Testimony on H.B. 465 by Dr. Jennifer R. Brumfield

Parent and Disability Advocate 4/14/2024

Chairwoman Schmidt, Vice Chair Miller, Ranking Member Denson, and members of the Families and Aging Committee,

Thank you so much for the opportunity to testify in favor of H.B. 465.

My name is Dr. Jennifer Brumfield and I am the founder of the C8 Foundation. I also own Finding Your Identity which is a private counseling agency. I have a doctorate degree in counseling. A masters in clinical counseling, a masters in human services and a bachelor's degree in multidisciplary studies with a concentration on psychology and accounting. I have been married to my husband for 32 years. He is CTO of a computer consulting firm. He has a doctorate degree in stragic leadership, a master's degree in human services with a concentration in executive leadership, and the same bachelor's degree that I have. He is also the Chairman of the Mental Health and Recovery Board of Wayne and Holmes County.

Together we foster parented for 14 years having over 100 children come through our home. We took the most difficult medical children that existed in the state at that time. We also took sibling groups, single children, emergency placements, and an occasional healthy newborn or young child. We completed our family in 2010 with the adoption of Carston. He made our 4th son and we also have 4 daughters. Making a grand total of 8.

Three of our sons had or have qualified for DD services and had IEP's. Many of our foster children also qualified for waivers. Included are the abbreviated stories of our 3 sons that are or were involved with DD services.

Our son Clayton was non verbal and non ambulatory and everyone had given up on him making progress when he entered our foster home at age 6 and weighed just 26 pounds. The police that removed him thought he was around 2. He functioned like a new born. He couldn't roll over or sit up. By age 18 he could walk if you held his hands and walked backwards with him. He had the best sense of humor. He pranked every new nurse that took care of him. I tried to warn them but he still got them. You see when they went to give him a bath he would hold his head under water until the nurse was sure he was drowning and started to yell his name. He would then vigorously raise his head out of the water and laugh so hard. He came so far in those 12 years.

Cj was born with most of his insides on the outside of his body. When I got the call to take him they asked me to come take this baby home and love him until he dies. We met him on his first birthday. They were sure he wouldn't make it until his second birthday. According to the director of the special needs clinic at Aron Children's hospitals testimony, CJ was the most complicated child he had ever seen. He has had 35 surgeries and we celebrated when he was 3

and managed to stay out of the hospital for 30 days straight. Cj will be 20 next week. CJ qualifies to live in a much higher level of care (ICF) then he is currently in, but we have him stable.

Carston is our youngest at age 13. I was in the delivery room when he was born at just 32 weeks. By 18 months I knew there was something different about him. He didn't talk at age 3 but knew over 50 sign language words and when tested for preschool tested over age 5! He also had fine motor and gross motor delays. It was a fight to get an Autism diagnosis but now the "experts" finally agree. At age 7 he became violent and we spent 6 months in and out of the ER due to this. They sent us home every time because there was no one to take him. Even though the doctors believed he needed inpatient care. Just as he turned 8 he attempted to kill he and I both by wrecking my car while going 70 miles an hour down the highway. Luckily, this ER trip we were in West Virginia and they would not allow him to leave the ER without a psychiatric placement. At age 10 he spent 9 months in residential and he would qualify for Ohio Rise and probably need residential services again if we didn't think outside the box about his placement and care.

Our family suffered the ultimate loss at the hands of a DODD provider. In 2017 our son was in an ICF and received no nutrition or water for at least 5 days. He suffered a massive stroke this type of stroke usually only happens in the dessert when you have no water. As a matter of fact, the coroner in Cuyohaga County had never seen this type of stroke. It was massive and unprecedented. He was severely dehydrated upon arrival to the ER. He died in hospice 9 days later. This DODD provider was found responsible for his death by both our county DODD and our counties children services. Yet......they still operated as an ICF for several years.

In 2022 another son CJ (18 years old at the time and now almost 20) was neglected to the point that his bladder ruptured due to not having the supplies he needed to empty his bladder. I serve as his legal guardian appointed by the probate court and C8 has been approved by the probate court to provide services to him due to the neglectful act of another agency. In February of 2022 just as I was starting the process to become an agency due to a myriad of issues we had experienced with other agencies, CJ suffered tremendously at the hands of an agency with DODD oversight. A DSP staff and the agency owner took him over an hour from his home, without my permission, with zero supplies. He requires a multitude of supplies every day to survive. He cannot eliminate his bowels or evacuate his bladder like most of us. He relies on a colostomy bag and a catheter to accomplish those things. CJ realized he had no supplies just one hour into the day and informed the owner of the agency of this and she ignored him and told him to shut up. She continued with her day and dropped him off at another agency clients house with a third staff, who was untrained in his care. Cj was supposed to have a staff totally assigned to him but he was shut in a bedroom with only a bed. No sheets for that bed were even provided. I cannot imagine the pain my son suffered in that room! His medical needs were ignored and his bladder began to fill with no way to empty it. He went approximately 13 hours without being able to empty his bladder. I got a phone call at 9:30 that night. I was on my way home and on a layover in an airport. The staff reported to me that Cj did not feel well and wanted to go to the hospital. When I asked to speak to CJ it was obvious that the staff was in

his car. I heard the door open to Cj's home and then I heard him screaming in pain. I spoke to him and asked the staff to call 911. I then called the ambulance dispatcher myself and the hospital and gave permission to treat as I was about to board a plane home. I also called my older son and daughter to go to the ER. The staff did not report properly to the ER what had happened that day and stayed in the room so CJ also did not report that he went too long without cathing. The ER assumed he just had a UTI. They gave him antibiotics and sent him home. I had to immediately attend to another child in a different city when I got home but asked how CJ was doing and was assured that he was fine. When he went to school 4 days after this event I immediately got a call from the school that he couldn't even stand up straight he was in so much pain. I advised for them to call 911 and met the squad at the school. He was pale and very disheveled. Later I was advised there was feces all over his abdomen. And the EMS reported it looked as though he hadn't been cared for in days.

He spent 31 days in the hospital and this was an event that could have killed him due to his past medical history and the danger of any midline surgery, let alone an emergency one. He has lasting effects of this event still today. As well as PTSD due to fear of dying like his brother, fear of surgery and recovery, and memories of being yelled at repeatedly for telling his staff he was in pain and needed to cath. He also reports that made fun of him for not being able to pee "like a normal man". Again both our county DODD and children services found the agency and their staff responsible for these injuries. Yet.....they are still in operation today. What about the abuser registry? Is this not in place to protect the most vulnerable population? Why is it that now 2 years have past and the key players in this incident are still caring for individuals with DD? One of them became an independent provider just 5 months after being substantiated of medical neglect! The other owns an agency and has an individual living with her utilizing OSL.

In August of 2022 our youngest son Carston now 13 was living in a congregate setting. He was held down on his bed and suffocated by another client. He was trying to scream for help and make noise so the staff could hear him. He was finally able to get away and found all the staff outside. Children services and DODD again investigated. CSB created a safety plan (the 2 boys were never able to alone together) and 2 days later I was notified that the same young man held my sons arm behind his back and tried to break it. CSB advised that we should remove Carston from that situation. That DODD agency is still in business as well!

Would you trust an agency if you were our family?? How much does one family have to suffer before someone recognizes the best one to be in charge is me or a family member? Would anyone in this room want to turn control over to another agency if you were me? With this being said I need you all to hear that I was told by a higher up in DODD that they "expect abuse and neglect to happen in this system". Wow! What a statement!

Now let me ask a question... would you trust any of your children to this system after what my family has been through? Would you trust providers that are hired and you have no say? Would you trust providers you have never met? Currently I have contact with the person who hires and fires staff. I have great communication with the DOO and other staff. I do not have daily interaction with the agency. But I know my sons are well taken care of. And I make

unannounced visits as they both live within 5 minutes of me. I am very pleased with the staff and the way my sons are cared for now.

No agency or SSA can make me feel comfortable with the care or best interest of my boys any longer unless I have more control than I had in 2017 when my son was <u>murdered</u> at the hands of an ICF and in 2022 when CJ and Carston were being cared for by other agencies. I now get to ensure they gets the care, love, and attention that is so lacking in this field. I get to make sure they are safe!

In closing I would like to beg you to concentrate on keeping this population safe. By giving families more options such as being paid 90% of what an ICF receives and allowing for cameras to be placed in ICF their safety can be increased dramatically. Not doing so puts the population in real danger of abuse, neglect, misappropriation, and yes even death.

I am also asking that you look at why providers who have been found guilty of these things are allowed to continue to serve this population. Not cooperating with an investigation should immediately get an agency shut down until the investigation is over. Being found substantiated should put one on the abuser registry immediately.

One last thing. You may be wondering where the name C8 comes from. On the day of Clayton's funeral 2 of my children got tattoos that portrayed our family's commitment to each other. It was a C to the eighth power. You see I have 8 children whose names start with C. We lost one of those C's and our family was affected deeply and will never be the same. His legacy is honored by this company that cares so well for not only his brothers but all others in the care of the C8 Foundation. I am no longer the owner of the C8 Foundation due to new rules that were put into place at the end of last year. I did leave it in great hands and the legacy of love, commitment, and quality care will continue.

Thanks for taking the time to read my testimony and I would be happy to testify in person and answer any questions that may arise.

Dr. Jennifer R. Brumfield and family