



Rita Young helped facilitate the HCBS community meetings held in November 2014.

## New Home and Community-Based Services Settings Rule Brings Focus on People with Disabilities

By Lindsay Gladu and Devika Rao

### New HCBS Rule\* requires that a setting:

- Is fully included in the community, is part of the community and provides full access to the greater community.
- Is selected by the individual from more than one setting option.
- Supports individual choice of services and supports.
- Ensures privacy, dignity and respect.
- Never forces an individual to do something they don't want to do or keeps them from doing something they do want to do.

**\* In Georgia, the new rule only applies to day programs, assisted living, group homes or provider-owned or operated settings.**

John-Mark Gaines, 24, of Lizella, GA, had the time of his life when he went whitewater rafting down the Ocoee River in North Carolina last summer.

“Cross that off his bucket list!” his mother Sheila Gaines said, explaining that it was possible because of the individualized service plan that his day program has in place for him, “They asked him about the things he likes to do and planned it accordingly,” she said. “It’s very individualized.”

John-Mark had waited five years to be on the COMP, or Comprehensive Supports, waiver plan, which now allows him to participate in his day program. He’s receiving individualized benefits and has a schedule brimming with activities like visits to the library, dining out and hopefully going on a ride-along with a canine police officer and his human partner.

With daily activities centered on John-Mark’s personal interests and unique needs, his is an example of the new Centers for Medicare and Medicaid Services (CMS) Home and Community-Based Services (HCBS) Settings Rule that went into effect in March 2014.

### The Final Rule

On March 17, 2014, CMS declared that programs receiving Medicaid funding under this rule are expected to maximize the opportunities for people to access the full benefits of community living and to receive services in the most integrated setting possible, consistent with the Americans with Disabilities Act (ADA) and the Supreme Court’s decision in *Olmstead v. L.C.*

The HCBS rule provides the definition and qualifications of a home and community-based setting under Medicaid, defines person-centered planning and conflict of interest for case management and requires transition planning to ensure states adopt and follow the new requirements. *(Please see sidebar for definition of an HCBS setting.)*

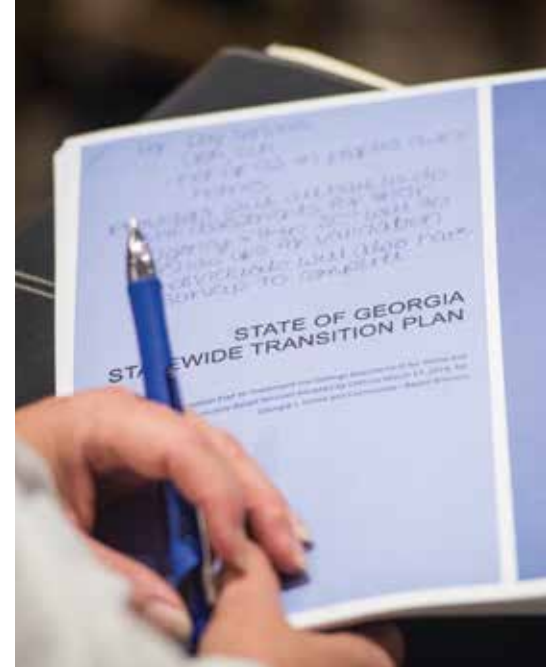
It brings attention to how HCBS should be delivered or helps the elderly or people with disabilities stay in the community by adding person-centered planning (PCP) and self-direction (SD). The person-centered planning will support individual choice in how, where and when people receive services as well as what services they receive. Self-direction would apply to certain waivers giving individuals more decision-making power about how their service dollars are spent and who is hired to provide services to them.

The HCBS rule is aligned with Section 2402(a) of The Patient Protection and Affordable Care Act (ACA), which was enacted in 2010. It requires that all states that receive federal funds for service systems respond to the needs and choices of those receiving services. States are to also ensure that those individuals are achieving maximized independence and self-direction; are provided with coordination for a community-supported life; and are able to enjoy a more consistent and coordinated approach to their support program.

“The rule gives states more direction on how to deliver and meet those person-centered planning objectives,” said Patricia Nobbie, PhD, program specialist for the Office of Policy Analysis and Development under the Administration for Community Living. “The rule focuses on the principles of integrated community living and brings a high level of consumer engagement.”

John-Mark’s experiences are an example of how Georgia’s new transition plan spearheaded by the Georgia Department of Community Health (DCH) is supposed to look in the future.

and all other states, to propose how it will develop tools and implement evaluations of the settings where the waivers are currently available. The transition plan will affect the Independent Care Waiver Program (ICWP), New Options Waiver (NOW), Comprehensive Supports Waiver Program (COMP), Elderly and Disabled Waivers, Services Options Using Resources in a Community Environment (SOURCE), Community Care Service Program (CCSP) and Georgia Pediatric Program (GAPP). The plan will also address methodologies to include public input and provider compliance checks.



## Cross that off his bucket list!



The new rule is centered around the idea that individuals “should have the full experience that life has to offer as if you did not have a disability or you did not rely on services,” said Marcey Alter, Deputy Medicaid Director, Aging and Special Populations, at DCH.

To comply, the State will have to submit a transition plan for all HCBS services to ensure they meet the new specifications. “This is the most substantial change to waivers in over 30 years,” said Nobbie.

In Georgia, the new rule only applies to day programs, assisted living, group homes or provider-owned or operated settings.

### The Transition Plan

The federal rule requires the State of Georgia,

DCH held four community meetings in Marietta, Macon, Athens and Fayetteville and three virtual meetings in November 2014 to receive stakeholder input for the direction Georgia will take in its services. The meetings allowed consumers and family members to learn about important changes to the HCBS rule from Medicaid leaders, participate in a focused discussion with other advocates and also review the draft of the plan.

“We wanted the community to understand that the federal regulation will have an impact on the people, from state to individual,” said Alter. “But, this is also an outlet to create the general understanding that this mandate is raising the bar on the quality of life and we are moving away from

John-Mark Gaines went whitewater rafting last summer on the Ocoee River. The outing was a part of his individualized plan.

“The new rule is centered around the idea that individuals “should **HAVE THE FULL EXPERIENCE** that life has to offer as if you did not have a disability or you did not rely on services.”



In November 2014, self-advocates, caregivers, guardians and providers attended the HCBS community meetings held by the Georgia Department of Community Health to learn about the new CMS mandate affecting Medicaid waivers.

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## POSITIVE LONG-TERM EFFECTS.

a ‘menu of services’ and towards a person-centered and self-directed focus.”

**In fact, the transition planning process will be broken into five stages:**

1. **Identification of all settings that need to be brought into compliance.**
2. **Assessment of the settings.**
3. **Remediation or how to get them into compliance.**
4. **Outreach and engagement with the stakeholders.**
5. **Monitoring and evaluation once the new rules are put in place.**

For the State of Georgia, settings are defined as provider-owned or operated facilities such as group homes, day programs, assisted living centers, etc. The rule will affect almost 3,000 settings across the entire State.

“It’s our intent to keep this engagement going,” Alter said. “Just because the public forums end doesn’t mean the dialogue ends. This is a five year process and we’re going to have touch points all along the way.”

### The Assessment

One of the most integral parts of the new settings rule and statewide transition plan will be the assessment component administered and reviewed by DCH.

The assessment will have three different kinds of input: a provider’s self-assessment, a random sampling administered by a caseworker to review the provider’s assessments and a consumer’s survey documenting their experiences with the provider.

**Providers will have to address the following questions:**

1. **Does the provider support the individual receiving services to be fully included in the full community and have access to the full, greater community?**
2. **Was the individual given a choice of provider and services?**
3. **Does the provider ensure individual privacy, dignity and respect?**
4. **Does the provider honor and respect individual’s daily choice?**



People took part in discussions about the new mandate and how it will affect their services once the State submits the transition plan in March 2015.

The same questions are written in first-person format for consumer input.

During the community meetings around the State, self-advocates and caregivers questioned the validity of provider self-assessments. Meeting participants weren't sure the assessment tool would provide an accurate litmus test on compliance.

"How would we know that the providers would be honest?" they asked.

It is important that the providers actually support individuals to make choices and let them do what they want to do as opposed to saying 'yes or no' to plans that were already laid out.

All three forms of assessments will be submitted to DCH for review and compliance check under the new mandate. The response from the surveys will allow DCH to determine the compliance level and remediation for alignment between the provider's self-assessment, case manager validation and the consumer survey. The assessments will also provide a baseline for future training to ensure that the person-centered planning requirements are being met.

This process is how Georgia, specifically, is choosing to evaluate compliance with the HCBS settings rule.

It is also giving a voice to consumers and pushing active engagement in the planning and service deliveries. This is not the first time the question about consumer's input has been asked – but now, "it went from a nice-to-do, to a must-do," said Kathy Floyd, executive director of the Georgia Council of Aging. "It is really good to give consumers a voice and bring more focus to the person-centered planning that has positive long-term effects."

Yet person-centered planning isn't without its challenges. Joe Sarra, an advocate with

the Georgia Advocacy Office who has two cousins with disabilities, said that people who have never made individual choices before have a harder time deciding what they want because it's scary.

The help of a support person and individualized service plan should allow for an easier transition into the community. And where people with disabilities don't use words to communicate, a support person, parent or guardian would help draft a plan with the individual's wants and needs in mind.

Giving an individual the ability to make personal choices such as what food they would like to eat for lunch or what movie they want to watch is something most people take for granted. More compliance will support people with disabilities to have the freedom of choice to live more meaningful lives.

"They are trying to close loopholes and make things more specific for a provider, but it is about trust," said Josette Akhras, GCDD Council member and parent advocate. "It is important that the providers actually support individuals to make choices and let them do what they want to do as opposed to saying 'yes or no' to plans that were already laid out."

Her son, Riad, who happens to be a purple belt in karate, says an ideal day for him would involve, "grocery shopping and picking out the things I want to buy instead of having someone do it for me," he said.

However, many self-advocates expressed concern about the new policy's effect on parents, guardians and independent living.

At the community meetings, Alter specified that if an individual lives in their own home or their family's home, or are under guardianship, the new settings rules and assessments do **not** apply to them. If they receive a day service outside the home, the rules do apply.

And, it's with hope that these rule changes also allow for innovation in areas such as housing and employment. "What are some other options and avenues we haven't taken yet?" asked Nobbie. "For instance, it opens up ideas to collaborate with the private

## Provider Survey Questions:

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2. Was the individual given a choice of provider and services?
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Riad Akhras (left) takes private karate classes with instructor Ray Saltamacchio.

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## INDIVIDUAL NEEDS.

business sector to develop and advocate for Employment First.

“We are going to learn a lot in the next five years, and it brings a real opportunity to change things for the better.”

### The Waivers and The Waiting Lists

Waivers allow states to test new or existing ways to deliver and pay for healthcare services in Medicaid and the Children’s Health Insurance Program (CHIP). Each state has about six to seven waivers, and most fall under Section 1915(c) of the Medicaid program.

The vision is a smoother transition and a system that will, “also make more sense to someone coming into the program,” said Floyd, citing the increase in the Baby Boomer generation (those born between 1946-1964) that will begin to seek services in the upcoming years. “Someone who is entering the system would get the resources they need right away to get their necessary supports. This is what they expect.”

### The Providers

As the HCBS settings rule is moving toward a person-centered focus and allowing states to



HCBS meeting attendees take part in discussions about the new settings rule that will focus on the quality of life of people with disabilities.

But even with the implementation of the new rule, one of the places a change won’t occur is the waiting lists. According to DCH, currently, almost 40,000 people receive services through waivers, but the problem is that there are too many still waiting. Over 7,000 people are waiting for the NOW and COMP waivers, while the CCSP waiver list has over 1,600 people. SOURCE currently has none, and ICWP has about 106 people.

Among those receiving services, 3,000 are under self-directed care. “This is stepping away from the ‘menu of services’ and allowing individuals to be the employer of record and create an individualized plan that adds to their quality of life,” said Alter.

The new settings rule establishes compliance measures for each waiver, but it does not provide quicker access, shorten the list or put more money in budget. What the rule does say is that those who are receiving services are to get the best services centered on their individual needs.

make their services more consumer-focused, the providers will bear the weight of the new mandate.

We are going to learn a lot in the next five years, and it brings a real opportunity to change things for the better.

Providers will need to make changes to comply with the new definitions. According to DCH, that could mean allowing residents/consumers more flexibility in their scheduling, access to food, visitation hours and privacy; training and evaluating staff on person-centered service delivery; and creating more opportunities for consumers to be active in the community.

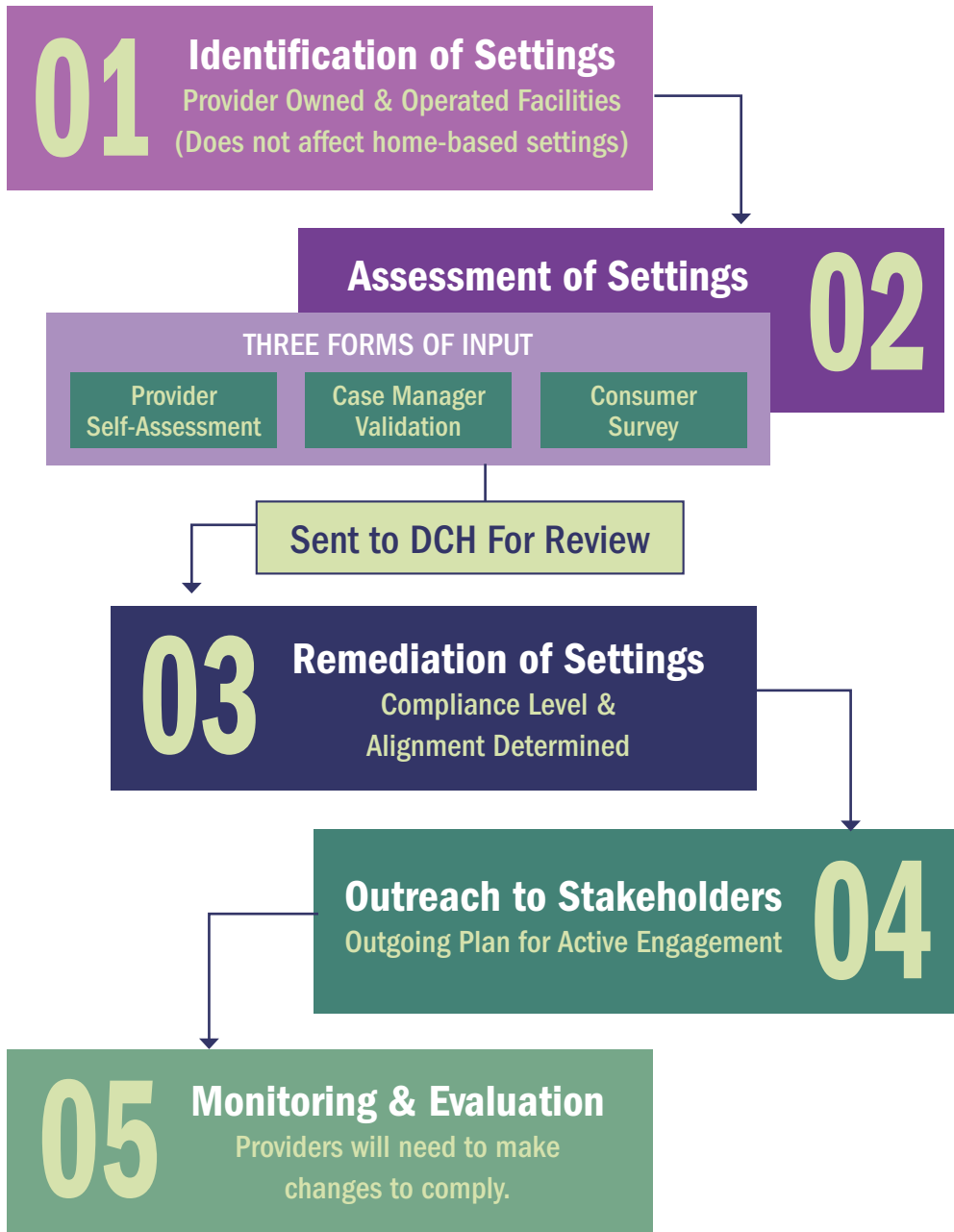
For additional questions to the Centers for Medicare and Medicaid Services, email [hcbs@cms.hhs.gov](mailto:hcbs@cms.hhs.gov)

For more information on the Home and Community-Based Settings Rule, visit [www.dch.georgia.gov/waivers](http://www.dch.georgia.gov/waivers) or [www.hcbsadvocacy.org](http://www.hcbsadvocacy.org)

# State of GA Transition Plan\*

## GA Department of Community Health (DCH)

\*Affects ICWP · NOW · COMP · Elderly & Disabled Waivers  
· SOURCE · CCSP · GAPP



“I’m very concerned about what is going to happen to day programs since they haven’t said what is acceptable,” said Allen Freeman of All Care in Macon, GA. “One of the things I asked for was that [the Department for Community Health] come up with a best practices plan. It’s very easy to put policies out there and say ‘Make this work in your company’ and that’s left to interpretation. What I want them to say is ‘Here is a model

that works really well and we want you to incorporate that into your company.”

The new HCBS rule aims to provide more opportunities for people like John-Mark or Riad to enjoy the life that is the most meaningful to them. As the new rule gets underway in Georgia and is fully implemented in 2019, the future looks like a more inclusive and person-centered community for people with disabilities.

## Georgia Medicaid Waivers:

- **New Options Waiver (NOW) and COMP (Comprehensive Supports Waiver Program)** provide supports to people who want to live with their family or in other kinds of community living arrangements. The services offered through these waivers can make it possible to have supports during the day, at night or on the weekends.
- **Services Options Using Resources in a Community Environment (SOURCE)** is an enhanced primary care case management program that serves frail elderly and disabled beneficiaries.
- **The Independent Care Waiver Program (ICWP)** offers services that help a limited number of adult Medicaid members with physical disabilities to live in their own homes or in the community instead of a hospital or nursing home.
- **Community Care Service Program (CCSP)** provides community-based social, health and support services to eligible consumers as an alternative to institutional placement in a nursing facility.
- **Elderly and Disabled Waivers** provide home and community-based services to individuals 21-years-old and older who would require the level of care provided in a nursing facility.
- **Georgia Pediatric Program (GAPP)** serves children who are medically fragile and in need of skilled nursing care.