

Testimony of Kim Mathews
Spouse of Tom Mathews, adult living with cystic fibrosis
HB49 as Introduced by the Governor
House Finance - Health and Human Services Subcommittee
March 23, 2017

Chairman Romachuk, members of the committee, my name is Kimberly Mathews. I live in Licking County, OH. Thank you for allowing me the opportunity to testify today in opposition to the proposed language related to the Children with Medical Handicaps program within the Ohio Department of Health.

My husband, Tom, is an adult Cystic Fibrosis (CF) patient. Recently, he celebrated his 53rd birthday. Tom received a bi-lateral lung transplant in March 1992. This week, he will celebrate his 25th anniversary. Tom also underwent a kidney transplant in December 2002 after spending nine months on dialysis three days per week. Tom has lived well past the expected years of survival. For this, we are grateful! Tom's prescription drug costs are astronomically high averaging around \$120,000 per year. His doctor visits range from \$500 - \$2,000 per visit. We visit at least two doctors per week, sometimes more frequent depending on the need. Outpatient labs are \$500 each time. He requires lab work every 3 days. Hospital bill expenses are massive! BCMH truly is our financial safety net!

BCMH has been a safety-net for those on both public and private insurance for almost 100 years. Some diseases like cystic fibrosis are so complex that it takes a team of providers and extra support to provide care for these children and their families. **This is not a hand out, but a safety net** to Ohioans caring for the medically fragile children and adults like Tom living with cystic fibrosis. **Contrary to what you may have heard, there are many coverage gaps in both public and private insurance.** If Medicaid and private health insurance could provide this level of care and coordination they would already be doing it. BCMH provides coverage for services that both private and public insurance don't cover or when there is limited coverage for these services. BCMH is the payer of last resort.

I have served on the BCMH Parent Advisory Council (PAC) for over a decade. Information about these proposed changes were never discussed with the PAC nor was the Council asked to provide input as to the proposed changes. ***This is unacceptable and clearly shows the Administration doesn't understand the well proven value of the BCMH program!***

- **After July 1, 2017, BCMH will not be an option for those making 225% over the FPL.** There will be no cost share provision. Families are worried that when their renewal date rolls around they will not have a pathway to continue BCMH. The elimination of folks from this program will result in children and families not getting what they need. **It will move families who are close to the edge – over the edge.**
- **With this proposal, the information isn't clear that our adult cystic fibrosis medically fragile individuals will be held harmless.** 300+ adults living with cystic fibrosis are in jeopardy of losing vital life sustaining safety net services.
- **With this proposal, the following programs within BCMH are also in jeopardy:**
 - **Diagnostic Program** – this program helps to diagnosis babies early so they can receive immediate treatment to have more successful health outcomes.
 - **Genetic Services Program** - The genetic services program funds a regional network of genetic centers that provides comprehensive care and services to those

affected with or at risk for genetics-related disorders, and education about genetics to health professionals and the public.

- **Metabolic Formula Program**- This program provides metabolic formula to individuals with phenylketonuria (PKU), homocystinuria and other metabolic disorders. Without special formula, individuals, especially infants and children, may develop brain damage and mental retardation.
- **Sickle Cell Program** - The program funds a regional network of sickle cell programs that provides education, hemoglobin counseling and follow up on abnormal newborn screening hemoglobin reports and educates health professionals and the public about sickle cell disease, sickle cell trait and other hemoglobinopathies.
- **Adult Hemophilia HIPP Program** - HIPP helps with payment of health insurance premiums for persons over 21 years of age, with hemophilia or a related bleeding disorder, who meet the eligibility criteria as defined in [Ohio Administrative Code 3701-43-16.1](#).

— **The proposed language does not support or keeping our BCMH public health nurses or hospital based service coordination.**

- There is tremendous concern is that Medicaid/Managed Care won't be able to manage our medically fragile. On January 1, 2017 Medicaid rolled in the final phase of BCMH kids – CF, Hemophilia, Cancer. Care teams at the Children's Hospitals are reporting this isn't going well at all. **Why would the Administration propose disrupting services performed well by our BCMH public health nurses and hospital based service coordinators to move the medically fragile to a system that hasn't yet been proven?**
- The team service coordinator works with the family and public health nurse to develop a plan to meet the needs of the child. CMH supports 62 teams that have been designated to provide special care to children with specific conditions such as cystic fibrosis, craniofacial anomalies, cancer, and hemophilia anomalies located in three tertiary centers and eight children's hospitals. **Service coordination services are managed by a hospital-based service coordinator and a local BCMH public health nurse.**

Why create a new program when the current program is obviously working? BCMH keeps privately insured parents working and fills the gaps when their private health care coverage isn't enough. BCMH is a program for our medically fragile who are Medicaid eligible. With Medicaid, and yes, even with Medicaid Managed Care, there are significant gaps related to coverage. **BCMH isn't broken, it simply underfunded.** The \$11 million deficit didn't happen overnight – it has accumulated over several budget cycles because the funding of the program wasn't appropriately funded to support the growth and the use of the program.

BCMH is the original model of care coordination. It works! BCMH keeps families intact and most importantly keeps medically fragile children safe. I respectfully ask for your supportive consideration to retain BCMH at the Ohio Department of Health as well as appropriately fund this vital program, which serves Ohio's most medically fragile.

Thanks again for allowing me the time today to testify. I would be glad to answer any questions.

Kim Mathews
45 W. Postal Avenue
Newark, OH 43055
PH: 740.334.2355
Email: tkemathews@hotmail.com