

Mary Custer
Testimony on HB 33
Supporting the DD Workforce

My sisters and I are trying to take care of my 60 year old sister, with down syndrome and dementia. Since the pandemic, although we have been allotted 14 hours of home, personal care services a day, we struggle to find HPC services for a few hours a day. The pay for Medicaid providers is far less than private companies. Also many providers have to drive miles to come to a western suburb to provide service without any travel reimbursement. Medicaid reimbursement for these providers must match the rest of the caregivers at competing companies. The cost to have my sister at home with HPC services is far less than nursing home care. Some accommodation in reimbursement needs to take place to keep her at home. This is a dire situation and it's only getting worse as my sister ages the need for help increases. We want to take care of her at home, but we have to have the support services. We have been trying to find adequate services for three years. Although we post to need no one response, hoping for more compassionate and creative responses toward the vulnerable population.