

Submitter:

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On Behalf Of:

Committee:

House Committee On Health Care

Measure, Appointment or Topic:

HB4040

I am in favor of the proposed changes to allow parents whose children are on the CEN (children's extraordinary needs) Medicaid waiver to work as a PSW (personal support worker). I am the parent of an adult with intellectual disability who is grateful that she can now hire me as a DSP or PSW. All nonparent employees who work in a similar capacity can be hired as either a DSP or PSW. Allowing parents to work as a PSW would save the state money due to lower administrative costs (the agency gets a good amount for its part in DSP hiring and employee management), allow children and families more flexibility and choice and allow more children to be served by the CEN waiver (because of the lower costs). Opponents argue that if parents work as PSWs a) parents will receive less training and accountability, b) children will have reduced choice and self-determination, c) leading to challenges when children reach adult age and that d) there will be difficulty changing to outside providers if caregiving income is the family's main or only income. I would like to address these concerns: a) Training is required similarly for all PSWs as DSPs. This will not change. The child also still has many other points of interaction with nonfamily case workers and other oversight including yearly ISP (individual service plan) development and usually going to school where they interact with nonfamily teachers and staff. b) Children actually have more reduced choices by prohibiting parents to work as a PSW. Such imposed limitation is what limits choice. Besides which, all children regardless of disability are always under their parents' guardianship. Parents are always expected to make many impactful decisions in their children's interests as well as assigned responsibility for their children's welfare. c) A child has the best chance of success in transition to adulthood when their needs are well met early and consistently. Allowing maximum choice for which paid provider and which service terms allows families to give their child the best developmental experiences possible. d) Again, there remains other oversight if parents work as PSWs. There are requirements for nonfamily oversight already in place. And for most kids their parent is their preferred provider, does have the child's interests very well at heart as demonstrated by parents doing difficult and extensive disability related care work for free. In summary, please remember that the vast majority of parents work extremely hard consistently to enhance and support their child's age appropriate independence while maintaining safety and do not want to isolate their child or just get a paycheck. We cannot assume ill of parents, especially while asking them to do upwards of two full time jobs worth of disability related care needs without pay. All the parents I know consistently want at least some of their child's Medicaid service hours to be with nonfamily providers, but struggle to fill those positions, and/or their kids go to school where they are actually away from the parent all day. It's pretty outrageous that some people presume parents (by which we mean moms, since that's who usually provides direct

care) are inherently less trustworthy than nonparent paid providers (whom one would presume, mostly want a paycheck). That bias against parents is completely opposite what I have seen from hundreds of parents (by far mostly moms) I've had the privilege of knowing who provide by far the highest quality care and are their child's strong advocates. Without paying parents and offering maximum flexibility, you leave families in deep poverty while they provide care for their children anyway or facing some horrible choices which include seeking full placement for their child outside the home, where the state would pay much more for care. It's very important to open as many spots on the CEN waiver as possible.