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Achieve with us.

For people with intellectual and developmental disabilities

Massachusetts' Statewide HCBS Transition Plan
Testimony to the Commonwealth
November 6, 2014

Thank you for the opportunity to testify on the "Federal Rules for Home and Community-Based Services (HCBS) Waivers" including both the transition plan and the new policy developed by the Department of Developmental Services (DDS) and the Executive Office of Health and Human Services (EOHHS). Time doesn't permit us to comment on elements of the plan related to the other waivers, which are held by the Commonwealth. I want to commend the leadership at DDS for the work they have done in a relatively short time. It is a significant undertaking.

The Arc of Massachusetts has been the leading advocate for those with intellectual and developmental disabilities for nearly 60 years. We represent 200,000 constituents and their families. Over the past decades we have played a key or leading role in the critical advances for our constituents whether in education, waiting lists or transition to adult services. We hope that our comments are accepted in the constructive manner in which they are shared. We stand ready to work collaboratively with the administration on the full implementation of the new CMS rule.

I. Discussion

No state in this country can probably meet the conditions of the new regulations which will govern the approval by the Center for Medicare and Medicaid (CMS) of existing and new plan amendments or waivers for home and community based services. That includes even the state of Vermont, which has consistently aimed to develop individualized options for its relatively small population. For CMS, in adopting its new

regulations, has developed standards that are based on the Americans with Disabilities Act (ADA) and L.C. vs. Olmstead ruling (Olmstead).

CMS has implemented regulations that will challenge our home and community services to offer supports at the most integrated level possible. It is a challenge to state officials, provider leaders and advocates alike. In one of the responses to the comments on the first draft of the new rule, CMS regulation authors state: "We believe the most effective and consistent way to assure that individuals receiving Medicaid HCBS, regardless of age or type of disability, are offered HCBS in the most integrated setting appropriate to their needs and preferences, is to focus on the qualities of 'home' and 'community' that assure independence and integration from the perspective of the individuals. We will provide additional guidance to states to identify any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS."

In other words, we [CMS] have taken the positive and instructive approach based on the ADA, but stay tuned; we [CMS] may be offering additional guidance on what is NOT acceptable.

It is ironic that these regulations were released only months before the passage of the "Real Lives" bill. One can argue that the new rules reflect the very essence of the goal of "Real Lives" (Chapter 255 of the Acts of 2014). The CMS authors noted at another point in their discussion of the rule: "We believe the requirements we are finalizing are critical to ensure that individuals have the opportunity to receive services in a manner that protects individual choice and promotes community integration." In the final draft of Chapter 255, a clause in the House bill was removed which allowed individuals to move to a more preferred setting within a reasonable time limit if this was their desire or need. Now this clause is made moot by the new CMS rule. That is how far-reaching we believe the rule is. We do not believe the present transition plan reflects that reach.

Commissioner Howe and the Department of Developmental Services played a key role in the development of "Real Lives," which we hope will increase access to self-direction for individuals and families. It also requires a new way of "doing business" for community providers. Most providers have been aware of policy evolution but it has been hard to move ahead for a variety of reasons. But this new rule now provides impetus to all of us to work collaboratively for the future of home and community services.

Massachusetts has made remarkable progress in a variety of areas such as offering self-determination options, policies that mandate respect and dignity in the provision of supports and related elements in its survey and certification process.

Massachusetts' leaders at the Department of Developmental Services (DDS) and MassHealth also engaged in new initiatives, which encourage personal choice and development of relationships in the community. Examples include elements of the One Care program, aimed at dual recipients of Medicare and Medicaid. The program includes supports developed around individual choice. In FY'2014, DDS initiated the Employment Blueprint to transition more than 2000 people from sheltered workshop settings to integrated employment and community opportunities over a multi-year period. During the previous year, DDS initiated the Friendships project, now Widening the Circle, a partnership effort to expand relationships for those who have disabilities with individuals who do not have disabilities. Additionally DDS reviewed behavioral strategies across the state as part of an effort to develop new regulations and approaches to positive behavioral supports. The program is now in the implementation stage. During the last decade, attention has been paid to expanding shared living; supported living and adult family or foster care.

These are some examples of the Commonwealth's ongoing efforts to ensure a system which consistently reflects its regulations or policies on respect and dignity. These regulations are stated in the "General Principles" [(115 CMR 5.03 (2) (f)] and in the "Definitions" to some extent [115 CMR 7.02], such as "Residential Supports" and "Outcomes for individuals" [115 CMR 7.03, (1) (a-e)]. Having said that, there are aspects of our HCBS services and supports that require further attention and review in relation to the new rule and the state transition plan.

Over the last two decades, DDS' residential system of supports has grown significantly due to four factors:

1) A significant movement of individuals from institutions into community settings in the early 1990s, the largest exodus since the consent decrees of the 1970s;
2) Residential appropriations since 1985 (nearly annually) for an average of 200 plus high school graduates who enter the adult service system;
3) Boulet wait list settlement of 2200 adults who transitioned to community residences or related alternatives over a five-year period; and
4) Rolland nursing home settlement of approximately 1500 individuals who moved to community housing options over a seven-year period.

This growth in services was largely addressed through apartment or community residence development supplemented with the use of openings in existing residential services. This approach was considered "best practice" at the time and it was commonly used across the nation. As a result the DDS home and community-based supports are primarily invested in homes where staff support is provided, resembling a "bundled" service. The Commonwealth developed state-run homes as an outgrowth of labor agreements.

The model of "group homes" or "staffed apartments" is based on cost effectiveness while attempting to meet the individualized needs of the participants. However, these models impact choice. Each house or apartment has three common features that have ramifications for choice:

1. Peer group – who is living at the house
2. The location of the house (geography and access to resources)
3. Staffing ratio

Although there may be more flexibility with a newly developed home, the same factors apply. An opening at a home may be near one's community but the peer group may be much older. There may be a better match with peers somewhere else, perhaps two communities away but the staff ratio may not work.

The second challenge with homes and apartments is the difficulties that arise to consistently implement individualized activities that reflect one's person-centered plan. The system of homes and apartments provides quality in terms of safety, health and respect for the individuals it serves. But we have more work to do to accomplish choice and integration given the model of supports. It is far easier to have staff go with two or three people living at a house, than actually tailor a schedule that allows each of 4 or 5 persons in a single home to do "their own thing" even three times in one week.

We have a long way to go in Massachusetts and the nation to meet the bar that CMS has set, a bar that reflects the ADA and Olmstead decision. Reaching that bar requires systemic change and an evolution in the design of the service system. Very small population states may find the transition easier if they have already invested resources in the community, but most states will require a longer review period, the development of a strategic plan and a multi-year transition which could extend past 2019. Home and apartment models will have a role in the future design but it is unclear at what scale.

The new rule requires a longer evaluation period to ensure that there is a thorough review of adjustments which may be required of present practices and proposed changes of the system to be consistent with the new rule. Some of the specific challenges in the new rule include:

1. Optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to daily activities, physical environment, and with whom to interact. [441.710, (a) (1) (iv)]
2. Independent and qualified agent [as in 441.720 (a) 1, also see 441.730, (b) (5)]
3. The person centered plan is driven by the individual [441.725 (a) (2), (6) and (8) (B)], and,

4. Ensuring that the personal representative is able to also lead the person centered planning process when the individual him- or herself is unable to do so due to communication limitations [441.735 in general and (b) specifically]

II. Recommendations for Changes in the Policy and Transition Plan:

A. Home and Community Based Settings Policy

The Arc of Massachusetts supports the DDS policy but recommends:

1. At the end of "Section D," include reference to individual representative: "The individual has the right to involve an individual representative in the process of exercising one's choice or one's rights; and this representative may be a parent, a family member, an advocate for the individual or other person as self-evident or identified by the individual."

B. Transition Plan

1. DDS review implementation of the individual supports plan regulations and policies with stakeholders, including but not limited to:
    a. Review of common deficiencies related to rights, choice and relation aspects in survey and certification reports
    b. Review NCI (national core indicators) results in Massachusetts in the same categories as recommendation "a"
    c. Hold three to five focus groups of those in residential services to ascertain constituent satisfaction with choice in residence, general satisfaction with the ISP process, actual implementation of ISP documented desired activities at HCBS setting, and other exploration relative to choice, autonomy and initiative
    d. Include in the review any additional barriers to integration faced by those with behavioral challenges or complex medical conditions
    e. Report on what factors or variables at agencies seem to increase or are related to higher incidences of integration
2. Review transportation services specifically and their impact on choice of work and personal activities; What barriers exist? Are there trends in these barriers?
3. Expand supported living and shared living options to ensure maximum flexibility of HCBS options for individuals.
4. Assessment of the competence/skills of staff to assist individuals on inclusion or community integration. A small random study could be utilized or other surveying of constituents and individual representatives.

5. Evaluate consumer financial capacity for integration – do individuals have the resources to attend community outings, some of which cost money for attendance? Should monthly client contribution levels be reviewed?
6. Review and address potential conflict of interest between agents (service coordinators developing ISPs, goals, services) and funding authority of supervisors
7. Include in the plan objectives developed from exploration of items of the previous recommendations

Thank you for providing this opportunity to respond to the transition plan for the Center of Medicare and Medicaid Services. We stand ready to work with the Commonwealth on advancing supports for individuals with intellectual and developmental disabilities.

Submitted by:

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