March 18, 2015

Ted Dallas  
Acting Secretary of Human Services  
Department of Human Services  
P.O. Box 2675  
Harrisburg, PA 17105  

David Alexander  
Office of the Secretary  
Department of Human Services  
P.O. Box 2675  
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RE: Department of Human Services Statewide Transition Plan

Dear Acting Secretary Dallas:

The Disability Rights Network of Pennsylvania (DRN) is the organization designated pursuant to federal law as the protection and advocacy system for Pennsylvanians with disabilities. Full implementation of the new federal regulations for home and community-based waivers will give people with disabilities “full access to the benefits of community living and … services in the most integrated setting.”\(^1\) In addition to DRN’s prior comments on proposed transition plans (dated June 18, 2014; September 16, 2014; December 24, 2014; and February 2, 2015), DRN makes the following recommendations for the Department of Human Services (DHS) proposed statewide transition plan for all waivers:

**Lack of Detail.** Transition plans need to have specificity with timelines, milestones, remedial actions, deliverables, and a monitoring process.\(^2\) DRN is concerned that the plan does not contain enough detail to show how

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2. Refer to CMS, Statewide Transition Plan Toolkit for Alignment with the Home and Community-Based Services (HCBS) Final Regulation’s Setting Requirements” (September 5, 2014).
DHS will ensure compliance and thus does not allow for enough public input. More information should be included in the plan, and there should be another public comment period. Many examples of the lack of detail are included in comments below.

**Participation by People with Disabilities.** “[O]ngoing transparency and input from stakeholders”\(^3\) are needed for a successful transition.

- **Identification.** Participation and input by people with disabilities and family members are important. The plan should describe how stakeholders will be identified and who they are. (Identification # 4).

- **Implementation Materials.** The plan should identify and describe tools, systems, and other implementation items to allow for adequate public comment. Existing materials should be attached, such as the HCBS quality assurance process (Remediation Strategies). The plan should also describe the public comment process.

- **Deliverables.** The plan should state that DHS will distribute all deliverables to the public through its website, advisory groups, email, and other venues.

- **Outreach and Engagement.** The plan needs details on “[o]ngoing engagement” and “[c]ontinued engagement” (Outreach and Engagement ## 6, 7). Providing information to the Medical Assistance Advisory Committee is not enough. The plan needs a specific public information and input campaign. Training sessions, email lists, Supports Coordinator visits, local meetings, work groups, webinars, advisory groups, other public forums, and letters should be included. Accessible formats and plain and person-first language should be used.

**Identification.**

- The plan does not describe the scope of changes that will be occurring. The plan only says that a list of providers “by setting” will be developed

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 Assessment. The plan needs a systemic review of standards and settings. The plan also needs to describe how statements of outcomes will be provided to the public.

- **Standards (Regulations, Policies, Procedures).** DHS only states that by June 2015, regulations, service definitions, and other standards will be identified and reviewed, and that internal collaboration will occur to identify needed licensure changes (Assessment ## 2, 3). The plan needs to detail a systematic assessment of residential and non-residential settings standards. DHS should identify each standard and measure it against each federal requirement. The plan should ensure that standards for unlicensed settings are reviewed. Provider-owned or controlled settings requirements need to be reviewed. A statement on outcomes should identify each standard and explain how it was measured against each federal requirement for assertions of compliance to be accepted.

  o Under Assessment and Remediation Strategies for regulations, waiver service definitions, licensing requirements, and other policies, the plan should state how people with disabilities will be involved before standards become final. The plan should also specify that there will be public comment via the Pennsylvania Bulletin and, if a regulation, the regulatory review process (Remediation Strategies, # 1). Another public notice and public comment period should be provided when revisions are made to the plan.

- **Settings.** A thorough assessment of all settings is equally key. The plan should specifically list all waiver setting types under each waiver –
licensed and unlicensed, residential and non-residential, provider owned or operated – and specify that they will all be evaluated (Assessment # 1). The plan should describe methods to identify and evaluate non-compliant or presumed non-compliant settings. The plan does not contain a best estimate of compliance and non-compliance.

- The plan proposes to rely on provider self-assessments (Assessment ## 5, 6). Self-assessment should not be used because it risks self-serving reports and will not adequately assure compliance. Further, the plan does not contain methods to verify these self-assessments, including self-reports of compliance (Assessment ## 7, 8).

- The plan references “Provider Self-Assessment Tools” to be completed in March of 2015 (Assessment # 5). The plan should identify and include these tools to allow for adequate public comment. The plan also needs to describe how the tools will align with each federal requirement.
- Methods to verify all self-assessment results should be included. A validity check is important.
- The plan states that DHS “may” do on-site visits of locations “seeming” to be non-compliant. (Assessment # 8). The plan should include a process for on-site visits of every setting, especially presumed non-compliant settings that may go through heightened scrutiny. The standard processes used to conduct on-site visits need to be included in the plan. Data collection reports should be made public (Assessment # 6).
- The plan needs to describe how DHS will engage people with disabilities and their representatives, including family members and consumer advocacy entities, in Identification and Assessment. The plan should also describe how participants, their family members, and consumer advocacy entities will be included in on-site visits as well as the tools they will use. While a “participant monitoring process” (Remediation Strategies # 3) is critical, upfront involvement by service recipients and the disability community to identify concerns and assess settings is equally critical.
Remediation Strategies. Remediation is general and vague. The plan states that Pennsylvania will “rely heavily on its existing HCBS quality assurance processes to ensure provider compliance with the HCBS rule” (Remediation Strategies). This will include “provider identification of remediation strategies” (Remediation Strategies). The plan does not include a “detailed description of the remedial actions that the state will use to assure full compliance with the home and community-based settings requirements, including timelines, milestones, and monitoring process” at the state level and at the provider level. The plan needs a robust remedial plan and needs to be updated with remedial actions that will be taken to remedy each compliance issue identified.

- Standards. The plan fails to include the existing HCBS quality assurance process or describe whether/how this process aligns with the new federal regulations.
  
  o “Documentation Changes” and “Change Licensing Requirements” are general and do not show how all regulations, policies, and other requirements will actually align with each federal requirement. (Remediation Strategies ## 1, 2). Standards for licensed and unlicensed, residential and non-residential, and provider-owned or controlled settings need to be included. The plan does not have a detailed description of the remedial actions DHS will take with respect to standards, including timelines, measurable milestones, and a monitoring process that will ensure the timelines and milestones are met. The plan does not indicate that DHS will take a sampling review after adopting new standards.

- Settings. DHS proposes to rely on providers to identify whether they are in compliance (Assessment ## 5, 6) and then allow providers to determine the corrective actions they will take (Remediation Strategies ## 5, 6). DHS should be more active in determining provider compliance and corrective action, rather than letting providers drive the process. The plan needs Remediation steps for DHS itself and stronger steps for providers. The plan should have specific timelines, measurable

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milestones, and a specified monitoring process to ensure that timelines and milestones are met.

- The plan contains little involvement by participants and family members. The “participant monitoring process” is important and should include active involvement by people with disabilities through meetings and other public forums (Remediation Strategies # 3). The plan should specify accessible methods to report non-compliance, such as a toll-free hotline, email address, Supports Coordinator visits, and other methods. (Remediation Strategies # 3). It cannot be emphasized enough, however, that for people with disabilities to report non-compliance, there needs to be widespread information, training, and education.

- The plan references “potential site visits” to verify corrective action (Remediation Strategies # 5). A paper review of Corrective Action Plans is not adequate. DHS needs to engage in a thorough remediation for all settings, residential and non-residential, licensed and unlicensed, provider owned or operated. Remediation Strategies should specifically list all setting types. The plan should include on-site visits to ensure proper remediation rather than relying on provider self-reporting. This is especially critical for settings that are presumed non-compliant under the regulations.

- The plan should provide that no new participant can get services in a non-compliant or presumptively non-compliant setting. The plan should also state that DHS will not allow new providers, provider moves, or expansion of providers in such settings. The plan, as explained below, should include actions by DHS to develop a robust community service system.

- Presumptively non-compliant settings should not remain in the system. The existing HCBS quality assurance processes

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7 Refer to CMS, “Exploratory Questions to Assist States in Assessment of Non-Residential Home and Community-Based Service (HCBS) Settings” (December 2014).
(Remediation Strategies) should reflect all federal regulatory requirements for presumptively non-compliant settings. The plan should state that DHS will evaluate and remedy all residential and non-residential settings that are farmstead or disability-specific farm communities, gated/secured communities for people with disabilities, residential schools, or “multiple settings co-located and operationally related that congregate a large number of people with disabilities together and provide for significant shared programming and staff such that people’s ability to interact with the broader community is limited.”

DHS should also carefully assess campuses that have residential and/or non-residential waiver services on the campus or next to the campus. These concerning settings exist across Pennsylvania. They isolate individuals with disabilities in an artificial environment away from the community. While some people may leave the setting for a few hours a week, often in groups, that is very limited community access. Bringing individuals from the community onto the segregated site periodically does not resolve the isolating nature of the site, either.

- The plan contains no details on the process DHS will follow and public notice to be provided to remedy presumptively non-compliant settings. The plan should also include public notice and a public process if for some reason DHS wants to ask CMS to retain a presumptively non-compliant provider in its system. DHS should do on-site visits of these settings.

- **Develop Provider Base.** The plan only states that DHS will “[a]nalyze whether access issues will be created” (Assessment # 9) and “develop a strategy to expand [the] provider base” where “access issues have been identified” (Remediation Strategies # 7).

  - The plan should include detailed steps for proactive development of a robust community system, rather than waiting for problems to arise. The system needs more compliant providers in all counties to

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8 CMS, “Guidance on Settings That Have the Effect of Isolating Individuals Receiving HCBS from the Broader Community.”
address all needs of the person. Lack of service access leads to health and safety issues and/or institutionalization. The plan should specify actions to build provider capacity so that there are enough compliant settings. Full funding for services (including startup costs and person-driven services and supports) is needed. Providers should be incentivized to develop individualized services in integrated settings and hire enough qualified, trained staff.

- The plan should define “access issues” and state how DHS will work with providers to develop services in compliant settings when “access issue” are identified. The plan should also explain how DHS will ensure that individuals do not end up without services for any period of time, in institutions, or in other segregated settings.

- Rights Protection. Remediation Strategies should state that persons who will have to transfer from non-compliant or presumed non-compliant settings will get advance, accessible notice through a phone call and/or visit from the Supports Coordinator in addition to a letter, which will ensure that this important information is received and understood (Remediation Strategies # 10). The plan needs to specify that at least 90 days advance notice will be provided.

- Transitioning. The plan contains no indication of the number of waiver participants who may have to transition to another setting. The plan should demonstrate how DHS will ensure that a person-centered planning process will provide the person with information and the opportunity to make an informed choice of alternative settings. The plan should also state that Supports Coordinators will work with participants, their family members, and the rest of the Individual Service Plan Team to 1) ensure a choice of qualified waiver providers and settings that comply with the new regulations, 2) facilitate a safe, timely transition to the new setting, and 3) assure that services and supports are in place with no gaps. (Remediation Strategies # 11).

- Public Information. The plan should describe how DHS’s data, tracking tools, reports, and notices concerning providers will be made public (some examples are: Report under Standard Review, Identification # 3;
Provider Setting Report, Assessment # 10; Provider Tracking Tool data, Remediation Strategies # 4; Statement of Findings to providers, Remediation Strategies # 8; Report of Providers with CAP/POC, Remediation Strategies # 9). Reports should include the provider, compliance status, location, services provided, waivers involved, number of participants served, and number of participants under age 21 served. No personally-identifiable or confidential information should be publicly disclosed.

- **Competitive Employment.** Transition-age youth and adults with disabilities want to seek work and work in competitive integrated settings. The new federal regulations require settings to ensure that this happens.

  - The plan should require each waiver to have a robust employment data collection system. Reports should be made public.

  - The plan should have steps to develop services, supports, and opportunities for people with disabilities to learn and build job-related skills, get training, seek employment, and get and maintain individualized, competitive employment. This includes, for example, adding to the waivers more individualized employment services such as job coaching, job searching, self-employment support, supported employment, and other services. DHS’s education of and collaboration with persons with disabilities, family members, providers, Supports Coordinators, employers, and other state agencies needs to be in the plan. The plan should also show how participants will be able to learn about work incentives and maintaining benefits while working.

  - The plan needs to demonstrate how DHS will ensure that waiver funding will not be used for settings that are not integrated, such as sheltered workshops, or to support the subminimum wage for persons with disabilities. The plan also needs to describe how any waiver-funded pre-vocational training program will have specific
timelines and measurable outcomes, and lead to customized, competitive employment chosen by the participant.9

- **On-Going Compliance.** Strong oversight and monitoring by DHS and participants and family members is important to ensure continuous compliance. The plan should specify more than the “[d]evelop[ment] [of] tools/systems within [the] established quality improvement structure” (Remediation Strategies # 12). The plan should identify and describe the Commonwealth’s oversight and monitoring process, including “tools/systems” to be developed, so that adequate public comment can be obtained. The plan should specify how DHS’s ongoing licensing and other oversight mechanisms will align with the new federal regulations. Monitoring and oversight reports should be made public regularly. The plan should include input from the disability community into the development of and revision of monitoring tools and systems.

DRN looks forward to further communication from DHS on this important matter. Thank you for consideration of these comments.

Sincerely,

Peri Jude Radecic
Chief Executive Officer

Cc: Linda Joyce, CMS
    Ralph Lollar, CMS
    Elizabeth Priaulx, National Disability Rights Network

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9 Refer to Center for Medicaid, CHIP and Survey and Certification (CMCS), “Informational Bulletin: Updates to the §1915 (c) Waiver Instructions and Technical Guide regarding employment and employment related services” (September 16, 2011).