

Submitter: Haile McIntosh
On Behalf Of:
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Measure, Appointment or Topic: SB538

My name is Haile McIntosh and I have been a caregiver to children with high needs for 8 years, 8 months. I began caring for my godsister the moment I turned 18, took some online training courses that were easy to mindlessly click through, and signed some papers. By that time, she was five years old. By that time, she had undergone several surgeries, including brain surgery and g-tube surgery. By that time there was a 5 year list of incredibly complex, traumatizing, and unimaginable conversations, and appointments. 5 years of sleepless nights, holding, pain, grief, love, joy, care, and endless scrolling through lacking research and dead ends, trying to find answers on her behalf - 5 years, held greatly by her mother and the hands of those who shared in it with her. She taught me how to g-tube feed, and administer medications. She taught me what to do when her daughter has a seizure, and so much more as things have endlessly changed and we have learned together over 8 years and 8 months. When I was 19, I began care with another child who has complex medical, high-care needs. Her mother is a nurse, who has taught me endlessly about how the shape of care is in constant flux, about attunement to changing needs. By the time I began care with her daughter, their family too, had a 5 year long list. You learn a lot in 5 years when your kid's life depends on it. Over the years I have seen dozens of caregivers come and go out of the lives of these people who have become my family. I have seen the pain and confusion these young people feel at the cycles of people coming and going, abruptly entering their most intimate moments, abruptly beginning to be with their bodies in the most intimate ways, and then gone. Again and again. These cycles and the impact of them are one thing that could be avoided for many, were children able to choose to have their parents provide the necessary care they are often most capable of providing. Children deserve the choice to be with their parents, and parents deserve to fulfill that choice without their ability to eat, pay rent, and meet their basic needs being on the line in the face of it. It is a shame that these children and their families have to metaphorically remove their clothes on stage, pull out their stitches, rip open their wounds with bare hands, and shove peoples eyes into the microscope that is on them, in order to be heard, believed, and given the least that they could ask for. Yet I have seen them do just that, over and over again. So hear them. Hear us. We can do a better job getting people the care and resources they need. We are fully capable and resourced to make it happen. We must demand together that people's lives and care matter more than the profits and power of few. We must do better for these kids, for each other. Pass Tensy's Law.