March 18, 2025

LD 769 An Act Regarding Access to Behavioral Health Supports for Adults with Certain Disabilities

Senator Ingwerson, Representative Meyer and distinguished members of the Health and Humans Services committee,

Good Afternoon. My name is Kim Humphrey, I am from Auburn. I am the mother of Daniel, an adult with profound autism. I am an a member of the state's Behavioral Stakeholder group and on the Maine Developmental Services Oversight Advisory Board. I urge this bill not to pass. This is my personal testimony:

Though my son cannot speak, his experience is just as valid as anyone else's. Every person deserves a plan that works for them.

All physical restraints are traumatic unless requested, like Temple Grandin's squeeze machine. She, an autistic adult with a Ph.D., invented a squeeze device to calm herself. **This highlights** the need for individualized approaches—what helps one person may harm another.

One-size-fits-all policies don't work. Touch helps redirect my son but could escalate someone else. Policies must allow trained staff to apply appropriate person centered interventions.

Key moments in Daniel's life illustrate these matters:

- As a toddler, Dan learned aggression when his support needs were unmet.
- At 6, he lost access to mainstream education from aggression that led to behavior plans that overlooked his pain— teeth issues he had six cavities and needed a tooth capped.
- At 9, he was out of control in a self-contained public school classroom, treated with disdain and hopelessness rather than as child in need by well meaning people that just did not know how to do better.
- At 10, in the same setting, his well being improved when an expert intervened using functional assessments, preferred activities, planned restraints, and trained autism specialists.
- At 11, though not aggressive at the time, inconsistent home supports forced him out of state because he needed 24/7 support to learn.
- At 18, a lack of access to a comprehensive medical evaluation led to an unnecessary 2+month psychiatric hospitalization, where a rigid behavior plan, "last resort" restraints and untreated pain escalated his distress.
- The hospital refused to address my son's underlying medical issues, forcing our family to manage them alone. This led to a near life-threatening attack at the dentist, prevented only by the dentist's quick bare hug restraint. I suffered nine bites that took a year to heal because the hospital's failed behavior plan escalated his aggression instead of discovering he was in pain.

For the past 15 years in his group home in Maine, Daniel has nearly eliminated the need for intensive restraints. His house makes a habit of understanding the root cause of each and every

reportable event to them in the prevent future. Today, aside from blocking and redirection, he has learned to self-regulate at his home.

Restricting behavior plans from the necessary support they need in the community is effectively a rights violation to community access, if safety can't be ensured.

If policy changes make providers doubt their ability to ensure safety, they may stop serving individuals that may use aggression, putting Daniel's housing at risk.

Over his lifetime, critical services required by law, have been denied due to "lack of funding"—a matter of priorities, not true constraints. Had he received consistent, appropriate support from the start, my gentle son would never have learned aggression.

I urge you to consider his story. This bill is not clear and opens the door to abuse. It needs to be clear and flexible to fit all individuals.—not rigid, blanket approaches that harm those they claim to protect.

This bill weakens independent oversight by restricting it to aggregated data, barring any individual Maine Developmental Services Oversight Board member from joining the team that is reviewing these case by case. Their access is crucial for identifying systemic issues. Meanwhile, those with conflicts of interest retain access, raising serious concerns.

Note: I fully agree with every point mentioned in the Maine's Developmental Services Oversight Advisory Board's testimony.