To: Senator Baldacci, Representative Meyer and esteemed members of the Heatlh and Human Service Committee
From: Kim Humphrey, Auburn
Re: Support LD 346 and LD 874 and Oppose LD 659

My name is Kim Humphrey and I am from Auburn. I'm the mother of Daniel, a 34 year old with autism that has been successfully integrated into his community through a group home program for the past 14 years. I'm also the founder and president of Community Connect Maine, a 501c3.

I'm writing to you in support of LD 346 (pilot to pay parent caregivers) and LD 874 (workforce shortage in children's services) and oppose LD 659 (lifespan waiver).

Last week, on Friday, for the first time in his life, my 34-year-old non verbal son, Dan, was able to communicate with his iPAD that he wanted to "call" "Mom". So the staff Facetimed me and it was a happy moment for both Dan and me. The family of Andrea Dole testified in favor of LDs 346 and 847. They said they had learned at her son, James', birth, that he was expected to live only for two weeks. But now with intensive support with much of it provided by her own family, he is 7 years old.

None of us know the potential of others. Providing people with disabilities with the support they need when they need it can help people make progress beyond what others may expect. While my son has received lots of quality services, the gaps in care have slowed his progress, and raised his cost of care. Families are overburdened with the responsibility of filling the service gaps, many of which occur when the state fails to provide legally required services. These significantly impedes the development of our family members' potential while driving up long-term cost for Maine.

I listened to the oral testimony of LDs 346 and 874 last week and was dismayed that people like the Dole family were in such dire circumstances. Doesn't the Early and Periodic Screening Diagnosis and Treatment EPSDT benefit apply to this situation? Wouldn't that essential service cover their need? https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html What about the Americans with Disabilities Act and the Olmstead case? Doesn't that demand that people at risk of institutionalization be covered?

I remember the years when my son was 8½ through 11 years old—years of his life wasted in turmoil while waiting for an out-of-state placement. For much of this time, he had out-of-control aggression and ultimately, he made no progress. By that young age, he already required consistent 24/7 support. In-home supports were too inconsistent to serve his needs in Maine. A year after he was placed out of state, we tried to bring him back. His providers demonstrated that they could serve him more cheaply than his out-of-state school, but Maine denied this request. There was no waiver that would support someone at his young age of 12.

I was dismayed to learn that the Department of Health and Human Services opposed both bills. The bills highlight potential solutions to situations that all of us would find unbearable if it happened to our families (and in my case it did). LD 346 proposes supporting families like the Doles in a pilot project. DHHS did not like that such a project would not pull in a federal match because it wasn't a waiver program. DHHS opposed LD 874, which could draw a federal match, because it would require making a federal waiver that is "time intensive" for them and might not get the job done. How can they oppose one bill because it isn't a waiver and another one because it is?

But

The LD 346 is only a pilot, which could draw money from the billion-dollar rainy day fund for two years. The rainy day fund is saved for one-time expenses. That fits a pilot.

If LD 346 is passed, the families in need are immediately relieved of financial ruin, while the DHHS develops a waiver. Other states have done this, so Maine could too.

Fortunately Maine is already working on a new waiver, the Lifespan Waiver, highlighted in LD 659: An Act to promote Seamless and Flexible Home and Community Supports Across the Lifespan for Individuals with Intellectual and Developmental Disabilities or Autism. Currently this waiver begins at age 14. How can it claim to cover a person's "lifespan" when it doesn't begin until age 14? But, it could!

A November 8, 2019, News Center Maine story entitled "Lists to Nowhere: Mainers with high needs wait for years for services," discusses a lawsuit:

"A class-action lawsuit filed nearly 20 years ago forced DHHS to reduce the list of children waiting for services. As part of an agreement, the agency pledged that children would not be waiting for more than six months for services – a requirement under federal law. Even with this stipulation, children are waiting for months to years."

Then the story quotes Commissioner Lambrew's response to the lawsuit:

"Addressing the wait times for children is a top priority. The agency is considering partnering with the Maine Department of Education to merge programs to develop a 'lifespan' waiver that would provide more seamless services from pre-K through adulthood."

DHHS opposes LD 874 because they would have to develop a waiver, but they already are developing a waiver that could incorporate LD874 *and* include children—one that actually serves people across the lifespan, and not just age 14 and over.

The DHHS' concern about time-intensive work shouldn't be a barrier to them. They have demonstrated that they have the capacity to develop new programs and ideas at a whirlwind rate:

- Think what went into creating the codified rate system that recently was made a law.
- In their own words, they created an ambitious Home and Community Based Service Settings rule reform to come into compliance with a federal rule. Most states did it in 9 years, but this administration did it in 4 years. (They got started 5 years late when no work had been done by the prior administration.)
- The new Home and Community Based global rule as developed in our state has been a huge change in what providers will do to protect the rights, choice and community inclusion for its members. But much of the details of how well this works is still unknown.
- There is a new person-centered planning process. Details of how well this this will work are still unclear.
- The lifespan waiver will replace the entire adult service system. That is a huge undertaking.
- This waiver will grandfather people receiving section 21 and 29 waivers and eventually eliminate those waivers through attrition.

New programs being considered and/or already determined within the Lifespan Waiver include:

- support coordination- we don’t know what this is or how it will work with case management
- technology options- such as?
- A self-direction option- (the members make lots of the administrative choices)- all in the details
- tiered shared living- this means paying higher wages to a family that lives with and supports a person who needs daily support for a disability that requires more intensive care.
- Implementing an assessment the Supports Intensity Scale (SIS). The details of how this will be used have yet to be made clear to the public.

In other words, our current ambitious DHHS can handle time-intensive projects such as LD 874 if they choose to.

All of these whirlwind changes demand public scrutiny. Many of the changes the DHHS is proposing could be very good, but that can only occur in an open and transparent process with unfettered public scrutiny.

But are they dedicated to protecting the rights of higher needs individuals? 75 group homes collapsed in the last few years and 20 more are due to collapse in the next 6 months. Higher needs individuals depend on them. The new codified rate model isn’t slated to re-examine the group home rate until 2025, yet it is clear that group home system is collapsing under ths current rate system. At the same time, we are asked by DHHS to believe they totally support the group home model within the lifespan waiver. I know of at least one family who has a family member that moved from a collapsed group home to a distance away to live in an institutional setting (ICF) because no other homes were available. I had the opportunity to ask the OADS what happens in the lIfespan waiver if someone like my son and others with higher needs, need a residential setting before the age of 18. I was told that they would get served within the children’s system that exists now.

The title of LD 659 is an Act to Promote Seamlessness and Flexibility Across the Lifespan. With the pilot in LD 346, develop a mechanism within the lifespan waiver where seamless flexibility across the livespan, like supporting James Dole at age 7, can be a flexibile exception. This pilot can be used to improve the lifespan waiver to live up to it’s name.

Considering my 30-plus years of experience examining the choices for people with very high needs like my son, I am opposed to LD 659, authorizing the development of the Lifespan Waiver, because it needs more public scrutiny. I want to know that higher needs people will not be relegated to restricted and isolated environments.I think others within the disability community across the continuum of care also deserve to understand if the services that they need, will work. I don’t think any of us can know this without more details, so LD 659 needs to be amended from routine technical to major substantive or voted ought not to pass. At the same time, let’s not repeat history by leaving families with higher needs individuals carrying a burden that is too big to carry alone. Please pass LD 346 and LD 874.

- Kim Humphrey, Auburn