[External]

Dear Senators – I'm writing to you with some information from a fellow Developmental Disabilities Housing Initiative parent who is too exhausted from many years of being the solo caregiver of her son to advocate widely on her own.

HER STORY IS THE STORY EACH OF US COULD TELL YOU. Nobody but us parents would believe the burden caring 24/7 for an adult child with a disability puts on people who were once functioning, active community members. This parent tells it in heartbreaking detail. How she still has one ounce of humor is beyond me.

AN ALTERNATIVE TO THIS STORY is for our legislature to create some small supported groupliving residences that would in turn create good jobs for good people who are professionally trained to work with our sons and daughters. Then their parents could get back to contributing to their communities once again.

PLEASE TAKE A MOMENT TO READ IT TO THE END. THANK YOU.

Ellen McKay Jewett, Ripton

From: cindy anne <<u>cindylewww@gmail.com</u>> Sent: Tuesday, March 28, 2023 2:53 PM To: Tristan Toleno <<u>TToleno@leg.state.vt.us</u>> Subject: [External] oy!

hi Tristan-

cindy coble here- a constituent and single mother to an adult with significant disabilities. i'm a member of the group {DDHI] advocating for housing [plus plus] for our kids.

DDHI has provided a boilerplate letter for asking you to consider supporting the S100 SEC42, support for a medicaid rate increase, and support for a rate review for home and community based services.

i'd like to invite you to my home- once very well kept and a center of steady stream of friends, neighbours, community activities-a bustling, happy place. my son is now 26, i've been taking care of him 24/7 with no help for years. my life, his life, the poor house's life- have done a 180.

i was very involved in local politics -we had the obama campaign party at your old restaurant!- i worked for the school district, had a non-profit which benefited local elementary schools, kidsplayce, boys and girls club. did girls on the run. you get it.

now i'm broken, broke, and exhausted in every way. my son is suffering mightlity, a large part of that could be remedied with reasonable supports. we are isolated, and that's a killer.

i no longer have people over due to the sad, chaotic mess life has become, but i think it could be a meaningful experience. i'm guessing you do support these initiatives, and if having the opportunity to see what happens without support may inform you in a visceral way., then come on over.

i'm spitballing here! i'm desperate for my son to be supported so he may engage with his community and have a reason to get out of bed, where he is most days.

thanks for your consideration, and my very best to your family,

cindy coble

From: Tristan Toleno < TToleno@leg.state.vt.us>

Subject: Re: [External] oy! To: cindy anne <<u>cindylewww@gmail.com</u>>

Hi Cindy,

I remember our Obama party well and I'm sorry to hear that things are so hard. The House is supporting Medicaid rate increase in our budget proposal. We need to do it and I hope the Senate will agree. Thank you for taking time to email me; I appreciate that with all you are carrying, you still could take time to share from your struggles and support a healthier system for everyone.

Warmly yours,

Tristan

I'm reaching out to my rep. i'm unable to do more at this time, other than dream of doing medically approved psychedelic mushrooms in hawaii. we haven't had any support since the beginning of covid. no nursing, no respite. zero. single mom, family dropped out. my ex has been 'busy' since my son was diagnosed at age 3. he's now 26, my ex remains 8 or 9. so, i thank you all heartily! you are all aware that flat-out parents like me exist in multitudes. i hate feeling sidelined, but here i am.

Cindy coble

-was once a person who could spell, shower and run a small country-

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