

I am the mother of an absolutely delightful young adult with a great sense of humor and a very fun-loving, bright outlook on life. She also has significant disabilities. I think it's important to note that her disability related care necessitates that she cannot be safely left alone at any time even now that she is grown. Generally kids at age 10 or so, could be left alone for a few hours and continuity of care becomes less of a concern for older kids and teens. That is not the case for my daughter.

In addition to support for ADLs(activities of daily living) and IADLS(instrumental activities of daily living), for nine years I managed a ketogenic diet, which my daughter's neurologist prescribed. This entailed planning, careful shopping and measuring each meal out to the nearest gram separately from what the rest of the family ate as well as managing multiple food supplements. This diet was amazing for my daughter's physical health. Without it, it's likely that she would still have frequent hospitalizations now. It is unlikely to have been successful if we relied on a rotating staff of non-family members to manage it and the amount of orientation for each new provider would have been extensive.

Until she was about 14, there were very few nonparental caregivers accessible to my daughter. After the hours were theoretically available to pay non-family DSPs, like so many other families, we could not find non-family caregivers for all the hours we needed. She also was always consistent and clear that she prefers her parents as providers, especially for assistance with very personal things like bathing and toileting.

As such, I was my daughter's unpaid caregiver for well over 40 hours a week, often closer to 80. I did this for 18 years. Now my husband and I are our daughters' most preferred paid direct support providers(DSPs) part time, along with her sister who grew up to be an excellent DSP, and non-family providers when we can find them. I have a better understanding of which parts of my daughter's schedule work best for her with non-family vs family. Being eligible for pay and not so overworked makes the extraordinary provider I already was even better. I am able to do a lot of things I couldn't before to show up much more refreshed, healthy and ready to work each shift. I am relieved of excessive pressure to earn income separately on top of my care work, and my whole household is more stable.

The ability for me to be a paid provider when my daughter was under 18 likely would have meant more stable housing for my daughter and that my daughter would have had better opportunity to grow up in close, long term friendships with peers and mentorship with other adults, secure in her wider community. This is especially important for my daughter with disabilities as she will forever rely on "informal" support one way or another throughout her life, probably long past the time that her dad and I will be gone. If I were paid from the beginning, it also would have meant that my attention could have been much less divided between the need for income and/or moving house frequently, my stresses and fears about those things and instead would be more fully on my daughter's needs when I was with her. I would have been able to afford more for my daughter: for example being more consistent with therapeutic horseback riding which was extremely beneficial for her yet expensive and wasn't covered by

insurance. And to do so without spending even more of my time seeking grants or gifts to cover individual specific needs. It would have been far easier to afford my daughter's supplements and other out of pocket costs of the ketogenic diet. In summary, if my daughter had been able to choose me as her paid provider from the beginning of her eligibility for in-home services, she would have greatly benefitted in multiple ways.

Parents go above and beyond both the DSP job description and "ordinary parenting expectations" even when there are also non-parental providers. 24/7 care equates to over 4 full time jobs. Our kids with disabilities need parent caregivers at their best possible capacity -in addition- to other non-family caregivers, school and other resources. Paying parent providers relieves the need for parents to worry too much about anything -other- than the child. It increases the total available caregiving workforce, keeping parents as caregivers who might otherwise be financially obligated to do another job reserving non-parental providers for when that is the preferred and most sensible solution. This is the same as people pay anyone else to do any other job so that the worker can focus extensively on that job. Do you think essential services like garbage collection or library maintenance would be done as effectively as it is by all volunteer staff? What if nobody was eligible for those jobs whose household received the services? The care our children with disabilities receive is similarly too important to leave to the luck and varied resources of individual families. Just because, in the absence of proper support, some parents manage to heroically provide sustained, extensive unpaid care well beyond the typical expectations in most paid jobs and also beyond "ordinary parenting expectations", does not mean that limiting the choice of caregiver is best for our children, parents or the general public and taxpayer.

SB 646 is the more inclusive and simpler of the two bills this legislative session regarding parent paid caregivers, allowing more children to choose their parent as their paid provider. I think this is very important. All children who are deemed eligible for DSP or PSW services through medicaid need to have those positions actually filled and choice among providers. There is an extensive eligibility determination process already in place. Kids who have access to any care hours via medicaid are clearly in need of extensive care. Kids who have a lesser need than others, or whose family situation doesn't line up to be able to comply with extensive rules, or whose parent's aren't skilled at very competitively recruiting non-parent providers, still have this extra care need. Because non-family caregivers are frequently either unavailable or, for very valid reasons, not preferred, then the way the general public can best support all kids with disabilities is by allowing the choice to pay the parent for such care. Bill 646 ensures that all kids with extraordinary care needs will have access to quality care.  
I support SB 646.