

Iryna Maitta  
Testimony on HB 33  
Supporting the DD Workforce

My son is now 10 yo and has been on Medicaid Waiver program since 6 mo (when he first was discharged from the hospital). He has RYR1 gene mutation that led him to be vent/trach dependent, g-tube dependent, complete immobility, scoliosis. As a result of all of the health issues, he needs 24/7 supervision. His current plan includes 16 hours a day of nursing care. For the last 3-4 years it has been almost impossible to find a nurse. He has not had a nurse for weekend day or night shift since he was 5 yo, night shift nurse for workdays since he was 7 yo and for the last year he has not have a nurse for workdays day shift. Not having night nurses does not give us, parents to get adequate sleep (need to wake up at least twice a night to turn him, change diaper, feed). Lack of day shift nurse limits our ability to attend to our other kids' needs such school events, school pick midday if needed, attend doctors appointments for my special need son (two people are required to go with him anywhere), etc. Both parents are required to excuse themselves from work for any appointments so one of the parent can stay home and the other one go to appointment, meeting, school event, after school activities for our other 2 kids (13 yo and 6 yo). Additionally, the quality of nursing services has decreased significantly and many candidates we have tried over 5 year period did not even have basic understanding of hygiene requirements when caring for the patient with respiratory needs. Lack of nursing has caused our son to miss school this year. It would be really appreciated if nurse's salary levels are properly adjusted so more people are willing to work in home care services through Medicaid.