



Governor's Advisory Council for Exceptional Citizens (GACEC) 516 West Loockerman St., Dover, DE 19904
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October 28, 2024

Vicki Schultes, Hearing Officer
Division of Public Health
417 Federal Street
Dover, DE 19901

RE: 28 DE Reg. 276 DHSS/DPH Notice Regarding Inherited Metabolic Disorders Regulations (October 1, 2024)

Dear Ms. Schultes:

The Governor's Advisory Council for Exceptional Citizens (GACEC) has reviewed the Delaware Health and Social Services/Division of Public Health (DHSS/DPH) proposal to repeal Regulation 4103 Inherited Metabolic Disorders. Council would like to ask DHSS/DPH to provide data on use and funding for this program over recent years and whether there are any current participants. Council would also suggest DHSS/DPH republish this proposed rulemaking with such information prior to taking the action of repealing the regulation, so that the public is truly informed in order to provide meaningful public comment. Council asks that information about alternatives be given to anyone who is using this program and requests information on the steps DHSS has taken to ensure that participants have actually received alternative means for this nutritional assistance. Council urges the DPH to seek funding through the State budget process if participants are not otherwise getting this nutritional assistance and to maintain this program. If that is not possible, the GACEC strongly expresses our concern and recommends that DHSS and DPH take the steps mentioned above to prevent or lessen any disruption to the current participants or to those individuals who could participate if the program was not defunded.

Rather than repeal Regulation 4103, Council believes the regulation should remain in the Delaware Code. There are a number of reasons that can be advanced to maintain the regulation. First, is that assistance under the regulation is dependent upon funds being appropriated by the General Assembly. (6.3). By its own terms, the regulation is self-limiting. If no monies are appropriated, no assistance will be provided. There is no need to repeal the regulation because there are no funds. There is also the possibility that the General Assembly could act and provide appropriations this term or in the future. Further, the DPH could seek funding through the State budget process.

Further, and perhaps more importantly, is action taken by Congress. On December 22, 2023, H.R. 6892—Medical Nutrition Equity Act of 2023 was introduced in the House of Representatives and was referred to several committees. The stated purpose of the bill is “[t]o

provide for the coverage of medically necessary food and vitamins and individual amino acids for digestive and inherited metabolic disorders under Federal health programs and private health insurance, to ensure State and Federal protection for existing coverage, and for other purposes.” The bill would amend, inter alia, the Social Security Act and provide coverage under the Medicaid Program. If the bill becomes law and coverage is mandated under the Medicaid Program, already having an existing regulation in effect about inherited metabolic disorders would greatly benefit children who could again participate in the program.

If DPH does repeal Regulation 4103 and the introduced legislation is not enacted into law, the primary concern becomes what happens to those individuals who are currently enrolled in the program and are receiving the specialty formulas. There is no indication from the public notice whether the funds have been totally exhausted or, if they have not yet been exhausted, when they will be.

Council notes that there are other relevant questions. Have the participants been notified? Have DHSS and DPH taken any steps to segue individuals currently receiving the specialty formulas into a Medicaid program such as the Children’s Community Alternative Disability Program (CCADP) so that their dietary treatment plan is not disrupted? If not CCADP, is Long-Term Services and Supports (LTSS) a consideration and possibility? To prevent a possible disruption or discontinuation of the specialty formulas, DHSS and DPH should establish policies and procedures to expedite individuals currently in the inherited metabolic disorders program into these other programs.

Another question to address is what happens to those individuals who are eligible for the inherited metabolic disorders program but will not be able to participate and receive the specialty formulas because the regulation was repealed and the program terminated. Like individuals currently in the program, DHSS and DPH should determine if these individuals qualify for the specialty formulas under the CCADP or LTSS and streamline their entry into those programs before repealing the program.

Thank you for your time and consideration of our request for information and request that the program not be repealed until additional information is provided. Please feel free to contact Pam Weir or me should you have any questions.

Sincerely,

Ann C Fisher

Ann C. Fisher
Chairperson

ACF: kpc