

Lasorsa, Megan

From: renelleray@aol.com
Sent: Monday, April 21, 2025 9:50 PM
To: Carney, Anne; Tepler, Denise; Hepler, Allison; Salisbury, Suzanne; Arford, Poppy; Cluchey, Sally; Ingwersen, Henry; Moore, Marianne; Nangle, Tim; Meyer, Michele; Daigle, Lucien; DeBrito, Flavia; Graham, Anne; Griffin, Abigail; Javner, Kathy; Lemelin, Michael; McCabe, Julia; Shagoury, Dan; Zager, Sam; Cmte HHS; renelleray@aol.com
Subject: Advocating for LD 1606

This message originates from outside the Maine Legislature.

- Re: LD 1606 - An Act to Require Data Collection and Major Substantive Rulemaking for the Lifespan Waiver Providing Home and Community-based Services for Individuals with Intellectual and Developmental Disabilities, Autism Spectrum Disorder or Other Related Conditions.

Senators and Representatives:

My name is Renelle Ray and I live in Cumberland County. I am the mother/guardian to my 36-yr old son who has C.P. (Cerebral Palsy), on the Autistic Spectrum; has Intellectual and Developmental disabilities.

My son has lived in a group homes since 2009. His needs have always been complex and individualized (assistance of a PCP (Person-Centered-Plan) has helped.

Good oversight and communication across systems is critical to getting the care he needs. LD1606 would help us avoid unintended harm as we transition to the Lifespan Waiver.

When communication breaks down, our kids are the ones experiencing more than normal anxiety/stress and cannot function, simply, day to day activities which are vital to thriving.

He has become more independent (subject to interpretation) over the years thanks to the support of staff who help him manage daily life at home and in the community. My son currently lives in South Portland and it has given him access to more readily visit his friends, grab a bite nearby, attend the local Concert in the Park, etc. location conducive to getting him out and about into the community. (parents are also close by)(his staff have also been instrumental in meeting this goal).

His progress and level of decisions about who gets what level of service, and how services are being delivered, can happen behind closed doors, without transparency or public accountability.

There is a belief that individuals in group homes are "overserved," and that savings are best achieved by consolidating or closing homes. More than 90 group homes have already closed. When DHHS sets low reimbursement rates and unsafe staffing ratios, agencies are forced to close more homes. For someone with complex needs, stability isn't just nice to have, it's a crucial form of care.

LD 1606 would require DHHS to track residential disruptions and changes in services. It would require the department to examine the **impact of relying on aging parents as caregivers** and ensure that the waiver's implementation is guided by real-world data, not just policy intentions.

The state must retain the ability to adjust course, promptly, when the waiver causes harm.

I urge you to support LD 1606.

Thank you,
Renelle Ray