Tara Congdon
720-235-0688
tschupner@gmail.com

February 14, 2023

Chair and Members of the Senate Education, Energy, and the Environment Committee:

Thank you for having me here today. I am speaking in support of SB346, the Maryland Sign Language Interpreters Act. I urge you to pass this bill because it is crucial to protecting the safety and well-being of not only Deaf Marylanders, but also their loved ones.

This is my fourth time testifying in support of interpreter licensure. My previous testimonies are more comprehensive, and I've resubmitted them as appendixes to my testimony today. I encourage you to read them. Today, I want to focus on a specific experience in which an unqualified interpreter put my daughter at risk.

When my daughter was a baby, her pediatrician referred us to a cranial helmet practice for evaluation because of some abnormalities in her skull. When I arrived at the appointment, I immediately recognized the interpreter as one well-known in the community for being dangerously unqualified to interpret in medical settings, yet frequently accepting such assignments. I'd had him before, myself, for an emergency room visit and an annual checkup. I dismissed him both times and used pen and paper instead.

Yet, here we were again. Yet again, I had to choose between using him and having no sign language interpreter. This time, I had little choice. My hands were full with my 5-month-old, and I could not use pen and paper. And because of masking, I could not lipread. I knew that entire appointment, even without being able to lipread the doctor, that I could not trust I was getting all the spoken information accurately. What was interpreted to me was that my daughter was being referred back to her pediatrician because the center could not treat her.

The next day, I called our pediatrician and asked them to email me the report from the helmet place as soon as they got it. A week later, when I opened the file, I was shocked. My daughter likely had craniosynostosis – one of the sutures in her skull had fused prematurely and was restricting her brain's growth. She needed to be referred to a neurosurgeon. None of that information was conveyed during the appointment. Not once was the word "neurosurgeon" ever interpreted. But the report stated that the doctor had explained all this to me during the appointment.

I immediately dove into research. I learned that there were two options: a minimally invasive endoscopic procedure to open up the suture, or an invasive cranial vault reconstruction. One would take 45 minutes, keep my daughter in the hospital overnight, and leave her with a one-inch scar, but require helmeting for a year. The other would require waiting for months to a year, the pressure in my daughter's head rising as the skull failed to expand with her growing brain, potentially causing irreparable brain damage including lifelong learning disabilities and emotional disorders. It would require about 6 hours in the OR, peel back all the skin from her skull, involve blood transfusions and several nights in the hospital, further increase the risk of brain damage and death, and leave my daughter with a zig-zag scar from ear to ear.

I also learned that most doctors will not do endo after 4 months old. Out of desperation, I called the surgeon who himself invented the procedure. He consulted with us and said he could operate on my daughter as long as it was before she turned 6 months. Fortuitously, he had an opening in his schedule in two weeks – when my daughter would be 5 months, 3 weeks old. Just one catch … he's in El Paso, Texas.

We scrambled. In the middle of a COVID surge hitting El Paso hard, we paid thousands of dollars to fly there and rent a car and airBNB for 10 days, and took that time off work. Since then, we've flown out two more times for follow-ups, spending thousands of dollars each time. Today, my daughter is a beautiful, smart 2 ½ year old. You couldn't find the scar, if you tried to look. She has no lingering damage – she can speak or sign over 300 words and loves to climb, run, and play. She knows no limits.

But what if I didn't know to not trust that particular interpreter's translation? What if I was less attuned to potential omissions or mistranslations? What if I decided to refuse that interpreter and reschedule the appointment to weeks later, in hopes of getting a different interpreter? What if I waited a few more days to follow up? What if I was less pushy? What if I was not as well educated or capable of doing my research and understanding the implications? What if we didn't have the resources to take an emergency trip to El Paso in the middle of a pandemic?

We would have missed that tiny window remaining to us to provide our daughter what we felt was the best possible medical treatment, for her health and future.

There was – and is – nothing we can do to protect ourselves and other families from that interpreter and numerous others like him. There is no way to file a complaint against these interpreters, and there is no system in place to ensure they do not accept assignments they are not qualified for. There is no protection for families like mine from being forced, the moment we arrive at an appointment, to choose between a dangerously unqualified interpreter and having no interpreter at all, or postponing necessary medical treatment.

It is my responsibility as a mother to protect my daughter, but I have very little power to ensure that particular interpreter – or any unqualified interpreter – does not show up to interpret another appointment for me or my daughter. I have no way to protect us from those interpreters hamstringing my ability to make life-altering medical decisions for myself or my children.

Only you have that power and ability. Please protect us and our children from those interpreters by passing this bill.

Thank you,

Tara Congdon

Appendix I: 2022 Testimony to House

Tara Congdon
909 Roswell Drive
Silver Spring, MD 20901
720.235.0688
tschupner@gmail.com

March 4, 2022

Chair and Members of the House Health and Government Operations Committee:

I am a Deaf Maryland resident and taxpayer who is fluent in American Sign Language. I use interpreters to access educational and employment opportunities and health care and other essential services for myself and my family. I am writing in support of HB1107: The Maryland Sign Language Interpreters Act.

It is imperative that you establish interpreter licensure for the safety and well-being of all Deaf people who depend on ASL interpreters to access health care, legal proceedings, employment, and other facets of life in Maryland. I am not being hyperbolic when I say our lives, liberty, and pursuit of happiness depend on this. Maryland has no mechanism to require that interpreters demonstrate their qualifications and ability to interpret, or to hold accountable individuals who pass themselves off as qualified but are not. As a result, abuse is rampant throughout the state and too many Deaf Marylanders have experienced horrifying, life-threatening situations. I describe only a sampling of those I have personally experienced in an appendix to this letter.

This bill is essential not only for Deaf people, but for all people who interact with, serve, or depend on these Deaf people. These people include children and relatives who depend on their Deaf parents or guardians to put food on the table and make decisions about health care and legal proceedings. When Deaf parents like myself are provided unqualified interpreters, we do not get the complete and accurate information we need to make decisions for our children, which can have serious consequences. These people also include doctors, nurses, lawyers, and other professionals who provide services to Deaf people. Doctors rely on interpreters to collect and provide the necessary information to treat their Deaf patients to the same level and quality that they do their hearing patients. Without qualified interpreters, doctors do not get the information they need to appropriately treat their Deaf patients, putting these patients at serious risk of injury or death and the doctors and hospitals at risk of medical malpractice lawsuits.

Five years ago, my husband and I embarked on our fertility journey and then our journey as parents. The journey was long, expensive, and heart-wrenching. It involved significant out-of-pocket expenses, time and energy, and painful losses. The last thing we needed was for unqualified and unethical sign language interpreters to make our journey even more difficult and painful. We began this journey with trust in our medical care providers and interpreters. That trust was repeatedly violated and we were repeatedly harmed and traumatized, nearly lost our opportunity to be parents, and then nearly missed the window of opportunity to get a lifesaving operation for our daughter. I am convinced that the only way to keep Deaf Marylanders like myself and our children safe from incompetent and unethical interpreters is for you, on behalf of the state of Maryland, to step in.

Interpreter licensure will not solve all problems, but it will take significant steps toward 1) preventing unqualified interpreters from taking assignments beyond their abilities; and 2) providing a mechanism to hold these individuals accountable when they do. Currently, no such mechanism exists beyond filing civil rights complaints, which is daunting for Deaf people who, for example, depend on keeping the same doctors for their health care, especially for chronic conditions and ongoing treatment. For example, once we paid $30,000 out of pocket for IVF treatment and drugs, went through egg retrieval, and had viable embryos, we were stuck with our clinic and its contract with an agency that repeatedly sent unqualified interpreters. We had to choose between accepting the frustrations, stress, and dangers caused by these “interpreters” versus sacrificing our sunk costs and worse, our embryos. We persevered and have a beautiful daughter, but I have post-traumatic stress disorder from repeated abuse at the hands of these individuals. I did not sue our clinic after the fact because suing doctors does nothing to stop the individual interpreters or their employer agencies from continuing to send them out to interpret.

You will hear objections from certain parties who benefit financially from the status quo. These parties own small interpreting agencies and rely on the lack of regulation to exploit the system by subcontracting unqualified, uncertified interpreters in order to underbid other agencies that could provide qualified interpreters. They make their profit by exploiting hospitals’ and doctors’ ignorance and taking advantage of a business model that ignores the voices (and hands) of Deaf patients.

I urge you to prioritize the thousands of Deaf Marylanders and their families over the handful of such parties and move this bill forward because lives are at stake. We have suffered enough at the hands of these unscrupulous business owners and unqualified interpreters. It is well past time for the Maryland legislature to do something about this. I told you my story last year. How many more times do I need to come before you to plead this case?

You have the opportunity before you to dramatically improve conditions for Deaf people like myself and the people who interact with, depend on, or support us throughout our state. Please do not pass up this opportunity.

Thank you,

Tara Congdon

Appendix II: 2021 Testimony to Senate (2/9/21) and House (2/24/21)

Tara Congdon
909 Roswell Drive
Silver Spring, MD 20901
720.235.0688
tschupner@gmail.com

February 9, 2021

Mister Chairman and Members of the Senate Education, Health and Environmental Affairs Committee:

I am a Deaf Maryland resident who is fluent in American Sign Language and rely on interpreters for access. I am writing in support of SB0431: The Maryland Sign Language Interpreter Act.

It is vitally important that you establish interpreter licensure, for the safety and well-being of all Marylanders who depend on sign language interpreters to access health care, legal proceedings, employment, and many other facets of life in this state. Our lives, liberty, and pursuit of happiness—including pursuit of education and employment—depends on these interpreters being trained, skilled, qualified, and ethical. However, no mechanism exists to require that interpreters demonstrate their qualifications and ability to interpret, or to hold accountable individuals who pass themselves off as qualified but are not. As a result, abuse runs rampant throughout the state and far too many Deaf Marylanders have experienced horrifying, life-threatening situations created by these individuals. I describe only a sampling of many I have personally experienced in an appendix to this letter.

This bill is crucial not only for Deaf Marylanders, but for all hearing Marylanders who interact with or depend on Deaf people. These include children and relatives who depend on their Deaf parents or caretakers to make decisions about their health care and legal proceedings. When Deaf caretakers are provided incompetent, unqualified interpreters, they do not get the complete and accurate information they need to make these decisions, which can have serious consequences. This bill is also critical for the doctors, nurses, lawyers, and other professionals who provide services to Deaf patients and clients. Doctors, for example, rely on interpreters to collect and provide the necessary information to treat their Deaf patients to the same level and quality that they do their hearing patients. When these interpreters are not trained, skilled, qualified, or ethical, doctors do not get the accurate and complete information they need to appropriately and competently treat their Deaf patients, putting these patients at serious risk of injury or death.

Four years ago, my husband and I embarked on our fertility journey and then our journey as parents. This journey in itself has been long, difficult, expensive, and heart-wrenching. It has involved out-of-pocket costs exceeding $35,000, failed cycles, and painful losses. The last thing we expected, and wanted, was for unqualified and unethical sign language interpreters to complicate it and make our journey even more difficult, expensive, and emotionally painful than it needed to be. We began this journey with trust in our medical care providers and interpreters. That trust was repeatedly violated and we were repeatedly harmed and traumatized. I am convinced now that the only way to keep Deaf Marylanders like myself safe from incompetent and unethical interpreters is for the state of Maryland to step in and regulate them.

The appendix to this letter details some of our experiences to help you better understand the critical need for this bill. I hope you will take the time to read the appendix in its entirety. If you do not, please at least read the incidents that took place in June 2018 and on April 18, 2019. They encapsulate the dangers unqualified interpreters pose to Deaf patients' physical, emotional, and financial well-being.

To be sure, interpreter licensure will not solve all problems, but it will take significant steps toward 1) preventing uncertified, unqualified, unethical, and/or inexperienced individuals from taking interpreting assignments; and 2) providing a mechanism to hold these individuals accountable when they do. Currently, no such mechanism exists beyond filing civil rights complaints against doctor's offices, which is daunting for Deaf people when they depend on these doctors for health care, especially for chronic conditions and expensive, ongoing treatment. For example, once we signed our commitment with our fertility clinic, paid $30,000 out of pocket for IVF treatment and drugs, went through egg retrieval, and had viable embryos, we were trapped because of the clinic's contract with an interpreting agency that repeatedly sent unqualified interpreters. We had to choose between accepting the frustrations, stress, and dangers caused by these "interpreters" and sacrificing our sunk costs—financial, time, and emotion—and worse, our embryos. We persevered and now have a beautiful daughter, but I continue to experience post-traumatic stress disorder from repeated abuse at the hands of these individuals.

You will hear objections from various parties to various aspects of this bill. Some of them, I agree with. Some, I don't. But I urge you to move this bill forward—with amendments if necessary to address concerns—because lives are at stake and Deaf Marylanders have suffered enough. Far too many individual interpreters, the agencies they work with, and the doctor's offices who contract these agencies are not putting Deaf patients' well-being first and ensuring appropriate communication access through qualified interpreters. This is why we desperately need mechanisms to screen interpreters and hold each of them accountable.

It is well past time for the Maryland legislature to do something about this. You have the opportunity before you to dramatically improve conditions for Deaf Marylanders and people who interact with, depend on, or support us throughout our state. Please do not pass up this opportunity.

Thank you,

Tara Congdon

Appendix III: Selected Incidents of Unqualified Medical Interpreting

- **June 2018** – I went to my OB-GYN for an uterine endoscopy to try to identify the cause of our infertility. An uncertified interpreter I had encountered before and requested *not* return showed up to interpret the procedure. She omitted vital information while translating the pre-procedure discussion between myself and my doctor, during which my doctor explained options if I was unable to withstand the pain from the endoscopy. During the endoscopy, I expressed that I was experiencing pain but could continue. Instead of voicing this, the interpreter laid her hands on me and attempted to comfort me, informing me that she had experienced it before – a violation of interpreting ethics and an overstepping of boundaries. This distracted me so much that I asked the doctor to pause a moment; the interpreter voiced to the doctor that I was requesting to terminate the procedure. The doctor stopped, withdrew the scope, and informed me that the only alternative was an outpatient laparascopic procedure under full anesthesia, which would cost me $2,000 and require 2 days off work to heal. I was stunned and told her I wished I had known that before we started, and she told me she had communicated that. But the interpreter did not translate it. I had to proceed with the more invasive laparoscopy, endure even more physical pain, and absorb the financial blow and loss of work time.

- **August 2018** – An uncertified interpreter showed up for a doctor's appointment in which critical information about fertility and treatment options, including surgery, would be discussed. This interpreter mistranslated 50 percent of the spoken content and could not accurately voice 90 percent of signed content. The doctor and I eventually gave up, asked the interpreter to stand in a corner, and resorted to pen and paper to communicate with each other. When I called the interpreting agency afterward to object about the interpreter they sent and that we were unable to obtain all the information we needed to make critical decisions about options for fertility treatment, they sent me Edible Arrangements chocolate-covered apple slices as an apology.

- **October 2018** – A recent graduate from an Interpreter Training Program outside Maryland and who had just moved to the area showed up to interpret an appointment with our fertility doctor, during which we were to receive very specific instructions for medication to take to prepare for our first attempt to become pregnant. The interpreter could not read my fingerspelling or signing, and she did not know the signs for very basic anatomical and medical terminology. I gave her a crash course about these signs in the waiting room. In the exam room, she voiced the complete opposite of everything I signed. When I asked the doctor to confirm that I should take a particular injection before another, and then take an oral medication at a particular time, she voiced that I was asking if I should take the second injection before the former, and *not* take the oral medication. Confusion ensued between the doctor and myself. I had to begin signing extremely slowly, to the point the doctor could understand me before the interpreter did. And the doctor had to come face-to-face to me and speak very slowly and clearly so I could lipread her and ensure I understood every step of the course of medication and exactly when to take each injection or pill so that our $4,000 investment in this procedure would not be wasted due to a timing or sequence error resulting from mistranslation.

- **December 2018** – A very young, very inexperienced, first-year Interpreter Training Program student showed up to interpret an OB-GYN appointment which included an annual checkup, pap, and discussion about our fertility treatment. This student confessed that she had never interpreted an OB appointment and did not know basic interpreting etiquette, including where to stand or how to facilitate a translated conversation between doctor and patient. She also kept making comments like "this is so fascinating" and asking me questions about how and why things work or are done the way they are to women's bodies and regarding pregnancy. Despite feeling extremely awkward—because it is not my job to do so—I strongly advised her to not take any more medical interpreting assignments until she had at least completed her training program, and more ideally, achieved certification.

- **April 2019** – At a cardiology appointment, while describing my historical and current symptoms (some of which were side effects of fertility medication to prepare for our first embryo transfer), and my family history, an uncertified, inexperienced interpreter struggled to voice what I was signing. Every time I started signing, she panicked and lost her voice. The doctor was perplexed and could not understand what was happening. I took pen and paper and wrote to the doctor that this interpreter was not accurately translating *anything* I was saying. Finally, I instructed the interpreter that I was going to switch to Signed English, in which I signed every single word, in English word order, and that she was to voice, word for word, every word I signed *as* I signed it, very slowly. I had to support her through the entire appointment, which took longer than necessary and during which I was not able to communicate to my cardiologist the full extent of my symptoms or get a satisfactory understanding of treatment options.

- **April 18, 2019** – Embryo transfer day. Also known as the first time in my life I kicked an interpreter out – not just out of the exam room, but off the assignment completely. She was an unqualified, unskilled, uncertified, recent ITP graduate who had just moved to Maryland. Her signing was unclear and I could not understand her translation of a nurse's instructions, three times. When she missed or misheard something, she did not ask the doctor or nurses for clarification or to repeat; instead, she skipped over the information. When I asked my husband to help me understand, the interpreter interfered and said to me, "You don't need to look at him, I'm interpreting this for you, you don't need to ask him for help." She continuously mistranslated what I was signing, to the point my husband had to step in and correct her several times. She spoke to me like I was an unintelligent, uneducated child, and made comments about how she had never interpreted an embryo transfer before and that this was "going to be *so* fascinating!" She also spoke rudely to my doctor and, when my doctor attempted to give me consent forms to sign before he proceeded with the embryo transfer, the interpreter interrupted and instructed him to read the forms aloud so she could translate them into ASL for me. This confused the doctor because he knew me well and knew I preferred to read the forms for myself before signing them. At that point, I had had enough. I asked her politely to please leave the room so we could proceed with the embryo transfer without her disruptive presence. She refused and argued with me that she could do the job. I became extremely upset and was in tears because an already stressful—but exciting—day was now a nightmare. My doctor was extremely concerned, and my husband and I tried to explain to him that this interpreter was very problematic. She interrupted, undermined us, and told the doctor that I was just upset because she didn't accurately translate my birth date. My husband and I both snapped at her blatant disrespect of us and our request, and with me sobbing, my husband yelled at her to leave the room, and we asked a nurse to make sure security escorted the interpreter from the building, to avoid any unpleasant scenes after the appointment. After the interpreter left, my doctor was staring at me in shock—he had always known me as a very calm, rational, unflappable person—and I had to explain, with my husband voicing for me, what had just happened. My doctor was so concerned about my emotional state that he was uncertain whether we should proceed with the embryo transfer because he was worried that all the negative hormones now in my system would affect the success of the transfer. But we had no choice because the embryo had been thawed. If we did not proceed, the embryo would have to be discarded. We proceeded, I became pregnant, and 12 weeks later, the baby died.

- **April 2019-November 2020** – a gap in incidents because I became far more assertive about demanding that doctor's offices allow me to select my interpreters for the rest of my fertility treatments, pregnancy, delivery, and pediatric appointments for our infant daughter. I spent many hours on the phone and email battling with individual doctor's office staff and corporate general counsel, explaining the legal risks to them of continuing to use uncertified, unqualified interpreters for their Deaf patients and that these risks outweighed any contractual commitment to interpreting agencies that repeatedly send such individuals to interpret high-stakes medical appointments. This became an immensely stressful part-time job even as I struggled with working full-time while experiencing pregnancy symptoms amidst the uncertainty of what delivering during COVID-19 would involve, and caring for our newborn daughter.

- **November 2020** – Our daughter was referred to a helmet place due to asymmetry of her skull. The practice refused to allow me to select the interpreter. An uncertified, unqualified interpreter showed up to interpret, and he provided extremely inaccurate and incomplete translations in both directions. When he misheard or missed spoken information from the doctor, he waved his hands or skipped over it but in a way that was so smooth that I did not realize he was omitting significant chunks of information. When the doctor informed me that his practice could not treat my daughter and that he was sending us back to our pediatrician for further consultation, I did not understand why but due to the interpreter decided to wait and speak with our pediatrician. The next day, I spoke with our pediatrician over the phone and he told us that the doctor recommended our daughter see a neurosurgeon due to the type of skull asymmetry she had. I was shocked because at no point during the appointment did the interpreter ever sign the word neurosurgeon or that surgery on my daughter's skull would be necessary to prevent intracranial pressure that could damage her brain and eyes. The following week, I received paperwork from the doctor's office and it included all the details about the recommendation for neurosurgery referral and that the doctor had discussed this information with me during the appointment.