

To: Ms. Sharon L. Summers  
Planning, Policy & Quality Unit  
Delaware Division of Medicaid and Medical Assistance

From: Kenan J. Sklenar  
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Re: Public Comments Regarding Delaware State Transition Plan

On behalf of Easter Seals Delaware & Maryland's Eastern Shore, I am submitting these comments in response to the Statewide Transition Plan for Compliance with the Home and Community Based Setting Rule. The plan was developed in response to a new CMS rule which establishes a definition of "community based" settings in which Medicaid waiver services must be delivered. Our comments specifically reflect the possible impact of the new CMS rule on adult day programs such as those offered by Easter Seals.

It is the belief of Easter Seals that the interpretation of the new CMS rule, as well as the path by which the State implements it, could significantly impact the lives of individuals served by Easter Seals both now and in the future. Because of this, Easter Seals strongly urges that a full range of stakeholders, including individuals with intellectual and/or physical disabilities and their families, be a part of the entire transition planning and implementation process so that the implications of the plan and its potential consequences on the choice of services are known. In addition, Easter Seals believes it is critically important that the cost for providing services in integrated settings deemed to be compliant with the new CMS rule must be a part of the transition plan so quality of care and availability of services are not negatively impacted.

Easter Seals provides a wide variety of services and supports to individuals with a range of disabilities and their families, including adult day programs. We currently provide approximately 1,300 adults throughout Delaware in programs under DDDS and the Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) to which the "integrated settings rule" would apply. Of those, approximately 400 individuals have chosen services which are provided primarily in congregate settings. Those services are likely the ones which would be impacted under this plan.

**Personal Choice:**

The CMS documentation emphasizes that the state's plan must maintain individual choice as the primary factor in determining what services should be available. Easter Seals fully endorses each individual's right to choose what his or her services look like. Services should reflect the individual's strengths, needs, and capabilities consistent with his or her person-centered plan. As such, the array of choices available must encompass the complete range of supports needed by individuals, including those who require intensive staffing and personal care.

For example, an Easter Seals participant who has quadriplegia as a result of a spinal cord injury when he was a teenager, attends our day program for adults with intellectual disabilities every day. It's an important part of the participant's person-centered plan that he spend a minimum of one hour out of his wheelchair each day to prevent skin breakdown from sitting in one position. Each day, it requires 2 to 3 direct support staff, utilizing a mechanical lift, to transfer him to a mat for alternative positioning. Mechanical lifts are validated as the only safe manner of lifting for many people who use wheelchairs.

Another Easter Seals participant attends our day program for adults with physical disabilities. He has a progressive neurological condition and needs two to three staff to assist him in using the bathroom in a safe manner. This person has repeatedly stated his choice to remain in a day setting where such staff is readily available when he needs them.

In addition, individuals served under the HCBS waiver have a right to make choices that assure the least risk, while affording them the opportunity for personal growth and independence.

With that in mind, Easter Seals urges that the State transition plan maintain a broad range of options in order to ensure the individuals can be served in an integrated setting most appropriate for the individual.

**Fiscal Impact:**

Easter Seals believes it must be acknowledged that it will require more funding to provide individual supports in a community setting as compared to the same service provided in a setting where services are provided to a small group of people. Current DDDS service rates are primarily based on 1:4 ratios which would not provide adequate safeguards for individuals with intense care needs. Also, transportation is a necessary support for community inclusion and needs to be considered as a part of the plan, as well as the fiscal impact of providing it. Given the fact that current services for persons with intellectual disabilities are underfunded by approximately \$33 million, according to a report completed by DDDS, the State transition plan will unquestionably require more funding to prevent the limiting of services. Easter Seals believes there is a very real danger that newly established rules without consideration of funding implications may lead to an overall reduction in the quality and quantity of critically needed services, especially for people with the most challenging support needs.

Therefore, Easter Seals urges that the State transition plan include an assessment of the fiscal impact of the transition plan on the State budget so that a plan can be developed to address it and assure that services are not limited.

**Broad Stakeholder Involvement:**

The State has proposed a process by which a lengthy process of assessments of services and settings will be conducted. In order for the process to address needs and concerns of all consumers and their families, we feel that it is critically important that representatives of all types of service recipients be involved, including individuals with the most challenging support needs. In addition to those already named in the State transition plan, this should include individuals with intellectual and physical disabilities and their families, as well as representatives from provider agencies from both residential and non-residential services. Easter Seals recommends that at least 5 to 7 individuals/family members and no less than 5 service providers should be included in the Steering Committee and subsequent work groups. These should be consumers and providers who represent a range of services in order that varied support needs are considered. In our experience at Easter Seals, consumers and their families welcome our involvement in the conversation based on our intimate knowledge of their preferences and needs, as well our experiences in providing the supports they need.

In summary, Easter Seals welcomes the continued opportunity to work with the State in delivering community services of the highest quality in the most integrated setting appropriate based on a planning process focused on individual's strengths, preferences and needs. As one of the state's largest providers of adult day services, we believe it is our solemn responsibility to assure that the rights and needs of all of the people we currently serve are considered as well as those who will need services in the future. In addition, we believe attention to the fiscal implications of the State's transition of services must be a part of the plan. Thank you for this opportunity to provide input to this process.