

Submitter: Sarah Reed

On Behalf
Of:

Committee: Joint Committee On Ways and Means Subcommittee On Human
Services

Measure: HB5026

To Whom It May Concern,

My name is Sarah Reed and I am currently a paid parent caregiver for my 12 year old son who has Down Syndrome, Autism, and is non verbal. We reside in Corvallis, Oregon. Despite the fact that Sen. Gelser Blouin says that I'm trying to get paid for normal parenting roles, my child's attendant care hours are based on what the State has assessed is "above and beyond" typical parenting. The need and the right to these attendant care hours are already agreed upon. The issue is who can best fill this need and provide this service. I want to tell you, that for so many reasons, for my child, I am the best person to do this. I am not advocating for this policy because I am attempting to gain "entitlements" that I don't need. I am advocating for this because I love my child and without paid parent caregivers, the system is not meeting my child's support needs.

Senator Blouin said herself that she has a conflict of interest with both paid parent caregiving proposals. How is she still able to constantly speak on this topic and put her bias front and center? While I am thankful to Senator Blouin for her service as a Senator, she does not speak for the majority of I/DD parents in the State of Oregon. She speaks from a place of privilege raising one autistic person with a vast support network. Her experience is not the same experience as most other I/DD families in Oregon.

Outside caregivers do not understand my son's nonverbal communication. Even his one long time PSW, see letter attached by her, does not understand my son's nonverbal communication and she has been supporting him for 4 years. This lack of functional communication and understanding leads to increased behaviors for my son. If he had access to me as one of his paid caregivers then his behaviors and support needs would decrease as he ages, lowering the total amount of support that he requires over his lifetime.

Attached next as a pdf document is a letter from my son's PSW, which she wrote on her own accord and gave me permission to share. We are in support of HB 5026. We are also in strong support of SB 646 and SB 91, both would allow a permanent program for paid parent direct support professionals.

Thank you for your time,
Sarah Reed