

Support

My name is Patti Saylor, I am a nurse working for people who self direct their DDA waiver services. I have worked for over 100 individuals and their families since the inception of Self Directed Service in 2005. I have witnessed the impact of the changes The DDA has made over the last 5-6 yrs. I volunteer with the Self Direction Advocacy Network to represent the needs of my customers, many of whom are consumed with the demands of their lives and rely on advocates to convey their concerns and work on their behalf.

I was going to illustrate to you the negative impact these changes are having through personal examples but I believe the point has been made clear to you through oral testimony.

I will instead tell you...about the human toll - In the course of my job I speak at length with my customers and their families. We laugh and we cry. I tell them it will be ok when they are no longer here... that we will protect the system so it will be here when they are not.

On a daily basis, I see firsthand the pressure they are under... **Families are the best natural resource, our State should value and protect them as such.** They continue shoulder the lion's share of financial and physical support to their loved ones. They love their adult child or sibling **This love and commitment should not be exploited by the government.**

While they are grateful for any and all support they get from the State. Grateful for more flexible services during the State of Emergency, they are exhausted... they are frustrated, they are angry and they are growing more fearful.

- For over eleven months along with the rest of us, they have protected themselves and their vulnerable loved one from COVID.
- Only 30 individuals who self direct their services reported testing positive for COVID. A clear benefit of not living in a congregate care setting. No deaths have been reported.
- Family have taken on the role of direct support to limit exposure from staff coming in.
- Endured economic and work pressures and gotten very little sleep and no respite.

In addition to this, they are being **overburdened by the growing bureaucratic system** of red tape, MDH/DDA systems that do not work and policies that **limit choice and control** over their lives. They must simply passively endure if they want services. Or it may be suggested if they are not "happy" perhaps self direction isn't right for them. When for most Self Direction is the option.

They/We need your help to alleviate what pressures you can – This Advisory Council gives them hope that their voices and concerns will be addressed and their lives become more manageable during and after the pandemic

