

**State of Connecticut**  
GENERAL ASSEMBLY



**PUBLIC HEALTH COMMITTEE**  
LEGISLATIVE OFFICE BUILDING, ROOM 3000  
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**Task Force to Study Rare Diseases**

Meeting Summary

March 31, 2017

Dr. Gulati convened the meeting at 10:05 AM with introductions of the Task Force members.

Members Present: Dr. Mridu Gulati, Lesley Bennett, John Morthanos, Lynne Sherman, Dr. Brian Smith, Dr. Michele Spencer-Manzon, and Michelle Cotton

Dr. Gulati stated that last month's Rare Disease Day on February 28th was a great success and it was very well attended by members of the public. NORD was the US sponsor for the event and this year's theme was research. Several diseases were featured like narcolepsy, PKU, glycogen storage disease hemophilia. She added that back in 2015 a bill was passed establishing a task force for rare diseases to look at the need for a permanent rare disease advisory board. Due to the delays in starting that taskforce, a new bill was introduced by Rep. Kim Rose to establish a new task force in 2017. Our first meeting was held on 2/24/17 and currently we are trying to advance the existing Task Force reporting period and potentially appointing other members to the Task Force.

Lesley Bennett stated that she asked the Public Health Committee to make technical changes to extend the Task Force current reporting period and add a requirement for Connecticut General Assembly members to be appointed.

Task Force members introduced themselves and Dr. Gulati introduced Dr. Zavoski, Medical Director of the Department of Social Services.

Dr. Zavoski stated that the Medicaid program was created in 1965 as an afterthought by President Johnson to get additional votes to pass Medicare. President Johnson did not have a way to fund Medicaid long term and there is still debate on how to fund Medicaid today.

Medicaid is a state federal program where the federal government sets the rules and the state implements the law. Medicaid programs vary from state to state but typically include people with certain health issues or meet the income requirement. In Connecticut

there are approximately 780,000 members or 22% of the state's population. The state's current model is unique in that they have a self-insured program that moved away from a managed care program.

Connecticut has four Administrative Services Organizations (ASOs) which administer the Medicaid Program. They are Community Health Network of Connecticut, Beacon, Benecare and Logisticare. The benefit of the Connecticut program is that there is one set of claims data that the state uses to do predictive analysis to identify cost trends and determine quality of care provided and identify existing high risk populations and potential high risk population.

Medicaid does not cover cosmetic care and experimental care. Under the Affordable Care Act, the state increased its medical payouts to doctors to get more people into care.

Medicaid covers prenatal screening, genetic testing and rehabilitation.

Dr. Zavoski stated that most needs of parents with children of Rare Diseases are covered. He further stated the Department has claims data but the issue with that is that the claims are only submitted to get paid and therefore are often incomplete and does not tell you what is really needed.

Dr. Gulati opened the meeting up to questions from the Task Force regarding Medicaid, diagnosis, treatment, testing, and the transition from children to adult care.

Lesley Bennett asked if there are special medical homes for children in the state.

Dr. Zavoski stated that the state provides medical homes for all people of all ages. There are 100 practices and 1000 providers that cover medical home care. These homes cover 45% of the state's Medicaid membership. The state pays extra for medical homes and tries to recruit practices into medical homes. The state requires these homes to have a plan in place for children when they transition to adults.

Lesley Bennett asked how many kids from the medical homes are sent out of state for care.

Dr. Zavoski stated the medical ASOs work in conjunction with the Department of Social Services to accomplish that task because it requires great logistics. The state sends many patients to Boston but Baltimore is a bit more of a challenge to do.

Lesley Bennett asked if enzyme replacement therapies are covered.

Dr. Zavoski stated that the state does cover enzyme replacement therapies. The 1990 Omnibus Budget Reconciliation Act requires Medicaid program to only pay for medications from manufacturers that participate in the Medicaid Drug Rebate Program. Therefore if there are only two brands of an enzyme replacement program therapy and only one manufacturer participates in the program that is the one that is covered. If there is only one drug available then Medicaid will pay for it.

Lesley Bennett asked what types of waivers are available for patients.

Dr. Zavoski stated he is not the person to provide specific details on the waiver programs. He stated waivers are used to waive parts of the Medicaid Act and the federal government in turn will require certain requirements usually to cost the government less money. There is a 19-15b waiver that allows the use of managed care companies. The Katie Beckett waiver provides care management for children. The federal government

sets the total number of slots available for these waivers. Connecticut currently has 200 Katie Beckett slots available and a waiting list that takes 2 years to get on.

Lesley Bennett asked if there are any waivers for PKU patients who are past the age of thirteen so that parents do not have to pay out of pocket for this expensive food.

Dr. Zavoski stated he could not answer the question but said at a future meeting he could bring Kathy Bruni who is an expert on waivers.

Dr. Smith asked how the program stays financially viable in the face of limited funds and avoids further cuts in the reimbursement rate. He also questioned if Medicaid is efficacious and effective for patients in it and if they receive the care and treatment they need. He further stated that there is debate if the overall health outcomes of Medicaid patients are any better than the uninsured. Lastly he asked if medical service organizations should instead block grant money to the various hospitals within the state and let them develop the programs patients need.

Dr. Zavoski stated that the per-member cost of Connecticut Medicaid has trended downward in the past 3 years. Primary and preventive care makes a big difference. Connecticut has been incentivizing the use of preventive dental care for 10 years, causing the cost of dental care to plummet. Whether Medicaid is unsustainable depends on the lens used. Nationally the driver of healthcare insurance cost is commercial insurance. While Medicaid has been driving the cost down, Connecticut has also increased access to primary care. As for as block granting, the Department and state are having discussions about it and are open the discussion.

Lynne Sherman stated that the impact of the increase of access for primary care and preventive care were very beneficial for the state and patients. She further stated that children with Rare Diseases despite being a small number are high utilizers and high expense for hospitals and the state.

Dr. Tucker asked what the future looks like and how the progress has been improved upon.

Dr. Zavoski stated he was hesitant to answer the question because he was unsure what the federal government will do. If the federal government Block Grants Allocations for Medicaid and with the way Connecticut has managed its programs, it will result in the state having to close a deficit in the hundreds or millions of dollars. The state currently runs a lean program with an overhead cost of 3.5 percent compared to Kaiser in California at 11.5%. For the state to cover a deficit of that size, it will require difficult decisions. Dr. Zavoski further stated that kids are 90% of Medicaid patients in most states yet require 10% of the cost. Adult care is very expensive and that's where the discussion should focus.

Lynne Sherman asked how many mental health providers participate on Medicaid.

Dr. Zavoski stated he did not have a number but is aware that there are challenges with access to mental health providers.

Lynne Sherman stated that certain states have issues getting reimbursements to parents for food and asked if that is the case in CT.

Dr. Zavoski said that should not be true. When it comes to medical foods Connecticut does not have those same issues. Based on the states definition of need if need is identified then the state covers it. With foods and medical services the state has been okay at providing those things.

Michelle Spencer-Manzon, a medical biochemist and geneticist stated that CT is good at covering services under Medicaid. She stated she spends 10-15 hours a week dealing with standard care matters. This intensive work load has been pushing folks like her out of practices and hurting her viability. She wants to know how these things can be streamlined to provide better care.

Dr. Zavoski stated he understands that Medicaid has two sets of rules requiring states to cover services but they cannot spend anything more than what is necessary. The genetic testing world changes hourly and the states medical team consist of five people responsible for covering 780,000 people. Dr. Zavoski gets letters twice a week from medical companies touting a new genetic test, but he does not have anyone to help him research it. He expressed the desire to work with providers to remedy the situation.

Dr. Gulati opened the meeting to public comment.

Gerta Stiefel stated she had been misdiagnosed with irritable bowel syndrome that manifested itself as stage four Neuroendocrine Cancers. She stated her concern was a lack of awareness about this type of rare cancer and lack of neuroendocrine specialist in Connecticut. She is worried that the state is not ready to handle this type of cancer that will create a financial burden for the state and individuals.

Dr. Gulati asked if there were any specific data request from Dr. Zavoski.

Lesley Bennett asked if there were any long term data on patients identified during newborn screenings.

Dr. Zavoski stated The Department of Public Health refers patients to specialists but there is no specific data collected on the patient. He went on to mention that a report is submitted every 3 months and they keep track of patients at the clinical level but insurance data is not tracked.

Dr. Tucker asked about what type of quality outcome metrics are used in children with rare diseases.

Dr. Zavoski stated that all the standard measures are used at the Department of Public Health to measure the effectiveness of a health program. That data could be provided.

Dr. Gulati announced that the next meeting will be held on Thursday, April 27<sup>th</sup> at 1:00 PM in RM 1C of the LOB.

Dr. Gulati adjourned the meeting