

## HF 1043 WRITTEN TESTIMONY

### Testimony concerning HF 1043

#### Task Force on Disability Services Accessibility and pilot projects

I am the parent of an adult son with multiple disabilities. Professionally, I was a service coordinator for children with disabilities until I had to resign to coordinate (and provide the majority of) David's supports in his home and community. I have continued to assist and advocate for other families as a volunteer because I understand the complex service systems and barriers to access.

Despite my privileges of experience, education, system expertise, social capital, and white middle class background, I have had to file multiple appeals for goods or services denied to David over the years. Reasons given varied from not enough documentation, too much documentation (case manager missed the "magic words" until I cited page, paragraph and sentence where they were written), case manager opinion of what is "reasonable" (individual bias), new case manager not knowing what was allowed, county guidelines stricter than state, no knowledge of previous appeal decisions or service approvals. It's worth noting that several of the appeal hearings were cancelled because the county agreed to provide the services after we filed, and we won all appeals that went to hearings—**because I am good at keeping records, filling out forms, documenting needs, and explaining why the requested items meet the needs and are allowable under waiver guidelines.** A visit to any online forum or Facebook group for individuals with disabilities and their family members demonstrates the inconsistencies in accessing services depending on county, language or culture, individual case managers or their supervisors, companies providing services, etc. Consumers should not have to be experts on the systems they are trying to access, be able to use the scripts required or DHS jargon, or personally know an advocate who will assist them.

I believe the proposed legislation will result in a more equitable service system that is easier to access. Establishment of the task force will be the first step towards identifying specific access barriers, and the pilot programs will address potential solutions. The preview process and communication about proposed actions would allow consumers to address any lead agency questions or concerns before moving to a time-consuming and costly appeal process. A peer navigator program will formalize and expand what already occurs haphazardly—those who are connected to someone who knows how to navigate systems are more likely to successfully get the necessary supports. Instead of being an additional burden on people with disabilities, our disability programs can be the systems of support they are intended to be.

**Please support HF 1043.**

Sincerely,

**Jean Bender, David's Mom**  
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**Saint Paul, MN**

