SB 538

After four years of advocacy, writing another testimony on why children need access to parent providers is a challenge. In the past, I've shared both heartfelt accounts of my life as a mother and detailed reports on attendant care utilization, costs, and equitable access. Over time, I've realized that our biggest obstacle is outliers who refuse to allocate funding. Without their support, our most vulnerable citizens are unable to utilize the care they need to live safely and independently in their homes and communities.

Today my oldest child, who had just turned six when I began this advocacy, said to me;

All these years you have been going there and telling them about the kids and all these years they don't listen. So, I don't think they are going to listen this time either.

She is now ten and advocating for herself, for choice on who provides her care.

I told her, that is why we keep trying, and that is why her voice is so important.

But we can only yell so loud.

We need the outliers to listen.

Asking to ensure every high support needs child has access to 40 hours of their attendant care, is a minimal ask.

Asking that children not be put on a waitlist decades long, is a minimal ask.

Asking the state to fulfil its promise to disabled children, is a minimal ask.

If the state cannot appropriate funding to cover a small percentage of attendant care hours for the highest needs children, it exposes a much larger problem: spending priorities that fail to support the populations who need it most.

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