I just wanted to make another comment and not to get away from the modification theme.

But, you know, a lot of times we get questions. You know... when the case managers authorize services we have to... the service being authorized, we have to meet the intent of the service definition of the waiver.

So, sometimes we're asking... and then we cannot duplicate services when it's being offered by other um organizations that they're involved with.

So, yeah, I'd have another conversation with your case manager, and then... (you know) to get it resolved.

Abby: Thank you! I see we're coming up on time.

So, let us take... questions in regards to when is this beginning...

So, has the modification process already begun with the case managers?

If not, when will this take effect or when will this be effective?

Sharon: So, the policy and the addendum form are currently under review with MedQuest, and they are imminent in terms of their release.

Case managers have been trained on this, and have been actively working through scenarios with the different with the form and preparing to implement this with participants. So, it should happen very very soon. We don't have a specific date.

But... this... because this has to be completed prior to that march 2023 deadline, we need to make sure that any person who is participating in a service in which their rights are or freedoms need to be restricted— that this is documented and in the ISP and completed by next year.

So, the case managers will be running through this for all participants.

I know we're out of time. I did want to answer one more really important question that popped up in the chat— which is... "does this only pertain to ADH and residential (not PAB)?"

It applies to... provider-controlled settings.

So, if PAB is being delivered in a home that is controlled by a provider (which means that they have to live in that home in order to receive...) I mean, excuse me, they have to receive service from a particular provider in order to live in that home (even if it's a private residence)— then that is all... this rule is also applicable to that circumstance.

So, it's not just about those services, but it's about a provider-controlled and / or operated... setting.

Abby: Awesome! All right. So, yes, we are up at the top of the hour.

Do... we do see all these questions coming in.

We will make sure that we circle back... and let you folks know additional follow-up resources.

We have also included (in one of the questions and answers) a site that has all the resources in regards to DDD's efforts towards final rule compliance.

Do we have any closing remarks Jennifer?

Jennifer: Yeah... I'll give a closing remark— which is... first of all thank you Sharon! And, thank you to everybody for attending today.

I just want to end by saying— you know... I know that this (as I just alluded in my last comment) is just such a huge shift for our system It's a huge shift for our thinking.

And also, to go along with the... "has case manager started this yet?"

I just want to remind everybody that this is such a process. You know... we're all... learning. We're all going through this together. This is all going to be effective in April. There's so many changes happening.

We are not going to get it right the first time— but we're going to do this together.

And, I just want to remind everybody... you know, we really are all on the same team.

And, we're really all trying to get the same things done— which is to continue to respect, and do everything that we can to ensure the rights of participants are upheld.

So, I just want to end by saying that... have a really good weekend everybody. And, thank you!

Thank you for taking time out of your busy schedule and attending today's webinar.

[Music Playing] Should you have an additional question for our community resources branches team, please feel free to reach out to us at doh.dddcrb@doh.hawaii.gov.

[Music Playing]

Also, visit our website for the latest news and events from the Developmental Disabilities Division.

Our website address is: health.hawaii.gov/ddd.

Mahalo everyone, and have a good day!

[Music]

