

03/02/23

Dear legislator:

I am writing in support of full funding for ODDS per HB 5026 and in response to Senator Gelser Buin's comments in the recent hearing on the bill. I also strongly support SB 646 to allow, on the simplest and most inclusive possible terms, parents to work as DSP(direct support professionals) or PSWs(personal support worker) for their minor children. Please also anticipate future increases in spending for ODDS.

I am the parent of an adult with IDD. I was my daughter's primary, unpaid caregiver for 18 years and now work as her paid DSP. The pay improves my capacity to care for her and would have made a tremendous positive impact on her childhood if it were available earlier. My daughter and I do not stand to gain from changes to the rules being proposed in bills 646 or 91, as she is already over 18 and already allowed to pay her father and I regardless at this time. But I still support the bills, especially the more inclusive SB 646.

In fact, I share the same concerns that Senator Gelser Bluin has for her son about my daughter's later life. I cannot, however, pit children's wellbeing against adults'. They are the same individuals over time. Children who grow up with stable home environments and consistent care are likely to require less hospitalization and less other support later in life than those who do not. They are more likely to become maximally independent. Thus, I urge you to fully fund services for people with IDD across their lifespans. Yes, and. We are talking about individuals with a high level of support needs throughout their entire lifetimes. And that includes a need for consistent, quality caregivers throughout that lifespan. I applaud Senator Gelser and the many other advocates who brought us to the current level of home and community based services. And it's time to take another step forward instead of back. People with IDD deserve full support throughout their lifetimes

These DSP and PSW(personal support worker) positions are for children that have needs clearly exceeding "ordinary parenting expectations". Children who utilize these services are carefully identified with an extensive application process to have care needs beyond that of a typically developing child. I would like to point out that a 17 year old does not typically require assistance cutting food or getting dressed. However, teens receiving home and community based services require such assistance. The evaluations for such services are already also carefully scaled to discount "ordinary parenting expectations". Thus, the youngest children already receive far fewer attendant care hours than older children and teens because the criteria presume parents already provide certain levels of care regardless for very young kids.

When we, collectively, rely too heavily on informal or "natural supports" for people with extensive care needs, we leave vulnerable individuals out. Such supports are inherently variable. A few families have a lot of resources, but many do not. I am especially concerned about kids in single parent households, kids whose parents have further barriers, such as limited English speaking, to access non-parent DSPs, and children whose care needs exceed one full time job.

All parents, appropriately, have responsibility for their children's welfare until age 18. We are the ones looked to for consistency of care regardless of any offerings from anyone else formal or informal. Parents of typically developing children are expected to make decisions about the children's care, but have many more options for hiring non-family and frequently more other volunteers besides the parents. When children have needs exceeding what typically would be expected, and to an extent that precludes working another job and limits nonparental options for care, the parents should have access to income while meeting those needs. It is that extraordinary level of care that parents are being asked to be paid for, especially when non-parental caregivers are unavailable or unsafe for our children. Parents want to be paid -while- engaging in our natural care for our kids precisely -because- we love them so much and place their welfare as our top priority.

Many of us would absolutely love to use more non-parental DSP hours, if only such hours were safe and consistently available. The testimony for SB 646 is full of examples of very valid reasons why parents do not fully utilize DSP hours by hiring non-parent caregivers. Declining such service is not a choice made lightly or without reason. It is a choice made in the context of those choices available to us, with the focus absolutely on our child's wellbeing. When the parent's choice is poverty while providing unpaid direct care, or an unsafe or inconsistent provision of non-parental care while the parent focuses on earning money elsewhere, neither of those choices is good for our children. And neither set our children up to be maximally independent and skilled when they are adults.

I applaud efforts to expand the non-family care workforce as well. That also has costs associated with it. Parents are not asking to be paid any more than non-parents already are and do not add as much recruitment and management costs to care. I think both parent caregivers and non-parent are critical. When families have choices in care, we can and will choose the best services for our particular needs. The more our options, the safer care is for our children.

Please support full funding of ODDS to meet the needs of our children throughout their lifetimes.