

On behalf of my child, Jayce. (09 year old with Phelan McDermid Syndrome)

Jayce qualifies for 480 hours of care. Jayce requires 100% assistance in his day. Jayce is wheelchair bound, Jayce is non verbal, Jayce weighs sixty pounds and needs fed, toileted, and meds given. Nurses get paid full time wages, therapists get paid full time wages, neurologists, doctors, and so many more. Who takes these children to appointments to continue care? Who takes them to multiple therapies a week?

Have you ever thought of all the roles parents like I, play? But remember we have to keep food in our children's bellies, we have to keep a roof over our head, we have to clothe, bath and keep lights and heat on. We also have to have vehicles to transport our children to the many appointments each week. Every week Jayce has 6 appointments that we go to during the week on top of school. If you add up the cost of living and the cost of having families, on a one income household- ITS IN THE NEGATIVE. Families cannot survive this anymore. Our disabled children deserve better!

DuringWith covid my husband finally could only work 50 hours a week instead of the 75-80 hours he'd been working just to keep us afloat. We are educated, my husband, a journeyman electrician, we almost lost our home, we couldn't get a loan for a vehicle for our children due to me not financially being able to help, we struggle every day financially to make ends meet in order to do everything we need for our disabled child. PLEASE PLEASE PLEASE think of all of the families like mine who have never had a choice but to do the best we can for our children.

This is a life changing bill for so many families to keep their children housed, warm, and tummies full. We didn't chose this life, but here we are fighting for Oregon to recognize how hard

the families of disabled children work. 24 hours a day, 7 days a week with no rest!



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