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Illinois Department of Healthcare and Family Services
Attn: Waiver Management
201 South Grand Ave, East, FL 2
Springfield, IL 62763
Re: Statewide Transition Plan

December 9, 2016

To whom it may concern:

Thank you for the opportunity to comment on the revised Statewide Transition Plan (STP). Health & Medicine Policy Research Group's Center for Long-Term Care Reform supports a diligent implementation of the home- and community-based services (HCBS) settings and person-centered planning rule that moves Illinois toward the broadest ambitions of the rule while conscientiously responding to the real-world needs of providers, consumers, and families in the midst of significant system-level change. We regard compliance with the rule as a floor from which further progress can be made toward a more just system of long-term services and supports (LTSS).

With regard to the Aging Waiver, we would like to highlight two key issues that arise in the latest revised STP: (1) dementia care and (2) reimbursement rates. Both present long-term challenges to deeper, transformative reform, and implementation of the HCBS settings and person-centered planning rules can either facilitate that transformation or strengthen barriers to its movement forward.

Many of the heightened scrutiny sites are dementia care providers, and several adult day service providers underscored their clients' dementia diagnoses while arguing for flexibility in implementing the settings rule. The rule requires HCBS providers to optimize participants' autonomy and independence in making choices about their daily activities, and demands that they ensure participants' rights of privacy, dignity, and respect, as well as their freedom from coercion and restraint. Implementation of the rule in Illinois should take into consideration the special circumstances facing people with dementia and their caregivers. As with any other population, day centers must provide the supports necessary for people with dementia to engage meaningfully in the activities s/he chooses. Based on a participant's individually assessed needs, self-directed activities should be modified to accommodate symptoms of dementia rather than simply prohibited outright for all participants with a dementia diagnosis.

Similarly, while day centers need to have the option to restrict a participant with dementia from leaving the center, that authority should be strictly defined, and should be based on a specific assessed need described in the person-centered service plan. Simply preventing those at-risk participants from leaving the center should not be the primary goal of service provision, however, and centers must maintain adequate staffing and ensure dementia specific training to allow for individualized attention and modifications to activities to optimize the autonomy, dignity, and well-being of participants with dementia.

With implementation of this rule as a stepping stone, State agencies, day centers, and stakeholders should continue planning to create a more humane service system for people with dementia and their caregivers. Illinois is fortunate to be home to Northwestern University's Cognitive Neurology and Alzheimer's Disease Center and our neighboring Midwestern states have incubated innovative practices that we can learn from, such as the TCARE Protocol out of the University of Wisconsin, Milwaukee and the Indianapolis Discovery Network for Dementia. With such resources, the Illinois Medicaid system can face the challenge of providing quality, person-centered services to people with dementia wherever they choose to reside.

Although the goal of the rule is to support reducing the institutional bias in long-term services and supports, it is important to recognize the simultaneous changes demanded of nursing facilities. To the extent that States can coordinate implementation and oversight of the HCBS rules with the September 28, 2016 revised nursing facility regulations that required changes to assessments, care planning, and discharge planning, we can ensure system-wide reform for all LTSS participants, especially those with dementia.

Rate reform will need to be part of any larger plan to improve dementia care and other long-term services and supports, beyond compliance with this rule. The revised STP includes several references to rates, including this commitment to rate reform:

“Relatedly, to ensure that rates remain appropriate for the services provided through its HCBS programs, the State will continue to evaluate, rebase, or negotiate its provider rates as required by commitments made in its HCBS waiver agreements with CMS.”

In response to comments, the State acknowledges that, “reimbursement may need to be addressed on a separate track.” While we recognize that compliance with a federal rule cannot be made contingent on appropriations from the Illinois General Assembly, we offer these recommendations to prepare for rate reform decisions that we believe are necessary:

- 1) Track the costs of administration of the new rules and the cost of changes necessary for Category 4 sites to become compliant and use that data to inform future rate reform.
- 2) Compile skill sets, core competencies, training and experience requirements needed for person-centered planning and complying with rules related to privacy, community integration, and participation, etc., noting distinct needs for different populations (Intellectual and Developmental Disabilities, dementia, for example). Quantify the costs associated with hiring, training, retaining, and continuing education of staff that fulfill those requirements and use that data to inform future rate reform as well.

Collecting and analyzing this data will give the State an honest picture of the costs of operating a person-centered HCBS system and better prepare it to tackle the complex problem of rate reform. Similar rate reform processes will be necessary to carry out the intent of these new rules for other HCBS waivers, including funding to increase direct service professionals' wages and benefits.

Just as with the Aging waiver, these new rules create a floor for Illinois' other HCBS waivers to build toward becoming more person-centered. Health & Medicine supports The Arc's proposals to include new service definitions for Individual & Residential Community Support Services and Supported, Individual & Customized Employment Services in the Adults with Developmental Disabilities waiver. We also support the suggestions from the Illinois Chapter of the American Academy of Pediatrics and The Arc of Illinois Family-to-Family Health Information Center to streamline and improve State administration of waiver programs for children and youth with special health care needs who have disabilities and/or chronic illnesses currently receiving any type of services/supports from DHS and HFS.

Health & Medicine supports continued implementation of the rules on HCBS settings and person-centered planning and we hope that the statewide transition plan for compliance will be a stepping stone on Illinois' path to more person-centered, outcomes-oriented, and cost efficient services for all participants in long-term services and supports. Thank you for your efforts to respond to stakeholder concerns with the transition plan. We look forward to more opportunities to partner with state agencies and advocates to improve access to quality services across Illinois.

Sincerely,

A handwritten signature in black ink, appearing to read "S. Post". The signature is fluid and cursive, with the first letter "S" being particularly large and stylized.

Sharon Post
Director, Center for Long-Term Care Reform
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