Serena Burks Interested Party Testimony on House Bill 606 House Civil Justice Committee 5/26/2020

Chair Hambley, Vice Chair Patton, Ranking Member Brown and members of the House Civil Justice Committee, thank you for the opportunity to provide testimony regarding House Bill 606. My name is Serena Burks. I'm a 37-year old, married mother of three. This bill will directly impact my family as our 7 year old has a rare disease, which is why I am contacting you today.

As the parent of a child with a rare disease, Kabuki syndrome, I know first hand the difficulties and challenges faced by our disabled population. Jaxson will be 8 in July and has already undergone 19 surgical procedures, including 2 open-heart surgeries (he has a mechanical valve now), multiple skull/brain surgeries, and more. He has a compromised immune system for which he receives infusions. He has vision and hearing loss, hypotonia, and is globally delayed. Despite this, Jaxson has a very happy demeanor, is extremely social, and doesn't let anything hold him back! He is a warrior.

Committee members, I would ask that you strictly revise the language of this bill. It is broad, far-reaching, and vague. It will have a large detrimental impact on the disabled community specifically, but also the elderly and even "typical" families who could potentially learn about underlying health issues the hard way. Viruses can trigger dormant genetic mutations which cause autoimmune disorders, among other things. Depending on age, certain heart conditions can go undetected until a problem arises. So while this bill directly impacts those of us who know of potential problems, it also impacts people who are otherwise unaware there is an issue.

My son receives the best care possible at Nationwide Children's Hospital, but doctors are people too. Business owners are people too. Everyone makes mistakes. COVID-19 does not earn ANYONE a free pass. No virus or disaster should. What if a surgeon is operating on very little sleep and accidentally makes an improper cut, resulting in the death of his/her patient? That has nothing to do with COVID-19, yet this bill would exempt the doctor from any disciplinary action or lawsuits. There are guidelines, rules and regulations in place in the healthcare sector for a reason. Passing this bill takes away the purpose of the medical review board and any authority they might have.

Businesses which do not follow the guidelines should absolutely be held accountable for their actions. If this bill passes, imagine how many businesses will NOT follow guidelines because of its cost, knowing that the citizens of Ohio have no recourse. If a business allows too many people inside its doors and doesn't enforce social distancing rules and someone contracts any illness, not just COVID-19, and that person suffers complications from that illness, the family has no recourse against the owner who decided not to follow the rules.

We are already taking extreme precautions by having only my husband leave the house and not interacting with anyone outside of family. This includes not allowing Jaxson's older brother,

Jeffrey (11), to play with his friends outside, or allowing Jaxson to have play-dates with his friends. It includes a very real possibility that I will have to homeschool both children while caring for their sister (11 months old) and working from home. All of this already puts a huge strain on our family, so imagine how we would fare if someone got sick or dies due to negligence and we have no recourse.

Add in that this bill gives medical providers legal authority to refuse treatment for a variety of reasons. Imagine if Jaxson suddenly presented with a life-threatening problem or something that hasn't yet been diagnosed and doctors refuse to treat him because they can. We have already experienced this in a sense. Jaxson needs to see an endocrinologist, I believe he is hypoglycemic. But because of COVID-19, he hasn't been seen yet. He has had a sleep study rescheduled (he has sleep apnea, which needs monitoring), a dietician appointment canceled, INR checks are modified and done in front of the hospital as opposed to on the hematology floor where exposures of any kind are deadly. Occupational therapy is done via telehealth, where I'm acting on the therapists directions, which is not the same as a licensed therapist providing treatment. If his heart would decide that it's time for his valve to be replaced, this bill would allow the hospital to deny the surgery altogether, putting unnecessary strain on his heart and lungs, which makes him even more susceptible to respiratory illnesses and can lead to death. It wouldn't be the first time I've seen him flatline, but it is my sincere hope to never see it again.

As you know, the COVID-19 pandemic has a disproportionate impact on people with disabilities. HB 606 puts individuals at an even greater risk of illness or death and allows businesses to injure, infect, or kill people without any liability. This testimony will address two provisions of the bill that will have a disparate impact on people with disabilities.

- 1) HB 606 will disproportionately impact on people with disabilities receiving care in hospitals, congregate care settings, and in home and community-based settings. The bill exempts healthcare providers from lawsuits and professional discipline for all negligent and reckless acts taken, or omitted, during the COVID-19 pandemic. This provision would provide a broad shield for healthcare professionals and allow discriminatory action against people with disabilities. Specifically, the bill prohibits individuals from taking legal action if a provider does not treat an individual for COVID-19. This puts individuals with disabilities living in congregate care settings and in home and community-based settings at an even greater risk of contracting the virus and potentially death.
- 2) HB 606 has a disparate impact on employees with disabilities. The bill prevents businesses from being responsible for the transmission of COVID-19 regardless if the employer has taken necessary safety precautions or not. As you know, people with disabilities are more likely to contract COVID-19 and as the economy begins to reopen it is critically important for businesses to take all precautions to protect their employees. Not following the recommended safety guidelines will put employees with disabilities at greater risk of contracting the virus.

Furthermore, HB 606 does not have an effective end date and provides immunity to providers and businesses during any public health emergency essentially ensuring long-term immunity for negligent behavior. The language in the legislation is overly broad and would have a disproportionate impact on people with disabilities in Ohio.

I would like to thank the committee for the opportunity to share our story and provide insight into our world. The disabled community already has to fight for so much, we already have to make our own adaptations to make life as "normal" as possible, please don't make it more difficult or stressful. I pray you take heed to these words. I would be willing to share our story to the entire House, should you desire. I can be reached for comment at 614-581-1821 (cell) or by email at serena.burks@gmail.com.

Thank you,

Serena Burks