20th March 2023

Dear Committee Members,

This letter has been a long time coming. I struggle to put into words the reality of the shortcomings within the current system that has a detrimental impact on the healthcare and basic human rights within the disabled population. The *struggle* part has been how to convey such a personal issue in a way that does not come across with a complaining tone. As you read please understand even though I am shining the light on a ginormous issue that plagues anyone that requires 24/7 care to just meet their human needs, there are aspects within this system that work. When care is implemented by people that are going above and beyond and are truly trying to make a difference for others. I am grateful for all the programs my sister and thru extension myself have been afforded that are vital for us on a daily basis.

With that said there is a great deficit that many are shining the light on when it comes to the vital services my sister's population requires. I have been my sister's legal guardian since the county approached me over twenty years ago. This responsibility is something I took on for my sister's well being and gladly "stepped up" out of my love for her. At the time this just meant I was to be her advocate and decision maker to ensure she received the highest quality of care possible. I took on this role while she was living in a licensed group home that provided her the 24/7 care she required while allowing her the family-like environment she deserved. This living situation allowed me to raise my young family and live my own individual life that I also deserved.

In time, I was presented with the reality; the home my sister had known for years could no longer meet my sister's growing digestive requirements citing state requirements they had to fulfill. In conjunction, I had a front row seat to the realization that the people on whom I relied so heavily on to care for my sister were operating on limited training and an astounding low rate of pay. Often, I left her house feeling frustrated that such a vital position was valued so little, as reflected in the extremely low pay and benefits these workers received. I learned not to get attached to any of her caregivers (DSPs), knowing ultimately they would move onto a position with livable pay and realistic work hours. This is a decision I could never fault anyone for making.

I moved her to an independent living home. She had two roommates in a regular home and an agency that provided 24/7 care for her and her roommates. This arrangement allowed her to have her personalized care requirements met that her health status required. While still living in a "family" style home. Which again allowed myself, her sister and guardian to finish raising my family and begin my career as a Registered Nurse. This arrangement, of course, was not without concerns. Again the lack of pay and benefits consistently resulted in extremely high turnover of staff. Unfortunately, this always ultimately leads to a lapse in quality of care for my sister. There is a difference between someone physically there to keep her safe and someone that is providing the care her level of disabilities require. The pay and benefits this field currently offers does not and cannot attract the individuals that are required for this intensity of care.   The current offering breeds poverty and a lack of familial comfort; ultimately, leading to a massive shortage of caregivers in this field. I, along with thousands of others caretakers and loved ones, are made to continue to live with the constant fear that one day I may get "that" phone call. The call from the agency I hired to provide vital care for her would call to tell me they just don't have staffing and can't provide care for my sister.

That fear manifested into reality in the beginning of the pandemic. I was increasingly receiving phone calls about staffing issues that were quickly leading to the resulting decision. My husband and I decided it was time to bring her into our home and keep her safe while we waited for things to get to a place where she could safely receive the care she deserves. Mournfully, this solution ultimately required a tearful resignation from my nursing position at a local hospital. My husband, for whom I have insurmountable gratitude, postponed his early retirement that his own health drove him to need.

There are all too many details that really paint the true picture this staffing crisis has caused; I cannot possibly put them all in one sole letter. I encourage anyone reading this to reach out to me with ANY questions I have prompted and I will gladly expand on the things I have mentioned in this letter. There is much more to our story than what is written here.

Alicia is here now. We have gotten into our new family routine during a time when my husband and I were expecting to be *empty nesting*. The last child is moving out within a month and we were looking forward to the typical time most parents get to put the focus back on them as a couple. As hinted before my husband has some cardiac issues that made this time even more special. I am grateful for every day I have him and how well he is doing. We are her only caregivers. Alicia requires aid in everything she does and needs. My husband has recollected the level of care she requires to having a full grown toddler again. Even though there is much joy Alicia has brought to my life and now my family's everyday life, it is still an emotional and physical struggle.

Could you imagine living with the question everyday; *Am I choosing one loved one's life over the well being of another loved one's life?* This is my new found reality. I did everything I was supposed to do. I raised my own kids. Put myself through college. Became a critical care registered nurse. Paid my bills. My husband and I created a life with which we were comfortable enough to allow him to retire early after his own health issues. Instead that financial plan that was so clear and promising has now been redirected to just allow me to care for my sister. The future seems so convoluted and uncertain now.

You see, she is my sister, not my child. This fact does not change my devotion or love for her by any means. It is a fact that naively left me not thinking I needed to personally financially plan for her care. She and I are both in our forties and I am too young for any government healthcare plan. This is a harsh reality that I have on my mind. I cannot retain employment with healthcare benefits during my limited 5 hour window of availability while she is at a day program during the week. If something were to happen to my husband's ability to financially support our household, my lack of income would be sorely noticed. The stipend I receive as her daily caregiver is so low it would be a major blow to my financial stability if I had to start paying for healthcare from the Ohio Shared Living compensation I receive.

I bring this up since it is a *real* issue that affects my family's health and daily life. We cannot be the only ones experiencing these tough decisions and emotional hardships. We have flipped our life around to care for my sister since that is what *she deserves.* Strangely, the state and taxpayers are benefiting greatly from the cost we are saving them by her living in our home and us providing care 24/7. Still, the system is set up in a way where her waiver was cut in half since she is living with a family member. We are left with no budgeted funds for respite care to care for ourselves let alone utilize my degree and accept even a part time nursing position. This is compounded with the fact the pay is so low there are not many people to provide respite care if we were to have the funds to pay due to the lack of money and benefits that field provides.

This struggle I share with you in this condensed story of our life is literally a heartbeat away from falling apart like a house of cards. I hope everyday that I will make the right decisions that day that will allow me to care for my sister. With the way funding is right now I am one decision away from this all tumbling down.

We need to start talking more about this and the real costs this crisis is having on people. We need to understand that my family's hardships are unfortunately not unique. This is a scenario that *will* in some way eventually touch everyone's life, even if the connection is not clearly seen.

Please reach out and speak up. Please help get these issues resolved. Reach out to myself and others and share in ways we can improve these issues. Help get the legislature passed that truly makes a difference.

Sincerely,

Emily Parrott

Sister, Wife, Mother, Caregiver and RN