



Governor's Advisory Council for Exceptional Citizens (GACEC) 516 West Loockerman St., Dover, DE 19904
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DMMA Proposed DDDS Lifespan Waiver Renewal Regulation [22 DE Reg. 697 (February 1, 2019)]

Dear Mr. Williams:

The Governor's Advisory Council for Exceptional Citizens (GACEC) has reviewed the Delaware Health and Social Services/Division of Medicaid and Medical Assistance (DHSS/DMMA) proposal to renew the Division of Developmental Disabilities Services (DDDS) waiver that has been in continuous operation since 1987. Council would like to share the following observations based on our initial analysis.

First, shared living arrangements (SLA) and community living arrangements (CLA) are not licensed by any health care organization. Neighborhood homes are licensed by the Division of Health Care Quality (DHCQ). SLAs are "credentialed" by DDDS but hands on, direct oversight is minimal. Council queries whether it is safe to allow skilled nursing services to be provided by individuals who are not licensed or overseen by agencies with experience in the provision of health care services?

A later section of the document indicates that in SLAs that provide Medical Residential Habilitation, the provider must be a registered nurse or an advance practice registered nurse. Council would like additional information on who is providing medical supervision to these nurses or to nurses in other settings. The language suggests that the providers are responsible for overseeing health care. Do the providers have medical directors or a doctor on staff who will provide supervision? If not, who is providing supervision to the medical aspects of care? In the CLA or SLA setting, who is supervising the medical aspects of care?

The waiver language indicates that nurses providing services in Medical Residential Habilitation "demonstrate the ability to work with individuals with ID/DD with a wide range of intensity of

support needs.” There is no discussion of who assesses for this degree of experience nor is there an indication that DDDS will develop specific credentials for these nurses.

Provision of this skilled nursing services will enable some individuals with intellectual disabilities to live in more integrated settings by providing skilled nurses in non-nursing home settings; however, it is vitally important for there to be sufficient oversight of the care that is provided in these settings. The waiver renewal document does not contain very many details on how this will be achieved. SLAs and CLAs should be a particular source of concern because they are not licensed by a health care agency.

The waiver states that Residential Habilitation service can be provided out of state. The language indicates that DDDS remains responsible for assuring the health and welfare of out of state placements even when onsite monitoring is being done by the local authority. Council would suggest that DDDS have an articulated robust policy regarding oversight of residents placed out of state.

There is language that indicates that “individuals under 21 must access services through EPSDT before the waiver can be accessed.” Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services do not always cover residential services, especially for those who do not carry a behavioral health diagnosis. How are children and youth under 21 to access this service through the Lifespan Waiver? DDDS must recognize that it has a role in providing services to individuals under 21 with ID/DD. EPSDT services often lack care coordination and may not always be a source of comprehensive services for young people with ID/DD.

Language has been added to allow payment for generators as a home modification under the waiver. Additional language clarifies that providers of this service need to be bonded, insured and have all necessary permits and licenses required by trade. They must also provide a one-year warranty for any work done. Council endorses these proposed changes.

Council appreciates the fact that the waiver was substantially amended to include services for individuals living in family homes since it historically only serviced individuals living in residential placements. This is a step in the right direction.

Please feel free to contact me or Wendy Strauss at the GACEC office if you have questions on our comments. Thank you for the opportunity to share our observations with you.

Sincerely,

Ann C Fisher

Ann C. Fisher
Chairperson

ACF: kpc