

Good afternoon and thank you for this opportunity to speak out in opposition to House Bill 49. My name is Michele Engling and I am a mother of four who has received benefits from BCMH.

No event in life happens in isolation from the rest of life. Unexpected medical decisions are no different. There is no convenient time or way to make the right choice. There's no "waiting until things settle down" or "until work picks up". The rest of your day-to-day does not stop so you can leisurely handle the unexpected.

I gave birth three years ago to quadruplets. They spent 3 months in the NICU. Each day was spent knowing that at any minute their status could change from fine, getting better, could die, or has died. Their status shifted multiple times a day, every day, like a three-month emotional roller coaster. During which, we made choices multiple times daily about life-saving procedures, possible surgeries, and questionable drugs - just to name a few. These decisions had to be made instantly most of the time. There was no time to worry if we could afford it and frankly, no one, regardless of income, should be put in the position of deciding if they have enough money to save their child's life. "Having enough money" should not factor into choosing the right care for your child - EVER.

Sure my story is unique to me, but everyone has a similar overwhelming thing in their life coinciding with their newly acquired medical situation. Being unable to financially care for your child compounds that.

Very early on one of my sons was diagnosed with cerebral palsy (CP). We were told early intervention was the key - the sooner the better as far as treatment. If we didn't start soon enough, a window of opportunity for mastering certain abilities would close. His CP is classified as "mild". Even with a mild form he regularly goes to physical therapy, occupational therapy, and speech therapy. We developed a home regime for him as well so he can work-out in-between therapy sessions. Our goal is for him to reach his full potential in these areas. A parent's guilt comes with the territory. Is stretching and working him out for an hour a day enough? Did I choose the right specialists, am I researching it enough to ask the right questions? Is what I'm doing enough to get him to his full-potential? Am I enough? I can't imagine the added guilt if I had to ask myself in the future, "If I could have afforded therapy, would he be able to walk today?"

If it sounds like I'm edging toward a universal approach, you're right. I know a lot of people find the adage "Pull yourself up by your bootstraps" reason enough to shoot down the idea of including all income levels in the list of those who receive benefits. The problem is, not everyone's boots come with straps. More so, what if BCMH is the proverbial bootstrap?

If the parent's mental well being and the child's future self-reliance and future ability for gainful employment isn't enough to persuade you to allow benefits to more people, let's look at it from a numbers perspective. Disabilities are often life-long expenditures. A child with a disability will outgrow his \$5,000 plus wheel-chair multiple times before reaching their adult size. Medical equipment is also so much higher due to supply and demand. A basic bath chair made of PVC, mesh, and hardware similar to what's found on the back of most office chairs cost us over \$1,000.

In 2013 a report suggested that expenses for a child with special needs could cost upwards of \$60,000 a year. The cost of a child without a disability is roughly \$13,000 a year. That's a \$47,000 difference. In other words, you need at least \$47,000 a year more to afford a child with a disability than one without.

The plan being proposed puts the new financial eligibility limit at 225% of the federal poverty level. The federal poverty level for a family of three is \$20,420. Using the new percentage, 225% of \$20,420 is \$45,945. Let's look at a hypothetical where there's just one child in a two-parent house hold and that one child has a disability. If \$20,420 is considered poverty level for a healthy family, they still need \$47,000 more to care for their disabled child. They need to make \$67,420 just to make ends meet. But with the proposed plan if that family's income is roughly between \$46,000 and \$67,400 per year, they won't be eligible for benefits nor will they be able to afford care on their own. That's a large number of families who will not be able to care for their child because they make too much to be eligible and too little to cover the total cost.

If universal eligibility can't happen, I'm glad to know the poorest of families will still get benefits under the proposed bill. However, the language in the proposed bill includes terms like "Comparable" treatment and services. That makes most of us uneasy. We need proof that it will be as good or better than the current services from BCMH. Also, we need to feel like this wasn't a hasty decision on the part of lawmakers. Make known the things you've tried before coming to the conclusion to cut eligibility. Did you explore ways to decrease costs of medical supplies, services and other outgoing expenses? Did you try fundraising? Did you create community awareness and survey or lobby tax payers to promote the idea of raising taxes to help raise money for BCMH? We want to know that this proposed bill was a last resort - not a quick fix to the budget. Are there other line items that could be cut instead of this? Making each line item of your budget known in a way that is easily accessible to the public, especially those who will be directly affected, would help gain acceptance for the proposed bill. Perhaps, those families currently scraping by and turning the last bit of food into another week's worth of meals could look at it and make sure you're truly stretching each dollar to it's fullest extent.

To state lawmakers, merging BCMH into Medicaid may seem like just a shift in the state's budget. To the 40,000 families who are now blessed with the services of BCMH and those who could be in the future, it is a major shift in life.

Please consider finding a way to ensure all families will be able to afford to care for their child.

Thank you for your time and consideration.