

To Rep. Morrell and Mr. Hall:

I was unable to attend the last meeting but was informed by some parents in attendance that additional information and clarification may well be helpful in avoiding bad outcomes for people with developmental disabilities relative to the workgroup's recommendations. To that end I'd like to again provide some input.

I recall a few years ago liberally using the word respite when referring to the relief my wife and I receive when getting help from a care helper in looking after our son Michael. What I learned from the folks at the ARC and others in the "system" is that there are indeed respite funds but those dollars come from a different "bucket" than say Medicaid Personal Care. I was told it was import to know the correct nomenclature and source of funds when talking about these issues.

Most certainly this is true and is good advice. However, it is also true that from the daily life of a parent's caring for a son with developmental disabilities call it what you will, respite, relief, emergency support, care giving, care providing, etc. is the greatest "gift" available to a parent to help nourish and sustain the daily care for a son or daughter. What name and what bucket of money such help is tied to matters only when there isn't enough or for that matter any available to help and when a "HB2284" surfaces dragging us (people with developmental disabilities) into a forum where we don't belong and only complicates the task at hand. Here we are trying to explain the differences and similarities of respite care, Medicaid personal care, emergency and crisis care and illustrate that for us the effect of the bill as written will create more challenges in recruiting people to give us some respite/relief. The number of hours available to us from any one of the above buckets mentioned aren't enough and are certainly too few to be thrown into the professional care provide career track. Professional and non-professional care providers together represent a "pool" of people we look to when in need of medicaid personal care help, respite hours, or emergency support. For us it is usually the non-professional that meets the need and it is that non-professional that will vanish from the workforce if more training hours are required.

As you have repeatedly heard, ours in the main is not a medical/aging model and what is now written will cause us great hardship. The current 28 hour Fundamentals course has proven to be a recruiting deterrent when hiring a non-career path care helper to come to our home for 10 – 20 hours per week. The "non career path helper" has been the backbone of our support system for 15 years. What they need to know they learn on site. It is not a specific skill set that's important it is geography that is essential. When interviewing I ask where do you live and where do you work? Being in close proximity to our home is paramount because the care helper comes to our home only for a few hours at a time for not very much pay so a long commute would quickly result in high turnover. If this attempt to further the aims of the professional care giver is in place it will most certainly displace those in the workforce that we have relied upon. That which narrows our choices and options is not good for us.

It is unfortunate that this bill has for us the "dragnet effect". If we have to leave the "forum" with some training requirement at least make the curriculum relevant and let the number of hours be dictated by the content. I would estimate that a relevant curriculum could be covered in six hours. The real learning again takes place in the home.

Earlier I said that the care help we receive is a wonderful gift. There are thousands of parents who receive no such help but are on waiting lists hoping that they can get 5 or 10 hrs per week of relief. In light of this it is disturbing, to say the very least, that we are on track to spend something north of \$100,000,000 for a perceived need that is questionable in concept and has little data to support that stated need.

Respectfully,

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