

March 18, 2025 100 State House Station Augusta, ME 04333

Testimony in Support of LD 769 "An Act Regarding Access to Behavior Health Supports for Adults with Certain Disabilities"

Dear Senator Ingwersen, Representative Meyer, and members of the Health and Human Services Committee:

My name is Monique Stairs and I am the Executive Director of Speaking Up For Us (SUFU). SUFU has been the self-advocacy network in Maine since 1993 and we are an established 501(c)3 non-profit. Self-Advocacy is part of the civil rights movement for people living with Intellectual and Developmental Disabilities (I/DD) to advocate and voice their opinions on issues that are important to them. Self-advocates are the people who have the lived experience of what it means to live with a disability. Our Board of Directors is made up 100% of adults living with I/DD, which makes us a unique organization.

I am testifying in support of LD 769 today and providing you some additional written testimony that I shared in a public listening session conducted by OADS in 2021 as I feel this information is still relevant and important to the issue of eliminating the planned use of restraints in Maine. As a result of that listening session, a work group met and this bill is a result of their work.

You will hear from several self-advocates mostly that their concerns are not to be restrained but also their concern that emergency restraints could increase if the proper checks and balances are not enforced. Self-advocates had some discussion about emergency restraint use being reported through the reportable events system and worry that this may not be enough oversight. The current system is in need of additional changes in order to prevent abuse and injury. When restraints are allowed it gives permission into the system to lay hands on people with disabilities.

SUFU values the work that OADS has done to include the voices of people with lived experience and their commitment to eliminate the planned use of restraints in Maine. Self-advocates agree that having a person with lived experience on an oversight and review committee is a positive step towards valuing people living with I/DD.

I leave you with additional written materials for your review on this issue. Thank you for your time and consideration in hearing testimony today.

Sincerely,

Monique Stairs
Executive Director, Speaking Up For Us
Caribou, ME
mstairs@sufumaine.org



March 26, 2021

Re: OADS Listening Session for Behavior Regulations

My name is Monique Stairs and I am the Executive Director of Speaking Up For Us (SUFU). I am also currently a NH-ME LEND Trainee and have focused my leadership placement and capstone project on trauma and the use of restraints. I am here today to advocate for the elimination of the planned use of restraints for adults living with Developmental Disabilities in Maine and to offer up a suggested change in organizational culture by adopting a Trauma Informed Care Model.

Many self-advocates and family members are sharing stories and opinions about the impact that the use of restraints has had on people's lives, the trauma it has caused and the lasting effects. I reviewed multiple research articles on this subject and I have found that most conclude restraints are rarely therapeutic and frequently traumatic resulting in injury or death. In much of the research I reviewed, there was limited representation from the perspective of individuals who are the recipients of restraints. I want to highlight this is as a gap in research as well as in the overall framework for how we talk_about people living with I/DD rather than including them in the conversation and decision making.

All of my research has brought me to the same conclusion every single time; putting hands on people and restraining them is not the answer to managing difficult behavior. I want to be clear that I am not referring to emergency situations but speaking specifically about the planned use of restraining people as part of a Behavior Management Plan.

Maine currently has many systemic issues within our service delivery system that are compounded by the pandemic. There is a staffing crisis among support agencies with extremely high staff turnover rates. We also place a high expectation and demand on DSP's who we pay minimum wage with the only qualification required being a high school diploma. We expect staff people to connect people living with I/DD to their communities, achieve their PCP goals and know how to navigate difficult behavior when triggered. Then the best tool we place in the tool box for them is using restraints? I strongly feel this is a poor tool to use to help people with disabilities to regulate their emotions and communicate what is happening to them. By continuing to give support staff the wrong tools to manage the issue we are perpetuating a lifelong cycle of systemic failure.

The system needs to give staff different tools that are evidence based, person centered, and treat people with disabilities as people. Behavior is a form of communication and treatment teams need to examine why the behavior is happening. I often think about the "River Story," a public health parable of going upstream to find the source of the problem. When we settle with restraints as the only tool in the toolbox we are not focused on prevention of the behavior we are

restraining against. When we talk about people living with I/DD as needing to be restrained, this communicates a message to society that people with I/DD are dangerous. This image further widens the divide that prevents true community inclusion from happening.

People living with I/DD deserve the right to be treated with dignity and respect. I really want to stress that these are real people we are talking about. People are allowed to have a bad day. They shouldn't have to constantly be worried that their emotions are going to cause them to be restrained or retaliated against. Historically, people living with I/DD have been victims of abuse, neglect and generally devalued by society. The planned use of restraints also communicates to the individual that it is allowed for people to touch them and desensitizes them to having their personal boundaries violated. A system that allows restraint sets up a power deferential in which it becomes the staff versus the individual living with I/DD. When we introduce violence into a care system we open that system up to further opportunities for abuse and traumatic experiences.

There are several models that have been researched and attempted in different care settings where restraint is used to modify behavior. This web resource from the National Institute of Biotechnology Information has a snap shot of alternative to restraints: Alternatives to use of restraint: A path toward humanistic care (nih.gov)

The model that I would suggest as an alternative to restraints is developing an organizational culture that is based on Trauma Informed Care. Generally, the trauma history of an individual has not been recognized at the forefront of service delivery for people living with I/DD and has not been a significant identifier in a person's life. (Keesler, 2014)

Growing research has emerged and brought forward the perspective and awareness that trauma has an impact on people's lives and the Substance Abuse and Mental Health Services Association (SAMHSA) issued a policy brief recommending adoption of a Trauma Informed Care Model where individuals and staff are valued and empowered by acknowledging their skills and abilities. (Keesler, 2014) The SAMHSA brief can be retrieved here: seclusion-restraints-1.pdf. I recommend that OADS look to adopt a similar policy and action plan in working with providers to phase out the use of planned restraints and develop a system that is strengths focused and person centered.

If we continue to allow restraints to be an option to use in managing behavior then restraints will continue to be used to manage behavior. Only by removing this tool from the toolbox can we move past this harmful practice and begin exploring and defining a new system. Self-advocates and allies have pushed to close Pineland, sheltered workshops, and eliminate subminimum wage in Maine. I think we can move beyond planned restraints as well and offer a service system that is person centered and built on dignity and respect for all people living with I/DD in Maine.