

Written Testimony Regarding the Impact of WR on People Living in Their Own Home

Chairman Hoffman, Committee Members, and Mr. Zak,

Thank you for allowing time for us to comment on the effects WR will have on our family.

My name is Alice Hulbert. I am the mother of four children, one of whom has tuberose sclerosis resulting in substantial disabilities. He depends on waived services for support, and without support he would find himself in life threatening situations on a daily basis. He is 38 years old and lives in his own home after trying and failing in two attempts at group home living. Under WR he will have two choices- remain in his own home without enough support to maintain his health and safety or move back to a group home.

I am a retired physician and have always been involved in my local and professional community, having served on my city Park Board, City Council and its associated advisory committees, the Mn DHS State Quality Council, and the MedPAC Board of Directors.

All of these community organizations invite and value input from the people they represent and serve, except one- the DHS State Quality Council.

I participated in the SQC monthly meetings for six years. We never once heard from any individual regarding complaints or compliments about the services or facilities overseen by the DHS. All agendas and discussions were tightly controlled by DHS to the point that the group was totally ineffective. I see the same pattern of control over the waiver Reimagine Advisory Committee, and throughout the culture of the DHS.

They stay in their silo, work in secret, have controlled ineffective advisory committees, and use spin and longevity to escape making any changes.

From my time on the MedPAC Board I learned that if you aren't at the table you are on the table. We families of people living in their own homes are on the table. The DHS will not respond to our concerns. Setting two vastly different budgets and program options for the same individual based on where they live is sending the message that DHS wants people in institutional settings.

We need the WRAC to be unmuzzled and to function as intended, to provide input and representation for individuals that actually brings change to the planning process. At present their only option is to rubber stamp.

Ultimately Mr.Chairman, it is the responsibility of this Committee to direct the work on WR when it has come off the rails. DHS has said this hasn't happened therefore it doesn't need to change. But the effects are being felt. Fewer providers are willing to serve people who live in their own home because they can make so much more money by having them move into a group home. It is a perfect storm to destroy the possibility of living in your own home in your chosen community for people with disabilities- a staffing crisis, less qualified staff when available, so few hours

allowed for care that needs can't be met... so group home living with a far higher price tag is the solution under WR. Don't let this be the future!