



Meet Desi – AKA Desmond Langston

testimony by Carol Custer

Desi has been living with multiple disabilities since being born prematurely. He has intense medical and physical needs. He has a staff of four non-family staff that have worked with him and provided excellent care for at least three years and some as long as 15 years. He loves his staff and wants to keep them with him when he moves into his own home that his parents, now in their 70's, have had built for him in 2020. Desi needs the consistency of having these staff to be successful in his own home and transition to a time when his parents are no longer able to support him in any capacity. A time that all parents with adult children with disabilities fear.

But, despite only needing an additional 21 hours of support to make the move, Desi can't move into his own home

Why? Because DDA policies do not allow him to have all the personal support hours he needs. DDA has been trying to force Desi into a provider-managed service to get his overnight support needs: Supported Living.

Desi will have budget authority over this service, but all that means is that he will be able to pick the agency that provides the service. He can't set their rate; he can't even get his staff to continue making their current hourly rate or keep their one benefit of getting holiday differential payment if they work on a one nine holidays.

You would think that DDA is doing this because this other service will save the state tons of money, but that would be incorrect! This option will actually cost the state a minimum of \$44,000 a year, but more likely over \$70,000/year. Please see the attached cost break down of the service based on DDA's proposed rate, what one provider offered to pay, and what it would take to match his staff's salary.

Desi and his team have been working over a year to get this resolved. During that time, Desi's house has been finished and sitting empty for over six months. Desi's mother's health has deteriorated because of the stress of dealing with Covid19 and the unresolved situation. No one from DDA offers solutions or help. They continue to state that Supported Living is a cost-effective service and he needs to pick an agency.

However, Desi's team has reached out to over 14 agencies, most of which never responded to the call or email. Those who have cannot come close to Desi's staff current salary and benefits. Many are not interested in working with self-direction. Desi faces the very REAL possibility of losing his treasured staff if their hourly rates are reduced. This situation is **LOSE -- LOSE.**

HB318 offers a way to give Desi and the State a WIN – WIN!

Please help Desi and the many other people in our staff caught in this situation there are a lot of them and there will be more.