

From: Kristyn Herbert, Self-Advocate from Boise
To: Senate Judiciary and Rules Committee, Idaho Legislature
Re: February 22, 2017 - Comments about Senate Bill 1090 Medical Consent

Dear Chairman Lodge and Members of the Committee;

My name is Kristyn Herbert, I live in Boise and I am a person who has a developmental disability. I experience the effects of cerebral palsy which affects my ability to walk, so I use a wheelchair. It also affects my ability to speak, so I have support staff that understand me and are able to translate my words to others when needed and sometimes I use a letter board to spell out words. As a 41 year old female of sound mind, I am more than double the legal age to make my own decisions, receive my own medical records, test results, etc.

I would like to speak in support of Senate Bill 1090 relating to medical consent by people with developmental disabilities. I have had many experiences in my life with medical and dental professionals when my wishes and decisions about my treatment were not followed because the professional involved did not believe I was able to make decisions for myself. Not because I was in medical distress and was temporarily “incapacitated,” but because they saw me as a person who was not able to make my own decisions. They didn’t believe I knew what was best for me or that I could review my own records and give consent. Let me tell you – I do and I can.

I have had a dentist pull my teeth while I was under sedation for a dental procedure after I expressly told them I did not want my teeth pulled because I wanted to consider all my options. I have had hospital staff ignore my answers or directions until one of my support staff repeated (very strongly) that I had made my decision and I am capable of doing so. I would like to tell you about one recent example in getting information I needed to determine my choice about needed medical and surgical care.

Although I live here in Boise, my childhood Mama and Papa live in Louisiana. They are very involved in all aspects of my life, including being totally interested in my medical health. Because of that, I have my Mama listed as an emergency contact, at my doctor’s office, along with all other offices.

I had an abdominal ultrasound administered at the hospital on Sunday, January 15, 2017, ordered by my doctor. This was done to determine whether or not I have a hernia. I checked, repeatedly, with his office during the week, to get the results of the ultrasound. I checked with them again on Jan. 19, 2017, at approximately 2:00pm. At that time, they claimed yet to have received it from the hospital. The receptionist staff became angry and rude at my last two times to check back with them by phone, stating that the hold-up must be with the hospital staff faxing to their office. (the hospital stated otherwise). Within two hours of that phone call, my doctor’s office staff called **my Mama** in Louisiana, **not me!!!**

They left a voice mail on her home phone, to please return their call, she wasn't at home. This was **no emergency**...not even close! My Mama didn't get the voice mail until 8:45pm, long after the doctor's office had closed for the day. The next morning, Jan. 20, 2017, at 9:03am Louisiana time, my Mama returned the call to the physician's assistant who had left the voice mail. She was quite kind and pleasant to my Mama and said that "she had my ultrasound results and wanted to give the information to Mama, then, Mama could pass the information on to me." She went on to tell my Mama that I did, indeed, have an umbilical hernia, and that they were giving me three choices of medical centers to have my surgical referral sent to, and she named the surgeon at each location. The P.A. named the three places to Mama and asked her if **she** knew what **my choice** would be! Mama told her that she was way over in Louisiana and had no idea, but that she would talk to me, then would get back to the doctor's office. After speaking to me later that day to convey the physician's assistant's message, Mama left a voice mail on her direct line, telling her which medical center I'd like the referral sent to.

Please don't misunderstand where my complaint lies! My Mama would have been kept 100% informed **by me**, immediately, when **I** would have gotten the results. We are extremely close and each knows what goes on with the other, even almost 3,000 miles away! The issue is...what if we weren't close?? What if I didn't want her knowing my medical business?? What if I hadn't wanted her to worry and hadn't told her that I had even had an ultrasound done?? This P. A. doesn't know a thing about me personally, nor about my Mama! She has never met me. I tend to believe that the receptionist staff didn't care to deal with me for another phone call, and that's why my Mama was called, instead. Even if that wasn't the case...this P.A. **did not have the right to call my emergency contact, rather than call me.** It was during their regular office hours and I was home!

Too often, medical professionals make judgement calls about differently abled patients! Many patients tend to believe that they are lower than the "big, king-powered" doctors. Its past time that this stops happening! Imagine if this happened to you or someone you care about. If all of us would speak up when our legal rights are abused...this would eventually cease to happen!

Sincerely,

Kristyn Herbert

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