

Date: 2/23/22

To: Chair Abeler and Members of Senate Human Services Reform and Policy Committee

From: Jean Bender, 1150 Fairmount Avenue, Saint Paul, MN

Re: Ideas for Cost -Effective Residential Services

Last week, Chair Abeler challenged providers, advocates, and family members to share our ideas for providing long-term residential services to disabled individuals. I've been thinking about what legislative changes might need to happen. But I realized that my family (and others I know) have already created the best options because they are individualized for the person and capitalize on each family's strengths and resources. The concern is that residential providers are no longer willing or able to serve individuals living in their own or family-owned homes.

My son, David, is 35-years-old. In his 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 DD waiver and uses Consumer Directed Community Supports with a budget that is about ¼ of the cost of the 24-hour care he would require in a traditional group home. In order to provide that care, I quit my job; I haven't had a vacation (or even an overnight away from David) for several years, except for 3 days to attend his brother's wedding in another state; I can't provide any in-person supports to my own aging parents; and my own health is being compromised from years of caregiving. I 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.

Our generation is the first to experiment with more individualized, person-centered living situations. 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. Because each 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 our adult children, we can't articulate what specific legislation we need. We can only say that 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 natural supports, David will lose his home if we can't continue to provide the majority of supports he needs. And families of younger children in transition will see that it doesn't matter in the end, so they won't even try. They'll focus their efforts on supporting their children's transition to more expensive, provider-owned residences instead of creating homes for them.

So I guess my ask is this: Don't forget about us. 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.