



Governor's Advisory Council for Exceptional Citizens (GACEC) 516 West Loockerman St., Dover, DE 19904  
302-739-4553 (voice) 302-739-6126 (fax) <http://www.gacec.delaware.gov>

May 7, 2012

The Honorable Matt Denn  
Lieutenant Governor, State of Delaware  
Carvel State Office Building  
820 N. French Street  
Wilmington, DE 19801

Dan Rich, Chair  
Delaware Early Childhood Council  
University of Delaware School of Public Policy & Administration  
184 Graham Hall  
Newark, DE 19716

**RE: Purchase of Care Program for Children with Disabilities**

Dear Lieutenant Governor Denn and Mr. Rich:

The Governor's Advisory Council for Exceptional Citizens (GACEC) would like to address an issue which was recently brought to our attention during a GACEC Infant and Early Childhood Committee meeting discussion. It is Council's understanding that in Delaware, children with disabilities have previously been eligible for Purchase of Care (POC). It is now apparent that parents of children with disabilities are no longer eligible for Purchase of Care, especially if the child's parents are not currently employed. Council understands that the Child Care Subsidy Program known as Purchase of Care option for children with disability was changed in the regulations during the most recent revisions so now children with disabilities have to meet an income guideline or be in DFS custody. Council has received feedback from parents and advocates in the disability community stating that the system is difficult to manage, especially if one does not know the correct questions to ask. This is especially disheartening when one considers the fact that parents of children with disabilities are often already overwhelmed by the many facets of caring for

their children every day. The last thing these parents need is to add a systemic pitfall to their already overstressed lives. The GACEC has also been informed that for parents who are currently working and have a child with a disability, there is a possibility of funding to provide support, but that this is not always the case. The GACEC would like clarification on the current eligibility requirements.

Council would like to share the following case scenarios which have recently come to our attention:

Concerning a young child who is legally blind and has separation anxiety and anxiety issues in crowds or in strange places: The child's mother and the school district representative agree that the child should be in a pre-school or day care setting with no more than five to six children. The child currently attends a home day care and is doing well. However, Purchase of Care will not cover funding for this setting because it is not a certified home day care. The family has to pay full price to keep the child in this day care, even though unemployment and lack of income are major concerns for this family.

Another case involves a young child who was adopted by their foster care family. The child has a chromosomal abnormality and chronic health issues. The family also cares for four children from the Foster Care System who are all under five years of age, including a set of twins who have chronic severe reflux and viral infections. The family was denied Purchase of Care because the foster mother must be employed or attending school to qualify. Medicaid will pay for the young child to attend a Prescribed Pediatric Extended Care facility for two hours per day. However, by the time the children's mother prepares the children for their day, assists them into the car and drives all of them to and from the care facility (which only one of these four children attends), the trip hardly seems worthwhile for a two hour stay.

Yet another case involves a young child with global developmental delays and stranger anxiety. The child clings to the mother and won't separate from her. The Licensed Clinical Social Worker visits this child and family weekly. The family requested day care for two days per week, but was denied because the mother is not working or attending school. The child's behavior has now progressed to head banging and is getting worse. There are no openings in Early Head Start for the child.

Concerning a young child with genetic concerns and in need of therapy: This child lives with a Guardian. The Guardian was in an automobile accident and is having difficulty caring for the child due to her injuries. She was denied Purchase of Care. This particular Guardian is willing to discuss her situation.

Another case involves a young child who is globally delayed and has vision and hearing issues. This child was recently adopted. Once the adoption was finalized, the Purchase of Care stopped. The day care was doing a wonderful job with the child. The day care setting provided time for the child to be with his/her typical peers and the opportunity to model their behavior. Purchase of Care was denied in this case because of the adoptive parents' income.

Consider the case of a young child who has therapy needs. The child's mother is in the end stages of renal disease and is in need of dialysis three days (or more) per week. This family is able to receive Purchase of Care three days per week; however, no day care facilities will accept the child for only three days per week. The child has therefore been left in the care of different friends at

different times. As a result the child has lost funding for his therapies, due to non-compliance caused by the constantly changing location of his care.

As a final example, consider the case of the young child with a gastrostomy tube and poor weight gain. The child's mother lost her job and is not enrolled in school. Purchase of Care is not being provided since the mother lost her job.

As you can see from these case scenarios, there appears to be a broken link in the current system. Council would like the opportunity to sit down with you to discuss how we can assist in making the appropriate changes. Please feel free to contact me or GACEC Executive Director Wendy Strauss at the GACEC office (302-739-4553) so that we may schedule an appointment to discuss this in more detail.

Thank you in advance for your time and consideration of our request.

Sincerely,

Janet Cornwell, Chairperson  
GACEC Infant/Early Childhood Committee

CC: The Honorable Rita Landgraf, DHSS  
Patricia Quinn, Office of Child Care Licensing