

Senator John Hoffman,
Chair Senator Jim Abeler, Minority Leader
Members of the Human Services Committee
2111 Minnesota State Senate Building
Saint Paul, MN 55155 March 18, 2024

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

My name is Kathy Ware and with me is my son Kylen Ware and his staff Kelly. I am a Registered Nurse and a Certified MnCHOICES Assessor and former Waiver Case Manager for the past 17 years. Kylen was born missing the MEF2C gene which results in significant disabilities. Kylen is 29 years old and has always lived at home with his family. He is meticulously cared for by me and by staff that I hand pick and train. Kylen lives an integrated and inclusive life in his "own home" where he is loved and adored. He is active in his community attending Saints Games, going roller skating, and attending University of St Thomas basketball games. He has had the same physical therapist and music therapist visiting him weekly at home for the past 10 Years. This life has been possible for Kylen using Community Alternative Care CAC waiver with self-directed Community Directed Community Supports CDCS which eliminates a reliance on formal providers and allows us to self-direct his waiver dollars.

Waiver reimagine will end Kylen's life that he has always known as MN DHS DSD returns to a forced reliance on formal agencies to provide Home Care Nursing. Waiver reimagine will coerce Kylen into a 4 person "provider-controlled institution" where AT BEST he is ignored and neglected and at worst he is physically and emotionally abused. Waiver reimagine will ruin his person-centered life that Kylen currently has in his "OWN HOME" and at the same time increase cost to taxpayers by over \$500,000 every year for what counties and the State have accepted and acknowledged as sub-standard abysmal care. Group home CRS providers have no accountability for the money they are paid and no consequences for being neglectful and irresponsible. Provider Controlled Community Residential institutional group homes rarely meet the basic needs of the person and NEVER meet a person's support plan goals for social activities and any actual choice for activities outside of the confines of the home. Kylen when forced by waiver reimagine to live in congregate care will never go roller skating, attend a Saints game, or UST Basketball game again. He would sit in front of a television all day and likely die within a year of a pressure ulcer, bowel obstruction, or peritonitis from his G/J tube site due to neglectful care.

I am asking that you prevent the Department of Human Services Disability Division from Waiver Reimagine changes that force a reliance on non-existent formal providers and defaults to Provider controlled group home for Kylen's life which is anti-Integration and anti-inclusion and ultimately against the laws as we know them.

With Sincerity,

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