



***LD 962 An Act To Appropriate Funds To Eliminate Waiting Lists for Home and Community-based Services for Adults with Intellectual Disabilities, Autism, Brain Injury and Other Related Conditions***

***LD 1360 An Act To Provide Services to Maine's Most Vulnerable Citizens by Eliminating the Waiting Lists for Certain MaineCare Services***

***LD 499 An Act To Eliminate the Waiting Lists for Older and Disabled Residents Who Are Eligible To Receive Home-based Care***

Senator Claxton, Representative Meyer, and distinguished members of the Health and Human Services Committee, my name is Kim Humphrey and I am from Auburn. I am the mother of an adult with severe autism living in a group home and I am the founder and President of Community Connect Maine, a 501c3 organization. It is a grassroots family driven network with the mission of connecting families, caregivers and communities to improving the system of care for the Developmental Disabilities (DD) community and related conditions. Our vision is that all people have the support they need, when they need it, to live full lives within their communities of choice. I am in support LD 962, LD 1360 and LD 499.

My son, Daniel, is 32 years old. The 30 years of experience has given me a personal understanding of the impact of waiting lists, the cost of waiting and the cost of inadequate care, for my son, and for others in the community that I have grown to know.

My son has received some of the best services currently available. As a result, he has acquired the ability to sweep floors with 96% accuracy, take care of his daily needs with prompting, and has a volunteer job delivering food to 15 'meals on wheels' clients a week. He is non-verbal, but can shake his head "yes" and "no" and has very basic communication skills with the use of an iPad. I am grateful for his hard-earned accomplishments, for those who taught him, and for all who contributed to the resources he received.

But throughout his life, he has endured an overwhelming amount of time waiting for access to basic resources. He waited for early intervention programs, though early intervention is the best predictor of long-range outcomes. He waited for appropriate school opportunities, in-home supports, communication devices, speech and occupational therapists, routine dental care and specialized dental care, behavioral support, specialist care, appropriate transportation, and other resources that were *essential* to how well he could function in this world. Access to speech therapists, and all of the support needed to make successful use of augmented communication devices would be one of the most helpful resources to improve the quality of life and reduce the cost of his care. But the waits and inconsistencies for access to these services have been some of the worst. Daniel left our family home at age 11 to go to school out of state. Without consistent in-home supports, he could not make progress in Maine. A year later he qualified for the waiver, but it was not funded. He remained on the waitlist for 8 1/2 years until he graduated at age 20 and came back to Maine. I testified before HHS over a decade ago on these similar issues, yet here we are again. Waitlist have grown.

The waits and inadequate resources that I just listed have held back my son's progress and greatly added to the amount of support he needs today. Throughout his life, whenever there were

inadequate resources, he became frustrated, and learned aggressive behaviors such as kicking, biting and pinching, These learned and aggressive behaviors are costlier to support. Unless he were to become a fluent communicator, he will always be at risk for this. He is not alone. Those with behavioral issues are at the highest risk of not being able to find a placement when they receive waiver funding. They are the ones stuck in emergency rooms, hospitals or, like my son, sent out of state. I once feared that my son would be stuck in a hospital the rest of his life. This is the kind of pain that is being created for individuals with ID/DD and their families when resources are not supported. These costs are often not calculated into decisions regarding waitlists. Are we headed for larger institutions and custodial care for this sub-population?

I have witnessed fellow community members watch the deterioration of their family members as they learned extremely challenging behaviors while on waitlists. Behaviors once learned can't always be rectified. I've seen it happen to people who were receiving "at least some support," but that support didn't quite fit the person's needs. Now their lives are forever impacted by what they learned while waiting for appropriate services.

It is also common for skills to be lost while people are on waitlists. These skills are not always regained when a person receives a placement. That means that the money invested on developing those skills is also wasted. Maine is creating a systemic higher-cost, lower-quality system by perpetuating the acceptance of any form of waiting lists that deal with basic needs. Within the last few years, I have witnessed comments about how the ID/DD stakeholders have interfered with systemic improvements by being squeaky wheels. Really? Eliminating waiting lists would significantly reduce more challenging, heart-wrenching and expensive behavioral issues and skills loss. We are speaking up to help our state do better.

Eliminating waitlists must be partnered with viable direct care worker wages. These wages must be competitive with Walmart and gas stations clerks in Maine. What works in one state isn't necessarily transferrable to Maine. While it is admirable to look systemically at the rate structure, the department noted that they did not include looking at the relationship of these rates to minimum wage. Minimum wage is a huge factor. Bringing the rate up to minimum wage is admirable. But why was it acceptable to keep the rate below minimum wage for the prior three years? The one exception is the inclusion of a 10% temporary three-month rate increase during a pandemic that is in its thirteenth month. Receiving retainer payments for community programs hurt by the pandemic is also helpful to sustain the system. While I am grateful for these financial allocations, I am also aware of the reality that providers have been forced to consolidate homes, and homes are closing. What is the impact of those who have lost their homes? I know I would find it devastating if it happened to my son's home.

My priority to help my son get the support he needed kept me from contributing to the Maine economy as part of the workforce. For twenty years I gave up a career that I trained for and loved. While he was on the waiver waiting list, I reached out to many people to learn everything I could about the process that might help me know how to get him a place to live when he graduated. Thousands of people today are on the waiting list. That may correspond to thousands of family members that are currently out of the workforce or with reduced hours, desperately hoping to navigate opportunities for a person they love. Maine's acceptance of waitlists costs Maine by depriving a sub-population of the ability to contribute to the Maine's economy.

There are other cost that are not normally considered in policy decisions regarding waiting lists and inadequate care. Behaviors that are learned due to inadequate care sometimes lead to pharmaceutical intervention in this population. In addition to studying rate structure, study the use

and cost of drugs prescribed as a solution to behavioral challenges. How often are drugs needed because adequate basic support is lacking? What does MaineCare pay as a result? This can begin in childhood and span a lifetime. What are the health implications from extreme stress on individuals and families that can't find basic necessary resources to support a disability? In 2008, due to my son's non-verbal status and behavioral issues, he was unable to receive a comprehensive medical evaluation. I was shocked to learn that he could be so easily excluded from access to healthcare just because of who he was. The lack of opportunities for this population comes with a cost that policy makers may not even be aware of.

If people were consistently given the right support at the right time—when it is needed—in the amount that fits them, they would have more capacity to develop themselves. They deserve this opportunity as much as each of us does. This would make it easier for them to overcome the stigma that society imposes on people with I/DD. With more skills and a greater ability to communicate, they would gain more confidence and be more independent. Community integration would take less effort, as would finding employment. Such inclusion would make it easier for society to know their value, which would make natural support more of a reality than it is now.

Try to imagine if your basic lifelong needs were determined by the decisions of policymakers, if a vote of the legislature were the one thing standing between an unsupported existence and a life of meaning. Have you ever had to come to the legislature to plead for the basic needs of a loved one?. An expert in the field of autism once told me “the hallmark of good programming is consistency and coordination”. Smooth transitions from program to program are critical to success. But the ID/DD population struggles for consistent opportunities to gain the basic lifelong supports they need. Such a setup is systemically discriminatory. Correcting the systemic discrimination calls for a humble outlook and a bold approach. Coming out of a life-altering pandemic is a good time to make this effort. ***We have an opportunity with extra federal funds coming to our state to clear waitlists and create viable workforce wages for marginalized populations.***

In a society that operates from budget to budget, it seems counterintuitive to truly and wholeheartedly address an issue when it creates a large expense. This is especially true when the beneficiaries belong to an invisible and stigmatized population such as those with ID/DD and other marginalized groups. But not doing this perpetuates all of the factors that create stigma. To not fully fund essential resources is the more expensive choice. The systemic lack of access and opportunity, low expectation and priority for the ID/DD population is a reality. But in my heart, I have to believe that the best in each of us, acting collectively, can turn this reality around. ***A vote to eliminate the waiting lists is a vote to eliminate discrimination and to stop putting people's daily lives on hold.*** I urge you to support the elimination of these waiting lists by passing these bills.

Thank you for your consideration.

Kim Fulmer Humphrey, MPH  
mother of Daniel, an adult living with autism

Founder and President  
Community Connect Maine

khumphrey.phadv@gmail.com