

Delaware Developmental Disabilities Council

Margaret O'Neil Building, 2nd Floor
410 Federal Street - Suite 2 Dover, Delaware 19903
Phone: 302.739.3333 ♦ Fax: 302.739.2015 ♦ Website: www.ddc.delaware.gov



Statement from the Delaware Developmental Disabilities Council to the Delaware Health Care Commission on the Benchmark Plan of the State Health Insurance Exchange August 2, 2012

Dear Chairperson Riveros and Members of the Delaware Health Care Commission,

The Developmental Disabilities Council (DDC) thanks you for accepting our comments on the planning of Delaware's insurance exchange. The DD Council considers benefits for a broad range of disabilities and from that perspective will comment on the items added to the benchmark plan as required by the Patient Protection and Affordable Care Act's defined essential health benefits (EHBs). We do realize the tremendous amount of work that the Commission has completed thus far on this Exchange and we thank you for the diligence and commitment that has been shown by all of you.

The EHBs of greatest relevance to our families are:

- Mental health and substance abuse disorder services, including behavioral health treatment
- Rehabilitative and habilitative services and devices
- Pediatric services, including oral and vision care, including pre-existing conditions
- Breast cancer screenings and other cancer screenings
- Accessible emergency services
- Prescription drug coverage
- Preventive and wellness services and chronic disease management

As you are probably aware, historically in Delaware and other states, mental health treatment and substance abuse disorder services have been sorely lacking and almost impossible to access for the general population with even less access for people with dual diagnoses with intellectual disabilities. We anticipate that with parity and your commitment towards quality care and treatment for all who may need this type of health treatment that access will no longer be an issue and that all Delawareans can expect their "health care" to include their mental health and that the benchmark will reflect that commitment.

The phrase "behavioral health treatment" was added to the EHBs by Sen. Robert Menendez of New Jersey to ensure that behavioral therapy for autism would be nationally available. Applied Behavior Analysis, the best studied and proven form of behavioral treatment for autism, can cost tens of thousands of dollars per year for the most severely affected children, and is not available through Medicaid's Disabled Children's Program. ABA has been shown to significantly improve function and reduce need for supports-improvements that may go so far as to cause a child to lose their diagnosis and enter mainstream schools without special education services- in half of children receiving the therapy. It is very rare for an insurer to include such coverage, and so it is unlikely to be found in a potential benchmark plan at this moment. However, we take the firm position that federal, and soon state, law require it be offered.



We also strongly urge that the benchmark plan recognize that people with autism and other disabilities need habilitative services and devices as called for in the EHBs. Treatments such as physical, occupational, or speech therapy are generally included in health plans but often excluded when used to treat autism and other existing disabilities. Federal employee plans do cover at least speech and occupational therapies, and we would strongly urge Delaware to choose one of those plans to most thoroughly cover children and minimize the cost to the state. In contrast to ABA, children with autism who are eligible for the Disabled Children Program under Medicaid can generally get these services covered through that program.

Autism treatment should be considered a crucial part of pediatric services. Autism now affects 1 in 88 children nationally, up from 1 in 150 five years ago, and up from 1 in 2500 in 1995. Delaware's public schools have seen a 546% increase in children with an educational (but not necessarily medical) classification of autism since 1991. The Centers for Disease Control has identified autism as "an urgent public health concern."ⁱ

Including oral and vision care in the Pediatric Services benefit is essential for good overall health care. We would encourage the state to seriously consider adding oral health care for adults to the list of essential health benefits or, at a minimum, to the list of mandated health benefits. As is described in the literature pre and post Affordable Care Act, one of the most important indicators of good overall health is good oral health. Because Medicaid does not cover oral health care for adults with disabilities, this population of people is often left with minimal or no oral health care which causes secondary overall health problems that carry with them a lower quality of life and higher costs to the health system as a whole. It makes good fiscal sense to add this benefit in Delaware.

Historically, as well, people with disabilities have not had access to cancer screenings, including breast cancer screenings for women and men. The system did not find it necessary to screen for these cancers for this group of individuals, or, if the opportunity presented itself, if the person had a physical disability that prevented them from standing, the equipment and environments were, and still are in a lot of cases, not accessible for them. We ask that the essential health benefit for cancer screenings ensure that people with all disabilities gain access in every sense of the word to this benefit on a routine basis.

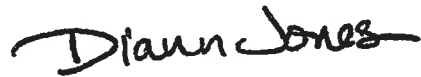
As with most other health treatment, the disability community has found emergency rooms, services, and other health provision to be non-accessible, in environment, equipment, and services. Please remain cognizant when choosing the benchmarks that accessibility in this day and age is still a barrier and ensure that the benchmark removes that barrier.

The Centers for Disease Control (CDC) has recognized that preventive care and wellness services and chronic disease management can enhance the quality of life for everyone, enhance the health of everyone, and lower the costs of health care for everyone. Over the past several years the CDC has granted funds to Delaware to bring awareness of the importance of these issues and to advocate for system change in this area, in particular for people with disabilities, through the Center for Disability Studies (CDS) at the University of Delaware. The CDS has issued annual reports on the research that they have done in Delaware and the steps that they have taken to bring systems change in a collaborative fashion with the Division of Public Health and other state and non-profit agencies. We anticipate that you will consider this information when choosing the benchmark for this particular area and choose a benchmark that will be sensitive to the needs of people with disabilities.



The Developmental Disabilities Council thanks you in advance for your consideration of our comments and we hope that should you need further information or assistance with your decisions that you will contact us at your convenience.

Sincerely,



Diann Jones
Chair

cc. Center for Disabilities Studies
Autism Delaware
State Council for Persons with Disabilities
Governor's Advisory Council for Exceptional Citizens

<http://health.usnews.com/health-news/blogs/on-parenting/2009/12/18/autism-called-urgent-public-health-concern-1-in-100-children-affected>

