

Hi Janet, Kimberly, Anthony, Andrew and Anne – I'm reaching out to you as I have many times regarding an issue that needs immediate attention during this challenging time by the Legislature.

I hope you will take the time to read this entire email and a poem at the end that I found to be inspirational during this challenging time. The poem is the heart of what we do every day but even more so now. Thank you for your time and service as well.

As I think you all know, we are longtime home providers (30+ years) caring for individuals that are part of our most vulnerable population – those with disabilities and significant medical issues. Here is what the recent C19 crisis has meant for those of us who dedicate our lives and share our homes serving these folks and the huge responsibility we have to ensure their health and safety.

As a result of C19, we are now literally on the front lines providing 24/7 care without any breaks anywhere near in sight. The two individuals that live with us both had day supports to take them into the community and overnight respite – this provided us with a chance to recharge our batteries and provided them with an opportunity to spend time in another setting giving them a break as well.

As the days and weeks and perhaps months go on, none of us will have a break from each other and because of their health status they cannot go out into the community not even to shop for essential needs. We must go shopping for those essential needs although on a very limited basis so as not to become infected ourselves and thus perhaps passing it on to these individuals which would most certainly end up in hospital.

One of my individuals attended Project Independence in Barre on a daily basis which provided her with an opportunity to participate in social activities, exercise class, arts and crafts, etc. The other individual had day support services and went to respite on a regular schedule. Both now do not have those opportunities and the load is on us.

I am not writing just for ourselves but for many, many other home providers as well. Here are some statistics:

- 1) There are over 1,400 individuals in Vermont residing in shared living homes. Some have significant medical and mental health challenges that require constant care and oversight and lots and lots of patience. Shared living providers were never intended as 24/7 settings without breaks. Most of these individuals served had robust community support and/or employment hours during the day. Those services have ceased and the home setting is now a 24/7 service provision situation. This also includes homes for people supported through the Adult Family Care homes who no longer are able to access adult day programs, or other types of day program supports.
- 2) Individuals served by shared living providers are often very dependent on their routines. The abrupt cessation of their community supports and employment supports causes heightened anxiety levels and increased behavioral challenges. At the same time, the shared living provider is dealing with their own personal and family challenges caused by the pandemic. This can accelerate rapidly into caregiver burnout.

- 3) Many shared living providers are receiving the same annual stipend they have received for many years, the increased stresses and duties resulting from the COVID-19 pandemic exacerbate the reality of inadequate funding.
- 4) An increased stipend at this time for shared living providers will enable the DS and AFC Systems to remain more whole at a critical moment, when the replacement of those home-based services will be next to impossible.
- 5) Vermont cannot afford any type of collapse of these essential supports in the midst of this declared emergency.

I am the caregiver, the watcher, the guide
I walk down the hall with you by my side
a smile, a laugh, a hug or embrace
I watch the worry fall away from your face
I am the caregiver, the watcher, the guide
I walk down the hall with you by my side
I am your compass, your shining north star
I try to remind you of just who you are
I am the caregiver, the watcher, the guide
I walk down the hall with you by my side
Pictures and letters, music of old
keep your mind warm and away from the cold
I am the caregiver, the watcher, the guide
I walk down the hall with you by my side
the routine of night shows no wear and tear
the light of the morning so soon will be here.”

– Lee McCurley

Denise Wheeler