

Submitter: Christopher Wilcox

On Behalf
Of:

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

Measure: HB5026

I would like to take a moment to voice my support of senate bill 646 and the funding of ODDS and to address some of the statements made by Senator Sara Gelser Blouin. My concern is that her statements describing parents of disabled children as being in her own words "entitled" and wanting to get paid to tie their kids shoes and cut their meat are a dismissive and harmful minimization of the incredible work that parent caregivers are doing on a daily basis. Parents of significantly disabled children are placed into an impossible situation where their child's needs require a significant level of care and there are not enough quality and reliable caregivers to fill these rolls. Parents are having to forego jobs and careers to fill this gap and they are having to do this unpaid. Vulnerable families are left trying to survive on a single income while doing the work of two. The pandemic unlocking the funds to pay parents was life changing for many families because suddenly the struggle of working and caring for a disabled child were not two different battles. Most importantly the people who benefited most from this program were disabled children.

Hospitalizations fell, outcomes and lives improved.

I am particularly concerned with Senator Gelser Blouin's admission of a philosophical problem with parents as paid caregivers. Her own feelings about parents as paid caregivers are not representative of my feelings or my stepsons feelings about the parent caregiver program. I urge anyone involved in this bill to listen to the voices of families who are in support because they are serving as the voices of the disabled children who in many cases may not be able to use their own.