

Submitter: Stephanie Dorr
On Behalf Of:
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Measure: SB1565

Parents are required to care for physical impairment, communication impairment, development impairment, learning impairment and other conditions that substantially limit life activities for their children; however, no legislation addresses the parent's role in this substantial care.

Direct support workers/personal support workers turnover rate is around 55 percent according to Oregon Health & Science University. Who is left to care for these children? THE PARENTS!

Oregon Public schools continue to be unable to fix the special needs education staffing shortages. Yet, the draft of LC0013 withholds support hours during school days and hours. I am the parent of a special needs child who once attended public school. I received phone calls every other day to come pick him up because the staff was unable to care for him. Are you aware of a paid job that allows you to leave every other day because your special needs child can't attend school?

(C) "Except as authorized by the department by rule, may not pay providers of attendant care services, including parent providers, to provide services to a minor child during school hours unless the minor child is temporarily at home recovering from surgery or illness and the temporary absence from school is recommended by the child's health care provider"

How many parents who send their children to public school are called by the school to pick up their children due to the teacher/staff's inability to address their child's needs? This section also causes issues with parents who are homeschooling their children due to issues within the public schools? Parents know when they need support, why do bureaucracies determine hours of support?

Families of special needs children bear significant financial burden for their child's care in the form of out of pocket care, special diets, lost work hours, higher routine expenses. "This puts families of special needs children at risk of financial hardship, medical debt, and poverty. About half of the families of special needs children have lower household incomes and require the use of public assistance." This information comes from The Institute on Development & Disability Oregon Health & Science University.

The divorce rate among families with a child with disability is estimated to be above 70 percent. This means an increase in poverty and a decrease in family support. Special arrangements are needed for every departure from home, for every

babysitter, for every school event, for every community event. The child's special needs from physical to communication to development to learning all combined cause constant disruption to the daily flow. Who handles these constant challenges? THE PARENTS!

Special needs parents face criticism, shunning, avoidance, and isolation, and constant financial instability. But yet at the beginning and end of the day, who cares for these children? THE PARENTS!

The average SSI payment in Oregon is \$630.43; however, the average housing cost in Oregon is \$988 to \$1699 per month. Do you see how this discrepancy between income and housing plays a significant role in why children of special needs and their families remain financially unstable?

The amount of paperwork, the bureaucracies, the public education system, the expenses, the medical requirements, and the actual needs of the child are the challenges every parent faces every day for the rest of their lives. This isn't something they wanted or needed in their lives but they live it and breathe it everyday. They don't do it to get paid, they love their child.

A PSW/DSP/therapist/Doctor/Dentist/Teacher, ect...they are all paid to do a job. Why not pay the parent who is a teacher, a therapist, a support worker, a dentist, a housekeeper, a money manager, a chef, a taxi driver, and medical assistant?

Thank you for your time.