February 20, 2015

NC Department of Health & Human Services  
delivered via email to: HCBSTransPlan@dhhs.nc.gov
ATTN: HCBS Transition Plan
3015 Mail Service Center
Raleigh, NC 27699-3015

Re: NC’s Transition Plan for Medicaid Home and Community Based Services (HCBS)

To Whom It May Concern:

We are advocates for people with disabilities and believe that people with disabilities should enjoy the rights and opportunities available to all people, including the right to live in the community; make decisions about where, how and with whom they will live, learn, work and play; and have access to the necessary supports and services to fully access the community.

We are submitting these comments to “North Carolina’s HCBS Transition Plan,” which was released to the public on January 21, 2015, and is intended to tell CMS and North Carolinians how NC will comply with the new rules for home and community-based services (HCBS) programs. These new rules defined for the first time “home and community based settings” eligible for continued federal waiver funding. While the State may continue to fund some institutional settings with Medicaid, it cannot fund settings that do not meet the standards of community with Medicaid HCBS dollars.

As advocates for North Carolinians with disabilities, we remind the State that although Medicaid funding can be used for institutional settings, increasing the number of institutional settings in response to these rule changes is not what CMS intended, nor does that response adhere to the Olmstead mandate. We are encouraged that the State’s vision for this plan is that North Carolinians with disabilities should be “in the least restrictive and most integrated settings possible” and that they “should have the opportunity to live in community settings that reflect community values and standards.” We commend the State for an approach that appears to be seizing this opportunity to move community integration forward. We offer our support in ensuring that people with disabilities in our state are fully integrated into community life and no longer segregated in any way – including in their day activities – from community members without disabilities.

We also appreciate that the State is using this process to evaluate its systems and policies. Although we recognize that these rules technically only apply to North Carolina’s 1915(c) waiver programs, the rules represent standards that should apply to all people with disabilities in North Carolina, each of whom should have opportunities to live, work, and spend time in their community. In North Carolina tens of thousands of individuals with disabilities are either waiting for waiver services, receiving minimal non-waiver services, or are residing in institutional settings because they do not have meaningful alternatives or the proper community supports. The time and resources spent examining and changing our system to comply with the HCBS rule should include consideration of the needs of people who do not currently have access to our waivers so that the State is moving forward on community integration and so that
the system changes are not so waiver specific that they will impede, rather than encourage, further integration efforts.

As a general comment, we would like to express our appreciation for the State’s approach that this plan requires a full evaluation of the system to ensure compliance with the rule. The plan to closely examine current rules, policies, provider qualifications, and rate structures as they relate to the vision, outcome measures, and core compliance indicators is very encouraging. In particular, the inclusion of rate structure in the plan is important because the rule may change how services must be provided and the array of services an individual may need.\(^1\)

Overall, we are pleased with the direction of the State's plan and offer the following analysis of the draft plan, which contains both positive and negative feedback.

**Outreach, Engagement, and Public Notice/Comment**

The State’s approach to outreach and engagement appears to be a solid plan to engage stakeholders. We particularly appreciate the State’s efforts to involve stakeholders early in the process with the HCBS Stakeholder Committee and its welcoming of input from all sources. We believe an important aspect of the Committee is that it is a good balance of participants, advocacy groups, and providers. The rules focus on the waiver participant’s perspective, and we appreciate that the makeup of the Committee respects the importance of participant and advocacy perspectives. We understand that this is also an important issue for providers, but we urge the State to continue on this path of focusing on what individuals and advocates are saying as opposed to the interests of those with a financial interest in the outcome of how the rules are implemented. There is a notable lack of representation of physical disability and aging populations, such as the Centers for Independent Living (CILs), AAAS, AARP or others, and we believe their involvement is critically important. The lack of information and clarity about whether the groups who have been included in the general stakeholder meetings are included in such areas as policy development, education, and rules changes is limiting and could be detrimental to the successful identification of issues. Participants, their families and friends, as well as advocates, know what needs to be changed to meet the obligations of the rules; input from these groups should be included throughout the planning and implementation process, both directly and through stakeholders. To this end, we ask that the State ensure that there is participant and advocacy involvement in all subcommittees and any review of policies, procedures, or training materials.

As recognized by the rules, public input from participants and the community is key to a state’s successful implementation of these rules. We are concerned about several aspects of community engagement:

1. **Reliance on web-based information severely limits outreach to participants and their families.** We appreciate that the State has made a dedicated website for the transition plan and intends to use this website to post updates, information, etc. This is an important step

\(^1\) As a reminder, the alignment of payment structures and goals is considered an essential element of Medicaid managed long term services and supports (MLTSS) and therefore must be evaluated for the Innovations waiver. That analysis should be extended to the CAP-DA waiver to ensure successful implementation. According to CMS guidance, “States must establish payment rates that support the goals and objectives of their MLTSS programs and these essential elements. In keeping with the intent of the ADA and Olmstead decision, payment structures must encourage the delivery of community-based care and not provide disincentives, intended or not, for the provision of services in home and community-based settings.” CMS, *Guidance to States using 1115 Demonstrations or 1915(b) Waivers for Managed Long Term Services and Support*, 8-9 (May 20, 2013), [http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/1115-and-1915b-MLTSS-guidance.pdf](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/1115-and-1915b-MLTSS-guidance.pdf) (emphasis added).
as it will help facilitate ongoing engagement. Many individuals with disabilities and their families are not frequent visitors to the NC DHHS website and in fact, may have limited Internet access. This is especially true for individuals in residential facilities, many of whom are reliant on providers to inform them about changes that may affect them. Although some providers will inform individuals and their families of possible changes to their services, the outreach and engagement cannot solely rely on Internet and provider networks to reach individuals. We would ask that the State use the methods available to it, including LME/MCO and lead agency contact mechanisms, which may use case managers and care coordinators, to spread and collect information. A strong, effective communication plan that provides information, as well as asks for information in return, is critical to the level of stakeholder input that the rules require.

A more specific change that needs to be made is that there is no link to this website from NC DHHS’s website under “For Beneficiaries” on Medicaid for Long-Term Care or on the link regarding CAP-DA. At the time of writing these comments, the link for the Innovations waiver was not working. In contrast, information about the rule and the website is prominently displayed on the NC Innovations webpage under the “For Providers” tab. The HCBS website needs to be easily located by individuals and their families for all affected service programs. Because many participants may have difficulties with transportation and arranging for appropriate supports, we would also recommend that any future meetings be accessible by phone and the Internet to allow access by those who cannot physically attend a meeting. We ask the State to remember that it cannot rely on the same mechanisms it uses to communicate with providers to reach participants and their families.

(2) A lack of knowledge about the rules makes it difficult for participants and others to understand what the plan means or how it will affect services. Some of us attended the listening sessions and were excited to see the level of engagement and openness that the State officials had with the audience, but we also saw that there was not a large turnout based on the city size (e.g., Raleigh) and that many people were confused as to what the meeting was about. For comparison, we have seen a public meeting convened by Alliance Behavioral Healthcare have two to three times the number of attendees. We applaud the fact that the State added some recipient/guardian/family-only meetings on the days of the larger listening sessions in some cities, but both the short notice and short duration of the two-weeks of listening sessions cannot be expected to produce thorough or sufficient feedback.

We appreciated that the listening sessions started with a brief overview, but this did not help individuals understand the standards set by the rule as to the community nature of a service setting. Without an understanding of the expectations of what community should look like, it is very hard to provide comment about what needs to change. We think the State is to be commended for creating a person-first version of the transition plan, which we understand is something different than what other states have done. However, we would ask that the State take that effort a step further and develop materials that would be accessible to individual participants and their families about the standards the rules are trying to set about community integration and engagement so that people will have a better context about what to expect. Although the person-first version is much more accessible than the original version, it is still seven pages long and very text heavy.

(3) The plan must include continued outreach, training and education, including training so that individuals and families will understand what changes they can expect to see and what will
affect their services. The plan was explicit about education and outreach plans for the providers, but it completely lacks a similar plan for individual participants and their natural supports. Information sessions and training to individuals and families should be planned for when providers may begin to change or when rules are changing. Lack of knowledge often creates fear and unrest. Because the focus of the rule is the individual, the plan must continue to focus on the individual. Trainings should be planned in such a way as to ensure statewide participation (including for those with limited technology access) and could serve as an opportunity for the State to receive feedback about the transition process.

(4) Clear milestones, particularly with expected dates, will help stakeholders know when to expect changes and facilitate meaningful comment on these steps. We applaud the plan’s recognition that the waivers and the plan itself will need to continue to evolve, include greater specificity, and continue to require public comment. It is also positive that the State plans to include greater specificity and milestones for achieving compliance. These milestones should include realistic timelines for bringing settings into compliance; building provider capacity; public input for changes to policies, rules, and standards; and public education.

(5) Education and technical assistance should be for all stakeholders. The State’s plan for educating and providing technical assistance, including facilitating peer support is an important piece of plan implementation. Providers need to understand how to comply with the new policies and rules, as well as the intent of the rule. Facilitating change among providers should help to decrease provider talk about shutting down, which should help stem participant fear about not having services or somewhere to go. We think that similar assistance needs to be available to participants and their families. Each LME/MCO and Lead Agency should have a designated individual who is clearly identified as a resource for individuals and their families. While we understand the role that case managers and care coordinators will play in this process, there needs to be an additional level of expertise that can be accessed for individuals to ask more advanced questions or to validate information provided by a case manager/care coordinator or a provider. An individual at the state level should also be identified as a point of contact.

To reiterate, we think the State has a solid initial plan for outreach, engagement and public comment and that this plan is well intended. The above comments are intended to ensure that the State is receiving the information it needs and that participants have a meaningful opportunity to understand and comment on the plan and its implementation.

State Self-Assessment and Remediation
We are encouraged by the State’s vision for the transition plan overall and urge the State to carry this vision through the assessment process. If the State becomes overly focused on provider compliance, it will miss the forest for the trees. We strongly urge the State to continue to focus on system reform and compliance, as that is what will bring the providers into compliance and will ensure ongoing compliance. We strongly believe that focusing on individual providers will not be the most efficient mechanism for overall plan implementation. We urge the State to use objective measures to help identify problems and indicate overall assessment inaccuracy, such as GIS mapping and NCI data; to use non-biased, educated, accessible participant assessments; to have statistically significant validation procedures; and to have a high degree of transparency in the assessment process so that the community can alert the State to issues. We think that the State’s current plan is good, and we particularly appreciate the inclusion of participants and the plan for a validation of the assessment process. We think that an assessment tool for individuals to use during the person-centered planning process is not only critical to a good
assessment process but also to an ongoing compliance mechanism. Information from such a tool would be an important piece of system reform that would facilitate monitoring of ongoing compliance.

The assessment process of the system is the first action for the State that will provide the information needed to determine how much change must occur. We encourage the State to take time on the system evaluation and the assessment process so that it has valid information to form the basis of the implementation and remediation plan. We are appreciative of the State's initial plan and offer the following:

(1) **Assessment Process.** The plan regarding assessment tools includes a piloting of the provider self-assessment, which is necessary to ensure that the tool provides sufficient indicators of the true nature of the setting. It is positive that this accuracy is measured to some extent by the experience of the individual participant, especially considering that the rule is intended to focus on the individual’s perception of their experience. It is not clear that the validation of the assessment will include other stakeholders, if the team will include other participants or advocacy groups, whether the initial assessments and validation report will be public, if the validation will be conducted for a statistically significant number of providers by provider type, or if the pilot process will be repeated if the results are negative. It is incredibly important that the validation of the assessments is done in an unbiased way that ensures that the participants are informed of what they should expect, not simply whether they “like it” or “get to have choice in what they do” as many may not have the perspective of what degree of choice they should be able to expect under the rules.

It is not clear if the State Monitoring Review Process will include on-site visits, but it is critically important that this Process have sufficient oversight and controls to make sure that the different LME-MCOs/Local Lead Agencies are applying assessments consistently and using the same definitions of what is sufficiently community based. There must be geographic, waiver type, and setting consistency to ensure the accuracy and integrity of the data collected and any future analysis or implications. We remind the State, as the single state agency, it is ultimately responsible for compliance with Medicaid regulations. We encourage the State to maintain control of the State Monitoring Review Process.

(2) **Lack of Transparency in Assessment Process.** It is unclear if the LME-MCO’s/Local Lead Agency’s assessment process plans will be public and open for comment. As part of the validation process, agency remediation plans, and provider remediation training, there should be both a posting of this information to the web-portal and an opportunity for public feedback. If the assessment process is all done behind closed doors, the State is turning its back on valuable information from participants and advocates about settings and how they truly function. These rules are about the individual’s experience and the State should always be seeking information about the individual’s experience, as opposed to a provider’s interpretation of the individual’s experience.

(3) **Incorporation of Assessments into an Ongoing Process.** Assessments of an individual’s experience are necessary. There must be ongoing compliance mechanisms that are focused on the experience of the individuals. The person centered planning process is an ideal opportunity to gather information about an individual’s current experiences, whether changes are necessary to their setting or services to meet the rule, or whether the settings need changes. This assessment should be done without the current provider being present so as to ensure the participant is free to be honest about their experience in that setting. This information can be
passed along to provider retention and be used as part of the provider’s next evaluation before licensure renewal to determine if they are in compliance.

(4) **Clear Identification of Current Providers.** The transition plan should identify the types of providers currently receiving HCBS funding, the services provided, sites at which services are provided, and the number of individuals served by this type of provider. This information should be publicly available as it gives the public an opportunity to provide information to the state about specific settings.

(5) **Use of Objective Criteria to Identify Isolating Settings and Assessment Accuracy.** In order to comply with the new rule’s requirement that the settings not be clustered together or have the effect of isolating participants, the transition plan should include objective criteria, such as the use of geographic analysis or other indicators (e.g., placement in industrial zones or proximity to other institutions), to flag potential problem settings. Other states are using GIS mapping or other information to identify such settings, including the extent to which the settings are close to community facilities such as mechanisms of public transit, schools, and local businesses. In addition, other states are using data sources, such as National Core Indicators to help determine whether, in a broad sense, the assessment results are valid.

(6) **Rolling Enforcement of Setting Compliance.** The transition plan must ensure stability for individuals and not decrease their community interaction. If the plan does not provide that enforcement of setting compliance will occur on a rolling basis, there is a strong chance that setting compliance will bottleneck and there may not be enough alternatives developed as participants need new settings. The transition plan should tier provider compliance and begin compliance early so there will be sufficient time to identify the needs and to develop new providers. Not knowing when individuals may begin to change services or if there will be sufficient alternatives available creates uncertainty and fear that may be detrimental to stability in the community.

(7) **Choice of Settings.** The HCBS rule requires that individuals be provided a choice of settings, including a choice of non-disability specific settings and, in residential settings, a choice of a private unit. Many individuals and families are unaware of the current array of services that may be available, so the State must improve its information delivery in this area as well as assess the array available, including whether there are available placements. The Plan gives no indication that part of the assessment process will be an evaluation of the array of settings. People cannot be offered that choice if there is not capacity. North Carolina must evaluate its indication that part of the assessment process will be an evaluation of the array of settings.

**Day Settings**

Advocates are particularly concerned about the implementation of HCBS in non-residential or “day” services. Although not the case in our current system, day services have the potential to be powerful agents for community integration. In order for these services to realize their potential, we must make a commitment as a State to the concepts of a “meaningful day” and “employment first.” That means that each of us, including waiver participants, should have access to a meaningful day of activity and engagement, with a clear preference for integrated, competitive employment. For most waiver participants this will mean competitive employment or services designed to move toward competitive
employment. For others, it may include supports to build daily living skills, providing service to the community, or engaging with the world outside the home in other ways. The inclusion of integrated day and competitive employment is a positive step forward in working toward compliance with not only the letter but also the intent of the rule. Choosing the word “opportunities” leaves the impression that the focus is on an opportunity rather than the outcome. We urge the State not to design any system that does not focus on outcomes.

Currently, waiver participants are given few, if any, choices of activities during the day. Many HCBS participants are getting group-based day services that are not 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. Or, there is purported “community involvement” because the participants work in the backroom or stocking shelves in a store that is open to the public, but with little actual interaction with people without disabilities. In some cases, community groups visit the center as a service project. Many are never presented with the option of seeking competitive employment or learning what steps would be required before that is a realistic option. The implementation of HCBS must mean an end to this lack of choice. We recognize this will require significant shifts in the provider network and service array and urge the State to choose a path of slow and steady progress toward compliance on this front. We caution especially against reverse integration as a solution. If providers of substantially segregated services may be deemed in compliance with HCBS because they invite community groups into the segregated facility for cultural or service projects, there is no real progress toward integration and this use of “reverse integration” does not meet the intent of the rules or the mandates of Olmstead. North Carolina should be like other states that are moving away from sheltered work. To do otherwise is merely delaying changes that must eventually occur. Therefore the transition plan needs to closely examine the current day program services and establish a clear plan for moving towards integrated day activities that focus on supported and competitive employment.

**Important Participant Protections**
The State’s plan identifies very positive pieces that will protect individual participants as the system undergoes necessary reforms to meet the new rules. We offer the following comments on the State’s plans in this regard:

1. **Notice to Participants in Non-Compliant Settings.** The clarity that all waiver participants will be provided a minimum of 60 days notice if they need to change to another provider, with more notice granted in instances where residential services are being secured, is a positive aspect of this plan. Extending the continuity of care requirement that exists for individuals with intellectual and developmental disabilities to other populations ensures consistency through this process. However, we believe that at least 90 days is needed as part of this plan to ensure that sufficient time is provided to identify a new setting, especially if settings need to be developed. We speak from experience with current and former clients that finding a new setting can be a very time consuming experience, and we do not think that 60 days is sufficient, especially given the potential for system instability during this time.

Also, it is not clear that the “detailed description/notice of the process and a comprehensive listing of providers to consider for continuation of services” will be just a general list of providers that may have availability. Individuals and families have long been frustrated by care coordinators who merely hand them a list and tell them to call around to find availability. Any list provided to individuals should indicate availability and population served as well as how recently the potential new providers have been reviewed for HCBS compliance. Individuals should receive all the information at the State’s disposal to help avoid repeated disruptions in
services due to rule non-compliance. In addition, the role of care coordinator should expand to include more robust participation in efforts to match a participant with an appropriate, available provider so that individuals/families are not bearing the burden of finding another placement because their provider is not meeting the new rules. This should be a permanent change in care coordination, and during the transition process more should be done on behalf of the individual. The State should consider and plan for any enhanced rates that may need to be paid to ensure this occurs. Individuals who have been identified as possibly needing to switch providers should have individual transition plans created as soon as possible.

Specifically, the State should begin actively planning for those individuals currently in the large homes that have been “grandfathered in” to previous transition plan sections of the ID/DD waivers. These large facilities, several as big as 120 beds, need to be closely examined for compliance with the rules. More importantly, the individuals currently residing in these facilities should undergo a person centered review process that is not influenced by the current provider and be provided a transition plan if necessary.

(2) Lack of Complaint Mechanism. Although there is a list of items under Ongoing Compliance, there is no mention of a complaint process available to participants that could resolve issues of noncompliance with settings. The State should develop a process for participants to complain or raise concerns about the community nature of a setting, or lack thereof, including those settings the State presumes to be compliant with the rule. The complaint mechanism must provide meaningful feedback to the individual complaining. An Ombudsman or similar role housed at DHHS with significant knowledge and communication with each MCO would be well-suited to this task. Complaining to the case manager or care coordinator is not a sufficient mechanism if there are no standards for a meaningful response to the individual or for gathering the information to be used during provider renewals.

(3) Evaluating and Using Person-Centered Planning. The rules regarding person centered planning are already in effect, but it is positive that the State plans to continue to evaluate how that process can be improved. Advocates urge the State to fully evaluate whether the current process, particularly for the Innovations waiver participants, is truly serving the needs of those individuals and if it is really encouraging community integration. Currently the individual, family member, or provider has to actually find the necessary services and advocate for them (even when they do not always have the knowledge or ability to do so effectively). Advocates also urge the State to incorporate into the plan the use of the person centered planning process to perform an individual assessment by participants, as well as encourage the State to continue this process through the validation period and ongoing monitoring. The role of the LME/MCOs makes this a critical opportunity to gather data from individuals about their experiences and gather information about providers for future enrollment renewals.

(4) Person-Centered Planning versus Care Coordination. As stated, we are generally optimistic about the State’s plan for HCBS transition and are encouraged that the State is looking systemically at the provision of HCBS. We strongly ask that as part of this review the State look closely at the effectiveness of care coordination in helping an individual access his or her

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2 The current Innovations waiver allows participants to receive services in facilities more than 6 beds if the facility was licensed before June 15, 2001 for more than six clients at that time. The approved waiver says that the State was supposed to review individuals in such large placements, but it is not clear that this has occurred. Regardless, this review needs to be done according to the current HCBS rules and in an unbiased way. These facilities can be found on the listing of all mental health facilities, [http://www.ncdhhs.gov/dhsr/data/mhlist.pdf](http://www.ncdhhs.gov/dhsr/data/mhlist.pdf).
community. As advocates, we have been disheartened and frustrated by how care coordination functions for Innovations waiver participants and strongly believe it is a considerable impediment to community integration. This is especially true because the State does not have independent advocates or Ombudsman services available to participants to help them navigate the system, understand their rights, and help resolve any problems that arise between the participant and the LME/MCO.

No matter the expertise or intentions of a care coordinator, there is an inescapable conflict in having care coordination performed by an LME/MCO employee, especially without an independent ombudsman available to help navigate those issues. We hear time and time again from individuals and parents who characterize their experience talking to their care coordinator as talking to a brick wall. Participants and families feel that every time they ask a question, they are either told that policies do not allow that person to receive a particular service, or they are handed a list of providers for a particular service. Consequently, the individual or family member becomes responsible for locating a new provider, without any knowledge of whether that provider would serve the individual’s needs or is taking new clients. Individuals and family members distinctly feel that they do not have an advocate in their care coordinator and that the care coordinator is always going to support their employer, the LME/MCO.

As advocacy organizations and consumer groups, we are overwhelmed with requests to help individuals because “the care coordinator is doing a horrible job” or “only tells them no.” We hear from our clients, multiple times, daily, that care coordinators have provided inaccurate, misleading, or absurdly sparse information. Although care coordination may be inescapable, the State must take responsibility for ensuring that HCBS participants are actually able to access services and necessary information. In addition, the person-centered process needs to truly meet the definition and intent. The current process does not do so. We recognize that the rules seem to allow a LME/MCO to provide person-centered planning, but the State should not assume that the LME/MCOs are doing so in a way that meets the rule. The current function of care coordination does not do so, and this needs to be reevaluated. In addition, we strongly urge the State to follow the CMS guidance that independent advocacy or Ombudsman services be available at no cost to participants.\textsuperscript{3} This advocacy must be accessible and, more importantly, be knowledgeable about an individual’s rights and have clear, realistic standards for enrollee to advocate ratios. Other states, such as Wisconsin, have had such systems with good success, and we encourage the State to follow such models.

We appreciate the opportunity to comment on this plan and ask that the State seriously consider our analysis. We are available to discuss our concerns and proposals further and look forward to continuing to work with the State as the plan evolves to meet the needs of HCBS waiver participants. Please contact Corye Dunn, Director of Public Policy, Disability Rights NC at corye.dunn@disabilityrightsnc.org or 919-856-2195.

Sincerely,

Corye Dunn
Director of Public Policy

Elizabeth Edwards

\textsuperscript{3} Id. at 10-11.