

Alabama Statewide Transition Plan Public Comments

Period February 2015

VIA ELECTRONIC MAIL

March 14, 2015

Ms. LaQuita Robinson

Long Term Care Services

Alabama Medicaid Agency

P.O. Box 5624

Montgomery, Alabama 36103-5624

RE: Comments regarding Alabama's HCBS Statewide Transition Plan

Dear Ms. Robinson:

I am writing to provide comments to the Alabama Medicaid Agency's ("Medicaid") HCBS Statewide Transition Plan ("Plan") on behalf of the Alabama Disabilities Advocacy Program ("ADAP"). ADAP is a federally-funded Protection and Advocacy program that aims to protect the rights of individuals with disabilities in the state of Alabama.

The Plan is an effort to comply with recent HCBS regulations promulgated by CMS. As Medicaid prepares to transition to offering true community services, proper planning and consistent implementation of the Plan is vital. With this in mind, ADAP offers the following comments and suggestions.

The Plan contains insufficient information

Unfortunately, the current Plan is woefully inadequate in that the Plan lacks detail for a variety of vital components to the HCBS requirements. For example, the Plan includes a broad statement all services provided under the Technology Assisted ("TA"), HIV/AIDS and SAIL waivers meet the regulatory requirements. This assertion is supported by merely stating "the state completed a review of all residential and non-residential settings in which HCBS are being provided." See, Plan at 4. Each of these waivers provides personal type services, such as personal care or skilled nursing services. The Plan, however, fails to describe whether these services can be provided in a community setting or while engaged in a community activity, such as a recreational outing or worksite. It is not adequate for plans simply to require that settings comply with the HCBS regulations. Alabama is expected to evaluate the extent to which its regulations, standards, policies, licensing requirements, and other provider requirements ensure settings that comport with the requirements. See 42 C.F.R. § 441.301(c)(6)(iv)(B); CMS, Statewide Transition Plan Toolkit for

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Alignment with the Home and Community-Based Services (HCBS) Final Regulation's Setting Requirements 5 (Sept. 5, 2014), available at <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/statewide-transition-plan-toolkit.pdf>

The Plan also lacks detail in how Alabama will improve access to more integrated services in order to replace any less integrated services that will no longer be covered. The Plan simply indicates that programs found not to be in compliance will no longer be funded. This is especially concerning since many waiver recipients may legitimately fear that that they will be "dumped" by non-compliant providers.

While the Plan does describe some milestone dates for providers to become compliant with the federal regulations, the milestones do not provide enough detail. The Plan completely fails to mention how Alabama plans to build provider capacity to serve people in more integrated settings and

whether Alabama will place a moratorium on new placements in settings found to be out of compliance.

The Plan, as currently written, only provides a brief, cursory description of high-level strategies. Supplemental information, including, but not limited to, information that addresses the issues above described, should be added to the plan.

The Plan focuses solely on residential placements

Medicaid's advertisement seeking public comment on the Plan states: "the Statewide Transition Plan is designed to ensure that individuals receiving long-term services and supports through home and community-based service waiver programs have full access to benefits of community living and the opportunity to receive services in the most integrated setting that is appropriate." (Emphasis supplied). The Plan, however, only seems to be mostly concerned with residential placements. While Medicaid's efforts to ensure residential placements comply with the HCBS rules, said rules go far beyond residential services. The transition plan needs to make sure that people are included in the community not just in terms of where they live, but also how they spend their day.

A service being provided in a residential setting does not necessarily mean the service is being provided in an integrated manner. Again, the Plan fails to mention whether highly personal waiver services can be used outside of a residential setting. The Plan, in fact, appears to indicate that most waiver services can only be provided in a person's residence. Medicaid claims, in the Plan, that "state completed a review of all residential and non-residential settings in which HCBS are being provided." See Plan at 4. (Emphasis supplied). This statement asserts no waiver recipient receives a waiver service outside of his residence or a certified program. This would mean that a person receiving personal care under the SAIL waiver could not use that service to assist with a simple task such as grocery shopping. While I realize that some waiver recipients receive services outside of their homes or segregated programs, the Plan does little more than make cursory mention of services that can allow a person to have "full access to the greater community." Medicaid's advertisement seeking public comment.

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The plan should detail how Alabama will transition to end segregated, non-residential day services. Currently, many HCBS participants are getting group-based day services that are not really integrated because people spend most of the day at a center that only serves people with disabilities. When they go out on trips "into the community," they are in big groups that inhibit interaction with people outside of the group. The Plan needs to closely examine the current day program services and establish a clear plan for moving towards integrated day activities.

Alabama provides two waiver services that, on their face, appear to be segregated: adult day health (provided under the E & D and SAIL waivers) and day habilitation (provided under the LAH and ID waivers). Regarding adult day health, "the state assumes Adult Day Health service settings are compliant; nevertheless, the state has determined that additional review is needed to ensure the service is provided in a manner that supports the autonomy and opportunities for community integration for all participants." Plan at 4-5. "This review will be undertaken through a provider self-assessment." Id. at 11. Using solely a provider assessment means that stakeholders are being asked to have faith in Medicaid and the providers to operationalize components of the plan that no stakeholders have had a chance to review and comment on. This approach is very worrying generally, but especially when it concerns services and settings that are critical to continued community integration.

For waiver recipients who want to work, the Plan should describe how recipients can access supported and competitive employment services. Instead of funding sheltered workshops and "work crews," Alabama should transition to funding supported employment services that help people find and keep real jobs that pay real wages, alongside coworkers who do not have disabilities. In sheltered

workshops, people with disabilities all work together – the only people without disabilities are supervisors and service workers. In work crew arrangements, people might be working in the same building as people without disabilities but they are still isolated because everyone on the work crew has a disability. Sheltered workshops and work crews also usually pay less than the minimum wage. These settings are not only segregated but also have a very bad record of helping people get competitive, integrated jobs. Many states, like Rhode Island, are already moving people out of sheltered workshops and into integrated employment.

The Plan should specify a point in the Plan to stop new placements in sheltered workshops and to transition people currently in sheltered workshops into more integrated settings like supported employment. This point should be as soon as possible in the Plan, taking into consideration the development of alternative services. This process should not be near the end of the transition period. For example, Massachusetts has created a plan, Blueprint for Success, which both diverts new admissions to sheltered workshops and includes a plan to completely transition all individuals in those segregated settings into integrated settings.

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ADAP believes the Alabama Department of Mental Health (“DMH”) is making concerted efforts to provide for integrated employment opportunities. Over the past couple of years, DMH has focused its efforts on improving access to employment opportunities for waiver recipients.

The Plan lacks meaningful stakeholder input.

The daily lives of waiver recipients will experience significant changes due to the HCBS rules. If done properly, these changes will improve the quality of life for waiver recipients and provide them with greater access to their respective communities. With that said, waiver recipients, the primary stakeholders to the HCBS rules, must be able to provide input into the Plan.

Much like its review of providers and services, Medicaid appears to have a cursory effort to obtain input from waiver recipients. The Plan indicates “Medicaid worked cooperatively with each of the waiver Operating Agencies, providers and various stakeholders to complete an initial assessment of the settings in which HCBS are currently provided.” Plan at 4. Other than providing comments, The Plan fails to describe how waiver recipients provided input into the Plan. The Plan is completely void of any examination of how current waiver recipients actually experience community inclusion, freedom of choice, and any barriers they encounter. The only people who can provide this information are the individual waiver recipients and, in some cases, their family members and friends. It is especially concerning that the Plan chooses to heavily rely on provider self-assessments to determine whether waiver services will be compliant with the HCBS rules. Reliance on providers or other potentially biased mechanisms will not provide a true picture of compliance. The HCBS regulations focus on an individual’s experience and a system that responds to the voices of non-participants would be contrary to the rule. At a minimum, Medicaid must develop a means for individuals to participate in their own self-assessment of the settings in which they live or spend their days. Participant assessments must be accessible to the individual and should be free from provider influence and be a part of the assessment validation process.

Recommendations

To ensure compliance with HCBS regulations and a smooth transition to full compliance, ADAP recommends Medicaid undertake the following:

- Amend the Plan to describe how all waiver services will comply with HCBS rules;
- Amend the Plan to describe, with realistic deadlines, how Medicaid plans to build provider capacity to serve people in more integrated settings;
- Provide a mechanism for waiver recipients and their caregivers to assess their waiver services and the setting in which said services are provided. This assessment should be readily available, simple to complete, and confidential;

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- Form a HCBS compliance workgroup tasked with ensuring compliance to the HCBS regulations. The members of the workgroup should include waiver recipients; caregivers of waiver recipients, appropriate personnel from other state agencies and advocates;
- Develop and distribute information to every waiver recipient and caregivers that describes the HCBS regulations, Alabama's plans to comply with said regulations and any possible changes to current waiver services;
- Provide information regarding the progress of Medicaid's transition plan and HCBS compliance efforts on an ongoing, regular basis. Said information should be readily available to and easily accessible by the public, especially waiver recipients and/or their caregivers;
- Establish a system by which waiver recipients and their caregivers can ask questions and receive information regarding changes to current waiver services.

Thank you for taking the time to read ADAP's comments and recommendations. If you have any questions or would like to further discuss any of the issues raised, please do not hesitate to contact me.

Sincerely,

J. Patrick Hackney

Legal Director, ADAP

(205) 348-6894 (direct dial)

jphackney@adap.ua.edu

THOMAS B. HOLMES
2117 Charing Wood Drive West
Mobile, AL 36695-2916

March 13, 2015

SENT VIA EMAIL TO:LaQuita.Robinson@medicaid.alabama.gov

Ms. LaQuita Robinson
Long Term Care Division
Alabama Medicaid Agency
501 Dexter Avenue – PO Box 5624
Montgomery, AL 36103-5624

Dear Ms. Robinson:

RE: Comments on Alabama's Home and Community-Based Service Waiver
Statewide Transition Plan

Thank you for the opportunity to submit comments on Alabama's Home and Community-based Service (HCBS) Waiver Statewide Transition Plan. My comments are focused on the Intellectual Disabilities (ID) Waiver and the Living at Home (LAH) Waiver. I am the father of a 38-year-old son with intellectual disabilities who currently receives services through the ID waiver. These comments are my own and do not represent any organization to which I belong.

My late wife and I have appreciated the opportunity for our son, Thomas, to receive day services in facility-based day programs, in Montgomery and now in Mobile, for the past several years. Through these programs, Thomas has had many varied opportunities to engage in community life, to have access to his community, to earn and control his personal resources, to receive education and job skills training, and to engage in meaningful work.

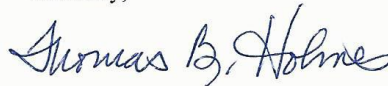
1. It appears to me that the new CMS Rule and the Alabama Medicaid Agency's (AMA) Transition Plan will remove my son's current choice of day services from the ID Waiver. I fully understand and support the goal of improving the quality of services available under the HCBS Waivers. I also support the purpose of providing opportunities to seek employment and to work in competitive settings in the community. These services should be available to all individuals with ID under the ID Waiver and the LAH Waiver, **so long as they are appropriate to their needs AND they are their CHOICE**. Unfortunately, there are many individuals with severe ID for whom these services WILL NOT be appropriate. In the CMS Rule, one size does NOT FIT ALL!
2. I question the Transition Plan's (TP) process for receiving public comments. The Plan states that the AMA wanted comments from the public, "particularly individuals receiving services" under the HCBS Waivers. I believe that the majority of persons receiving services under these Medicaid Waivers do NOT possess a personal computer, or have access to one, much less have access to the Internet and the AMA's website. The TP states that "one

additional option for public input is required.” What is it and how were the consumers and families affected notified? I would be interested to know how many comments were received from the “individuals receiving services.”

3. It is obvious to me that the new CMS Rule was written by persons who do not have a family member with ID, and/or persons that have never worked one-on-one with an individual with ID at the community level. I believe that the same is true for the persons who prepared the ID and LAH Transition Plans. They appear to have little, or no, understanding of the impact their actions will have on the individuals served and their families. As a parent who has cared for my son all of his life at home, his free public education, and now his day program services, have enabled my late wife and I both to be employed outside of our home over the years. This situation is true for most parents and/or siblings who care for a family member with ID.
4. I will support competitive employment in the community for my son when he is provided with the appropriate supports to secure and retain a job in the community. Our governor and legislature do not now provide adequate financial resources to provide existing ID and LAH services, much less these employment supports. I have no confidence that they have the political will to provide the necessary financial resources to implement these Plans in the future.
5. I understand that, if the ID and LAH Transition Plans are approved and implemented, individuals with ID will be moved from Day Habilitation Services and placed in Pre-Vocational Services which will be time-limited (2 or 3 years). After these services expire, if the individual is unable to be placed in a competitive employment in the community, we are told they will be placed in “adult day care”. This does not meet the test of “participants will not be left without services as a result of this rule”. These actions will force family members of individuals with ID to choose to keep their family member at home during the day, thus causing a family member to cease being employed themselves and reducing the economic well-being of the household.
6. I am deeply concerned that CMS, AMA, and the Alabama Department of Mental Health (ADMH) Developmental Disabilities Division (DDD) have decided what services are best for my son and other individuals with ID without due consideration about the impact on our families.

Thank you for this opportunity to comment.

Sincerely,



Thomas B. Holmes

Please consider the below as part of the Public Comment for HCBS.
These are current practices in some Alabama provider “homes”:

“certain settings are presumed to have institutional characteristics and will be subjected to heightened scrutiny if states seek to include these settings in their HCBS programs”

Settings where food is purchased in bulk for those living semi-independently vs the individual being included in the community via grocery shopping as well as learning to budget is an “institutional characteristic”.

Commercial grade paper towel dispensers in bathrooms is an “institutional characteristic”

“The final rule clarifies that when an individual chooses to receive home and community-based services in a provider owned or controlled setting where the provider is paid a single rate to provide a bundle of services, the individual is choosing that provider, and cannot choose an alternative provider, to deliver all services that are included in the bundled rate.”

All inclusive rent and utilities is OK. Bundled “services” is OK. But, all inclusive resident and services combined is very much an “institutional characteristic”. People should be able to change service providers, just like those without disabilities, without losing their home. It takes years to build social capital . . . people who care without being paid . . . and when an individual decides, or worse, an agency decides, the person and the agency are not a good fit, it’s the person with the disability who has to start over by moving, often to a new community where making friends can be very difficult. It should always be that the person keeps their home and the service provider leaves and a new service provider comes into the person’s home. Never should someone lose their home because they are not happy with how they are treated . . . or worse . . . stay in a forced, coercive situation just to avoid losing their home and community. Moving is traumatic for those with significant intellectual disabilities and sensory issues present in those with Autism.

“person-centered planning process that addresses health and long-term services and support needs in a manner that reflects individual preferences and goals. The rules require that the person-centered planning process is directed by the individual with long-term support needs, and may include a representative whom the individual has freely chosen and others chosen by the individual to contribute to the process.”

There needs to be consequences when/if a person centered plan is not followed . . . otherwise, it’s just a good “idea”, but pointless. My brother was discharged from his group home because they were not following the person centered plan and when we complained, they retaliated against him. He had 90 days to find somewhere to live and this was the only provider in his community of 10 years. Any complaints need to be resolved and all the burden of proof that the issue was resolved should be on the agency who is getting paid, not the family.

Thank you for your consideration as these are issues we have experienced first-hand and know how devastating they can be.

LCSW - Parent and Sibling to individuals with developmental disabilities

I really hope this program will continue. I have a 16 year old daughter with a dual-diagnosis of Down Syndrome and Autism. I am hoping to have her in her own home in our community as she is not really a candidate for a group home situation. Please keep this program. Thank you.

MJ

