

Dear Legislators,

I am writing in support of *LD 1114, An act to eliminate the annual medical eligibility determinations of need for families of children with disabilities.*

My son, William, is 8 years old and has Down syndrome, also known as Trisomy 21. He had a third copy of his 21st chromosome before he was born and every cell in his body will carry that extra copy until he dies. Yet, every year I need to provide a ream of paperwork to demonstrate to Kepro/MaineCare that he still (and will always) has Down syndrome.

Because Trisomy 21 affects every cell of the body, there are predictable systemic impacts to his body. William has low muscle tone, which impacts his ability to run, jump, chew food, and speak. William has a congenital heart defect (bicuspid aortic valve) that will never go away and that needs to be monitored periodically by his cardiologist. Like others with Down syndrome, William's delays and health concerns may change over time, but will never go away.

Down syndrome was first described by Dr. John Langdon Down in 1862 and the extra copy of the 21st chromosome was discovered in 1959. We've known DS is the result of an extra chromosome, and is therefore permanent, for over 80 years. And though we still have a long way to go to understand how best to nurture the health of folks with DS, we know that increased access to appropriate services and healthcare has increased the average life expectancy of babies with DS from 12 years old in the 1940s to 60 years old today (and climbing!).

Despite all that we know, every year I need to prove to the State that William still has a third copy of his 21st chromosome and the resulting medical and behavioral complications that come with DS. Every summer, I track down reports from his pediatrician, cardiologist, pulmonologist, ear nose and throat specialist, orthopedist, dentist, ophthalmologist, audiologist, speech therapist, physical therapist, occupational therapist, lead teacher, school psychologist, and case manager. As if coordinating all of these supports was not enough, I need reports from each of these providers to prove to MaineCare that the appointments that they pay for (and therefore have records of) are still necessary. That he still has a diagnosis of Trisomy 21. That he still has diagnoses of global delays, bicuspid aortic valve, alopecia, asthma, obstructive sleep apnea, ear tubes, "other specified disruptive, impulse-control and conduct disorder", "unspecified intellectual disability", "developmental articulation disorder", "mixed receptive-expressive language disorder", and several other diagnoses.

Every year I am terrified that if I don't provide adequate documentation to prove that he still has these diagnoses, that he will lose his MaineCare coverage and his services and healthcare will be disrupted.

The process is onerous, time-consuming, stressful, and prone to mistakes. I need to request (and often have to sign for in-person) paperwork from 13 different providers every year. I have to follow-up with most of them at least twice to ensure that they forward the paperwork to me in time.

All of this in addition to the financial paperwork required for MaineCare recertification.

On top of coordinating my son's care

On top of IEP meetings, psychological assessments, and extra medical appointments

On top of worrying about his health and development

On top of caring for his younger sister

On top of maintaining a job

On top of maintaining my marriage

On top of the guilt of having no time for planning social activities for my kids or myself

On top of advocating for the services that my son is legally entitled to

We are asking the parents of kids with permanent disabilities to prove that they still qualify for services...

... only to sit on waitlists for years for many of those services.

Please help remove this one, onerous, unnecessary task from our list.

Thank you for your time and consideration.

Please also consider supporting LD346 and LD874 to help Maine families who are struggling to care for their children with disabilities.

Abby Pearson

Bath, Maine