As presented and submitted publicly on 3/29/23 to the Health and Human Services Committee Public Hearing, 131st Maine Legislature.

Good afternoon members of the Health and Human Services Committee. My name is Andrea Dole. I live in Belfast with my husband Patrick and our two young sons, James and Rafe. I'm here today to support the intent of LD 874 and LD 346, to create strong, effective policies that can improve systems of care now and in the long term.

I am a mom on call 24/7 in a way that most parents of typical children can't begin to imagine. My former occupation as a social worker no longer exists while I'm living this painful paradox of working continuously, intensely, with no possible avenue for employment.

My son, James, now 7, was born with a rare recessive form of microcephaly, cerebral palsy, a seizure disorder, and visual impairment. He receives water and medicine through a g-tube. He is nonverbal and will always require complete hands-on support for all of his daily activities. James's team is very proud of his incredible spirit and numerous unique traits. His growing awareness and skills are clearly the result of his spirit complemented by the work we have done as a team.

However, as a parent without any medical training, I have no respected place on this "team," while at the same time I must be the expert who trains all the paid staff, and whose job it is to constantly provide skilled nursing-level care and be available whenever staff leaves or needs a day off.

I strongly recommend moving forward with the intent of LD 874 and LD 346 by considering expanding "special circumstance nursing" under section 96 to include PSS and CNA certifications for parent caregivers. Working with home care teams that already exist creates an efficient and fiscally responsible system. It also provides parents with appropriate training and oversight. "Special circumstance nursing" is already working well in Maine while programs in other states train and employ parents at varying levels of certification. In Maine, we also must provide a roadmap to a solution that works for everyone.

This critical care is work our children require for safety. They have a legal right to receive it. According to a recent letter from the DOJ, Maine is currently out of compliance with federal Medicaid funding due to the high level of unmet needs among children with disabilities.

Federal best practices demand family-centered systems of care.

We are the "Fabric, not Fringe."

I am available for further questions and to become part of a parent advisory board to support these crucial efforts.

Thank you.

Supporting documents submitted (paper copies and links):

https://www.lpfch.org/publication/paid-family-caregiving-children-medical-complexity-and-disabilities

https://www.lpfch.org/publication/family-engagement-systems-level-framework-action

https://coloradofamilycaregivers.com/

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LD 346

This testimony was also submitted for LD 874