

Dear Governor Gregoire,

Recently, I learned of a task force which has been mandated to study long term caregiving within the state. This is a very personal issue for me since I and my family are the caregivers of our 26 yr. old disabled son and brother. Our son/brother, Nathan, has multiple medical issues on top of numerous developmental delays. He is non-verbal and has not learned any form of communication other than fussy noises and limited gesturing. Autism is part of the picture as well as being totally dependent on others for his daily needs including diapering. The list of medical issues literally goes from head to toes. The caregiving challenge is even more complicated due to not knowing if his fuss noise is related to a physical discomfort or merely a need or dislike. Trying to be brief in describing Nathan's needs does not reflect the magnitude of the 24/7 caregiving challenges, patience, energy and diligence required. Throughout his 26 years I have pursued any information that I thought had some relevance to his growth, learning, or caregiving. I wish I had kept track of all the workshops I have attended through the years in hope of finding some clue, some small idea of how to do something different that would improve his life and ours. There was a sharp learning curve in the beginning, and for many years, before the workshops started being less new information and more redundant. Nathan's dad has his Ph.D in biochemistry and I have my M.S. in nutrition and we continue to absorb medical and disability information hoping that new information may be helpful. When a discussion concerns our son, we are the experts of his current caregiving needs. I believe this is true for most parents who are caregiving for their disabled adult children at home.

The reason I am introducing our family to you and sharing these thoughts is that I am quite distressed about the information I have received that there is no parent of a disabled adult child or any disabled child on the task force. I understand that the definition of "long-term care provider" has already been decided, prior to the task force, and that it includes parents and occasional caregivers as well as those who have chosen this field as a career. It may simplify the picture to put apples and oranges in the same orchard, but you can't treat them as equal in the growing process. The same is true for caregivers. I remain upset and extremely frustrated with the proposed idea that parents need to have additional basic caregiving training of their disabled adult child or the option of being tested on their basic caregiving skills. Is there a parent anywhere, who has nurtured their disabled child, who would not be upset with this proposal? I wonder how parents of typical children would react if someone suggested that they had to take parenting classes. Parents in our situation are evaluated annually by a DSHS case manager in the home and if there were concerns about the quality of caregiving the adult child is receiving then it should be addressed on an individual basis.

Requiring training or a competency test for parents of disabled adults is not only ridiculous and an insult, but considering the cost to the state is ludicrous. The lack of funds in this state for services for our children is disturbing to say the least. The case load that DSHS case managers are expected to supervise is unreal. The statistics and information available in these areas make a strong case that these should be the priorities for the budget, not parent training.

My husband and I are 59 and 60 yrs. old and we have managed to do the caregiving without the help of occasional caregivers outside of our other children. This may change in the future as our other children create their own lives. I worry that the proposed

training will dramatically decrease the number of people willing to help a few hours here and there. Full time caregivers wouldn't be available for this occasional work and the summer time or weekend college/high school student, or next door neighbor, would not be willing to go through the training at the number of hours being suggested. From all that I hear, I fear the future even more.

I have so much more to say but realize that I shouldn't try to do it all at once. As I review the task force members' job titles, I see the overwhelming number of administrative positions, and the SEIU representative. I question why there is no one at the table representing parents. This just doesn't seem right especially when there is a SEIU representative and the SEIU will financially benefit from the training proposed. How can this be fair that they are at the table and not parents? I seek fairness, logic and reason and hope that you find my concerns valid and can give guidance to make sure that the task force has studied the issue of long-term caregiving from ALL angles. I would be more than happy to discuss this in greater detail or share with you more thoughts related to adult developmentally disabled issues. The hope that there will be some medical breakthrough for our son has long since faded. Now I can only hope that my voice and concerns will be heard.

Thank you for taking time to listen.

Sincerely,

Martha Schulte, mom, primary caregiver, and legal guardian

Tom Schulte, dad, and caregiver