



Senator John Hoffman, Chair
Members of the Human Services Committee

Dear Chair Hoffman and Members of the Senate Human Services Committee,

In the past few years, our family has had many conversations about the future for David, our 38-year-old family member with multiple disabilities. He is one of three adult children, but he has always needed significantly more support and more of the family resources than his siblings. As parents, we wanted to make sure that David has the supports he needs and his siblings can accept a guardianship role in their brother's life without totally disrupting their own lives and families. With current waiver reimagine plans, that won't happen because, instead of receiving more support dollars when his parents can't provide the majority of his care, projected waiver budget guidelines indicate he will receive significantly fewer because he lives at home. David's dad has terminal cancer; as we redid our wills and David's guardianship documents, David's sister was so scared of the future as David's guardian, she declined and asked to be removed from the will and any legal responsibility for David. David's brother, who lives out of state, is terrified of doing it alone when David's mom can no longer continue because of aging, illness, or death.

In David's early 20's, we bought a duplex so he could move to his own home while we lived upstairs and could be actively involved in his transition, provide unpaid caregiving, and ensure that he had the necessary services to transition to independent living with supports. Our son has a CAC waiver (hospital level of care) and uses Consumer Directed Community Supports with a budget that is, at maximum, $\frac{1}{4}$ of the cost of the 24-hour care he would require in a traditional residential facility. In order to provide his care and life coordination, David's mom quit her job over a decade ago; she's been unable to leave David and cancelled multiple trips to Oregon to visit grandchildren; she could not/cannot provide any in-person supports to her own aging parents, and her health is being compromised from years of caregiving. We had always believed if we provided everything we could while we were healthy and able, we could rely on formal residential services in my son's duplex when we were not able. But now my friends who have implemented similar creative living situations, and rely on providers, are in crises. Providers are no longer willing to serve them, and since the current proposed waiver reimagine budgets are based on where one lives, he will never have the funding to stay in the home we created for him. Take a look at the attached picture of the keys with the word "imagine"—that was the first thing we put on the walls of his house; our dream of David having his own home with the supports that he needs in place.

Our generation is the first to experiment with more person-centered living situations for individuals with disabilities. Our situations are hard-fought struggles with a service system not designed to support individuals, no matter how much we say we value person-centeredness. Each person/family has figured out how to cobble together the supports needed through personal sacrifice, individual research, and a focus on the strengths and human dignity of the disabled adult. We are scared that our sacrifices will result in family members losing the homes we have helped create for them when we can no longer physically fight for them. The fact that the waiver system is changing to focus budgets based on where a person lives, and those in their own or family-owned homes receive fewer support dollars, means that no matter how much we sacrificed to create an independent living situation in the community and how many decades we provide unpaid supports, David will lose his home. And families of younger children in transition won't even try; they'll focus their efforts on supporting their children's transition to more expensive, provider-owned residences instead.

Our ask is this: Please support SF2215 and don't allow DHS to call David and his peers "outliers" whose supports will be figured out later in the creation of waiver reimagine or a secret "exceptions" process. Don't let our creativity and sacrifice mean nothing. Use our experiences to improve the system without yanking our family members' safety nets. Most of us would be more than willing to be a case study for the Waiver Reimagine Work Group, working with DHS to cross-walk the services we receive now to create what needs to exist under Waiver Reimagine. We would welcome visits to the residences we have created and discussions about how we did it and what we need in order to continue. We are here; our adult children are getting the supports they need in the best individualized settings; and we are saving the system hundreds of thousands of dollars each person, each year.

Sincerely,

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